

Closing the Gap Through Enhanced, Family-Centered Approaches to Care Navigation Increasing Successful Referrals for Developmental Delays With Colorado Project LAUNCH

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Abstract

Increasing numbers of young children are now routinely screened for developmental delays during well-child visits in primary care settings which support early identification of developmental delays. Unfortunately, research indicates that there is often a gap between the number of children who receive an abnormal screen and the number who successfully follow through with a referral for further evaluation. This article highlights how, with support from Colorado Project LAUNCH, care navigation services in South Adams County, Colorado, have evolved over the past 4 years to address these issues and successfully reduce the referral gap.

Following the recommendation of the American Academy of Pediatrics in 2006 (Council on Children with Disabilities, 2006), increasing numbers of young children are now routinely screened for developmental delays during well-child visits in primary care settings (Radecki, Sand-Loud, O'Connor,

Sharp, & Olson, 2011; Schonwald, Huntington, Chan, Risko, & Bridgemohan, 2009). Screening is important because early identification of developmental delays can help young children and their families gain access to intervention services during the critical first years when those interventions are most likely to improve developmental outcomes (Kavanagh, Gerdes, Sell, Jimenez, & Guevara, 2012). Unfortunately, there is often a gap between the number of children who receive an abnormal screen and the number who successfully follow through with a referral for further evaluation (Dawson & Camp, 2014; King et al., 2010; Talmi et al., 2014). Research has

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shown that lack of follow-through or unsuccessful referrals are linked to a variety of issues such as agency procedures, parent misunderstanding or inaction, lack of systems coordination, and poor communication between intervention services and pediatric practices (Bricker, Macy, Squires, & Marks, 2013). This article highlights how, with support from Colorado Project LAUNCH (COPL), care navigation services in South Adams County, Colorado, have evolved over the past 4 years to address these issues and successfully reduce the referral gap. This enhanced, family-centered approach includes placing a care navigator in participating health clinics as well as in early intervention and mental health settings where they are responsible for ensuring families who receive a referral are provided comprehensive, high-quality supports in following through with a referral.

COPL Background

COPL is a federal initiative funded by the Substance Abuse and Mental Health Services Administration. COPL is grounded in the public health approach, working toward coordinated programs and systems that take a comprehensive view of health and promote the well-being of all young children (birth to 8 years old) by addressing the physical, social, emotional, cognitive, and behavioral aspects of their development.

The goals and objectives of COPL are to improve and strengthen the early childhood system by increasing (a) the coordination of key child-serving systems, (b) the expertise of behavioral health providers in primary care and other local programs, and (c) access to and availability of evidence-based prevention and wellness promotion practices that support young children and their families. COPL addresses health disparities by incorporating the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (U.S. Department of Health and Human Services, Office of Minority Health, 2018) and by implementing the five LAUNCH Prevention and Promotion Strategies (Project LAUNCH, 2014) to increase equity in access, service use, and outcomes for racial and ethnic minority young children and families, military families, and those from other diverse backgrounds. The five strategies include: (a) screening and assessment in a range of child-serving settings, (b) integration of behavioral health into primary care, (c) mental health consultation in early care and education, (d) enhanced home visiting with a focus on social-emotional well-being, and (e) family strengthening and parent skills training.

An important emphasis within the first strategy, and the focus of this article, are efforts to increase successful referrals for developmental delays after abnormal screens, especially for those children from racial and ethnic minorities, military families, and other diverse backgrounds. These efforts support COPL's long-term goal to ensure that all children in South Adams County, the local community for this grant, enter school healthy, ready to learn, and able to succeed.



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Early identification of developmental delays can help young children and their families gain access to intervention services during the critical first years.

South Adams County, Colorado

Adams County is among the most urban and populous counties in the state of Colorado with the following demographics:

- Children younger than 8 years old represent 11.9% of the overall population (Kids Count Data Center, 2019).
- 15.3% of the population is foreign-born (U.S. Census Bureau, n.d.).
- 28.6% of children sometimes or always speak a language other than English (U.S. Census Bureau, n.d.).
- 13.7% of children under 18 years old live under the federal poverty level (Kids Count Data Center, 2019).
- Almost 40% of children (under 5 years old) are enrolled in the Women, Infants, and Children nutrition program (Kids Count Data Center, 2019).
- The K-12 population in South Adams County is majority Hispanic or Latino (74.6%), followed by White (18.2%; Colorado Department of Education, 2019). For students in K-12 in South Adams County, 73.7% qualify for free and reduced lunch in public schools. For comparison, in Adams County overall, 49.4% qualify, and in the state, 41.7% qualify (Colorado Department of Education, 2019; Kids Count Data Center, 2019).

The cumulative risk model indicates that the number of risk factors a child and family share is more predictive of many negative outcomes than any particular combination of risk factors (Zeanah & Sonuga-Barke, 2016). The various risks reported for families in Adams County as a whole, and for those in South Adams County specifically, highlight the need for a strong and comprehensive, culturally responsive approach to health through screening, referral, and provision of indicated services in order to support their overall health and well-being.



Colorado Project LAUNCH has a long-term goal to ensure that all children in South Adams County, Colorado, enter school healthy, ready to learn, and able to succeed.

Implementation of Care Navigation Services in South Adams

In South Adams County, COPL provides care navigation services through the local early intervention program, North Metro Community Services, which is a Community Centered Board (CCB), and at three health clinics, Every Child Pediatrics, Clinica Family Health Services, and Community Reach Center/Mountainland Pediatrics, which is also the community mental health center. During the first year of implementation in 2015, priority was given to those families considered to be at highest risk of not following through with a referral on the basis of the following criteria:

- family still needs support (to follow through with referral) after three contacts (not just contacts to reschedule, etc.),
- family has more complex needs or multiple referrals,
- family has needs that require more immediate attention (e.g., child abuse/neglect, suicidal ideation, domestic violence), and
- child needs support and referrals pertaining to an autism diagnosis (process for evaluation is intensive, and the resources are much more limited).

Care navigators were available to help all families, but at that time, had no standard protocol for engaging with families who were considered to be at lower risk of not following through with a referral.

Through our LAUNCH evaluation efforts, we began to track and report outcomes for all children who received a referral, not only for those whose families were considered to be at highest risk (of not following through with a referral). Initially, the data indicated that, overall, there was little to no increase in successful completions among the majority of families. Over time, we recognized that most families would likely benefit from even limited

contact with a care navigator around referrals, and leaders at the Early Childhood Partnership of Adams County, along with administrators and care navigators at the participating agencies, set about to make that happen. Participating agencies worked to think differently and implement infrastructure changes intended to increase successful follow-through for referrals by meeting all of the families they serve “where they are” and working to address the many barriers those living in the South Adams County often face.

Meeting Families Where They Are: Enhanced, Family-Centered Care Navigation

LAUNCH care navigators have been key in promoting best practices in screening and referral, and, depending on the site, now connect either in person or by phone with many or most of the families who receive a referral but in a more limited way than for those at highest risk. While the workflow and general duties are different across the four sites, care navigators are available to meet with families either upon referral or when the family has not initially followed through with a referral to identify needs and barriers to successful follow-through (e.g., transportation, family culture/beliefs, food security, overall child health needs). The following descriptions focus on the unique approach each participating site brings to care navigation.

Care Navigation at Community Reach Center/ Mountainland Pediatrics

The care navigator at Mountainland Pediatrics helps bridge services across the physical and social-emotional/mental health continuum by supporting both the pediatric practice and the Early Childhood Services Team. In an effort to begin building relationships with families even before they come to the clinic, this care navigator calls all new patients and upcoming well-child check-up patients to inform the family of the supports available through her role and to identify potential barriers to attending the upcoming visit. This strategy has proven effective and has had a positive effect on the clinic’s “no show” rates, as well as an increase in follow-through rates to more than 90%.

When dealing with referrals, the care navigator

- receives early intervention or Child Find referrals when the referral coordinator has had at least two unsuccessful attempts to contact a family;
- continues outreach to contact the family and serves as a referral source to provide additional assistance;
- navigates the family to the referral location and follows up 1 week after the appointment to see whether the family got connected, made it to the scheduled appointment, and/or is eligible to receive services; and
- helps identify/address barriers to get or continue services and/or assess whether they need additional resources.

Care Navigation at Every Child Pediatrics

Following a developmental screening, the care navigator:

- participates in a provider visit if “red flags” present to help review options with the family, consider the need for a referral, and clarify the referral process and expectations (e.g., what referrals for services are, how they are helpful, and why it is important to follow-through)
- collaborates with the service coordinator for early intervention referrals and documents the process in the medical record. The care navigator follows up with the family, the appropriate CCB, or both if there is a breakdown at any point in order to identify and address barriers. In Colorado, the Colorado Department of Human Services administers the Early Intervention Colorado Program and contracts with CCBs statewide to provide early intervention supports and services to infants, toddlers, and their families within the community.
- conducts outreach calls for Child Find referrals to Child Find teams and to the family to ensure that implementation of intervention plans are on track
- follows up with families via their next visit if the family cannot be reached, if questions arise regarding referrals, or if other barriers need to be addressed

Care Navigation at Clinica Family Health (Local Federally Qualified Health Clinic)

In July 2018, Clinica hired a second care navigator. The two are working together to refine early childhood developmental screening and referral practices across three health clinics while exploring ways of expanding implementation of a screener for social determinants of health.

The care navigators

- reach out to families following any developmental referral/ other child-related concern to assess needs and barriers, provide education on developmental milestones, and provide resource and care coordination support;
- provide additional follow-up with families if the referral is incomplete to identify and address barriers, provide further education or additional resources, and/or coordinate with the referral site as needed;
- identify and resolve workflow issues, create and build new workflow with care navigation practices embedded throughout to ensure efficient screening and tracking systems, coordinate with community partners; and
- connect families to additional resources and provide intensive care navigation services as needed.

Care Navigation at North Metro Community Services (CCB)

It is important to highlight a basic difference in the work done by North Metro’s care navigator in comparison to the work done



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Needs and barriers to successful follow-through include transportation, family culture/beliefs, food security, and overall child health needs.

by the care navigators at the three health clinics. The primary role of North Metro’s care navigator is to support incoming referrals. This is in contrast to the role of the other care navigators who support outgoing referrals to other agencies or services.

The care navigator

- receives early intervention files for children whose parents have been difficult to reach or declined an evaluation;
- continues outreach to contact family;
- follows up after a family declines services to provide more in-depth information and additional resources;
- receives Child Find files and helps with scheduling and confirming evaluations, as well as with providing additional resources (i.e., preschool enrollment information, developmental information, and resource lists); and
- supports families at the Community Resource Center, which is a shared (co-located) services space at the Department of Human Services.

In the last year, the care navigator at North Metro began to provide increased support to families who have been referred by the county’s Department of Human Services. As noted previously, the care navigator at North Metro typically works with families who have not followed through initially and whose cases are about to be “closed.” She often does home visits to help break down barriers related to transportation and time



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The number of risk factors a child and family share is more predictive of many negative outcomes than any particular combination of risk factors.

and will do developmental screenings during these visits to help further differentiate the need for evaluation. This approach has been extremely successful in saving these most difficult cases, many of which would have otherwise been closed due to eligibility requirements. Of 37 incoming referrals received by the care navigator, 83.8% had a successful follow-through with an evaluation.

As the preceding descriptions illustrate, there are differences in workflow and general duties for care navigators across the four agencies. However, there are also similarities in the work done as well, which include:

- providing support to families throughout the screening and referral process;
- explaining what referrals for services are, how they are helpful, and why it is important to follow through and receive intervention if needed;
- supporting families in making an informed decision and empowering them to navigate the system;
- problem-solving a range of barriers faced by families at the personal, organizational, and systemic levels;
- helping identify appropriate services within their community; and
- incorporating a social-emotional component to screening-for-service protocols.

The following quote from a mother of three highlights the positive differences these services have made for her and her family.

I don't feel as lost as I once did. I feel more confident, especially because I know [my care navigator] is there. I can call her and she is there. I feel supported. I know I can count on her whenever any issues come up. She is willing to help me. Finding people like [my care navigator] makes the load a bit lighter.

Two of the participating clinics shared their thoughts on how care navigation has helped families with more complex needs navigate systems, self-advocate, and overcome barriers to follow-through on referrals.

"With the connections made, patients are able to access the care they need," shared Mountainland Pediatrics.

It's all about trust and relationship building. Patients before were not calling or were not connected. Now, [parents] are calling because they know exactly who to talk to.... I have seen a change from a family not being open to the referral, to them following through, to accepting supports, to coming back and saying "I can't believe I wasn't open to this before," added Clinica.

System-Wide Changes to Support Enhanced, Family-Centered Care Navigation

In addition to the individualized approaches developed by each agency to meet the specific needs of their own client families, a number of system-wide changes were adopted to facilitate integration and support overall efforts in care navigation.

Professional Development

Care navigators attended various trainings, including those focused on improving the delivery of equitable services, trauma-informed care, risk and protective factors, (i.e., Strengthening Families; Center for the Study of Social Policy, 2019), toxic stress, multidisciplinary approaches to child development, Appreciative Inquiry (Cooperrider & Whitney, 2005), and Motivational Interviewing (Miller & Rollnick, 2012),

Care Navigation Learning Collaborative

The Care Navigation Learning Collaborative holds a monthly meeting of Project LAUNCH and non-LAUNCH care navigators in Adams County to discuss best practices, lessons learned, needed supports, data collection, and evaluation. The Learning Collaborative also allows for care navigators to share resources and reflect upon challenging cases in which families are experiencing multiple barriers and to work together to develop strategies to address barriers.

Quarterly Data Review and Goal Setting

All care navigation teams participate in quarterly data review and outcome measures meetings with the Early Childhood Partnership of Adams County and the Project LAUNCH Evaluation Team. Meetings are designed to clarify data collection

procedures, discuss individual clinic/location outcome measures, and plan for sustainability.

Care Navigation Quality and Fidelity Monitoring

Twice each year, each care navigator and their supervisor complete the Care Navigation Fidelity/Functions measure designed to assess how well they are meeting nine quality and fidelity indicators for care navigation, such as, “Our care navigator identifies desired outcomes with the family and child,” and “Our care navigator provides information around purpose and function of recommended referrals, services, and supports.” (See Box 1 for a list of the indicators.) In year four, overall, the care navigators are “usually” or “always” meeting the nine indicators.

Adoption of the National CLAS Standards

In an effort to improve access to services for all families, LAUNCH requires incorporating the National CLAS standards (U.S. Department of Health and Human Services, 2018) into services and trainings. Examples include “Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area,” and “Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.” Participating agencies are making progress in meeting these standards. For example, four of the five care navigators are bilingual in English and Spanish, which supports the high percentage of Spanish speakers in Adams County.

Implementation and Outcomes

The comprehensive changes to care navigation practices at the individual agencies as well as across agencies have been implemented over the course of 4 years. During that time, there has been an increase in both the number of completed developmental screens and the number of successful referrals, especially for children of Hispanic/Latino/a or of Spanish origin. This result aligns with the demographics of South Adams County where the K-12 population is almost 75% Hispanic or Latino.

The first year of data collection, 2015–2016, serves as a baseline. Of the 4,953 completed developmental screens (81.5% for children birth to 4 years old), 238 (4.8%) resulted in a referral. The majority of children who received a referral, 166 (69.7%), were Hispanic/Latino/a or of Spanish origin. Of those who received a referral, 94 (39.5%) had a successful follow-through with an evaluation. Of those 94 children, 73.4% were Hispanic/Latino/a or of Spanish origin (Kubicek, Davidon, Viitanen, & Bauman, 2016).

In 2016–2017, of the 6,641 completed developmental screens (74.1% for children birth to 4 years old), 352 (5.3%) resulted in a referral. The majority of children who received a referral, 235 (66.8%), were either Hispanic/Latino/a, or of Spanish origin. Of those who received a referral, 132 (37.5%) had a successful follow-through with an evaluation. Of those 132 children, 69.7% were Hispanic/Latino/a, or of Spanish origin (Kubicek, Davidon, Luna, & Bauman, 2017).

Box 1. Care Navigation Fidelity/Functions

These nine statements are rated on the following scale: never, sometimes, usually, always.

1. Our care navigator assesses, with the family and child, strengths as well as unmet needs across life domains.
2. Our care navigator identifies desired outcomes with the family and child.
3. Our care navigator identifies all sources of referrals, services, and supports; facilitates connections with these sources and manages continuous communication across these sources.
4. Our care navigator provides information around purpose and function of recommended referrals, service, and supports
5. Our care navigator contacts the family within 30 days after facilitating an outside referral.
6. When service/support needs are high, the care navigator ensures that a comprehensive written plan of care and services is developed with the family that includes a plan to address family and/or child goals.
7. Our care navigator establishes accountability or negotiates responsibility for desired services, supports, and outcomes.
8. Our care navigator supports and facilitates transitions including transitions through various levels of care coordination as needed.
9. Our care navigator shares knowledge and information and facilitates communication among participants in the family and child's care.

Source: Thompson, L. J., & Davidon, S. (2014). *Care navigation fidelity/functions measure*. Unpublished document.

In 2017–2018, of the 6,785 completed developmental screens (79.0% for children birth to 4 years old), 260 (3.8%) resulted in a referral. Once again, the majority of children who received a referral, 173 (66.5%), were either Hispanic/Latino/a or of Spanish origin. Of those who received a referral, 166 (63.8%) had a successful follow-through with an evaluation. Of those 166 children, 67.5% were Hispanic/Latino/a, or of Spanish origin (Kubicek, Luna, Bauman, & Davidon, 2018).

In 2018–2019, of the 4,339 completed developmental screens, (81.5% for children birth to 4 years old), 158 (3.6%) resulted in a referral. The majority of children who received a referral, 113 (71.5%), were either Hispanic/Latino/a or of Spanish origin. Thus far, of those who received a referral, 127 (80.4%) had a successful follow-through with an evaluation. Of these 127 children, 70.9% were Hispanic/Latino/a or of Spanish origin. It is important to note that these results align with the demographics for Adams County where Hispanics/Latinos/as or people of Spanish origin represent 72.0% of the overall population. These data are summarized in Table 1.

Although the majority of children who are screened and receive referrals are from birth to 4 years old, the preceding data include children from birth to 8 years old, the target ages for COPL. It is encouraging that an analysis of data available that focuses on

Table 1. Developmental Screenings, Referrals, and Successful Referrals by Year for All Children and for Hispanic/Latino/a or Spanish Origin Children Only

LAUNCH Fiscal Year	Number of Developmental Screenings	Percentage HSLp	Number of Referrals	Percentage HSLp	Number of Successful Referrals	Percentage HSLp
2015–2016	4,953	65.3%	238 (4.8%)	69.7%	94 (39.5%)	73.4%
2016–2017	6,641	67.7%	352 (5.3%)	66.8%	132 (37.5%)	69.7%
2017–2018	6,785	65.5%	260 (3.8%)	66.5%	166 (63.8%)	67.5%
2018–2019	4,339	59.1%	158 (3.6%)	71.5%	127 (80.4%)	70.9%

Note: %HSLp = Hispanic/Latino/a or of Spanish origin

referrals to early intervention only from the three health clinics shows a similar promising trend. In 2013, the average for successful referrals was 48.4%. In 2019, the average was 63.0%.

Participating agencies have recognized the value of care navigation, as is reflected in the following comments from Every Child Pediatrics and Clinica:

Our care navigators have become an integral part of our team . . . The role supports the providers' ability to work at the top of their licensure, and the team functioning supports the fulfillment of many organizational [and] contractual requirements. — Every Child Pediatrics

Clinica Family Health noted

Having the care navigator position has provided the opportunity to work on process improvement and has paved the way for its future care management structure. Piloting care navigation activities will now be spread to all care teams. Additionally, staff now has greater awareness and "know the importance of developing screening and connections," thus raising the total level of care provided to families.

Furthermore, the care navigation system has also created the opportunity to collect better data. Reporting systems are now built into the care provision, which allows for better tracking of outcomes and screening and leads to more follow-up and identification of opportunities for improvement.

As a result, agencies are approaching sustainability in various ways including use of Medicaid dollars, grants, and existing organization funding. All agencies have embedded the care navigation best practices into their workflows, and most have expanded these practices into other positions serving young children and their families.

Summary

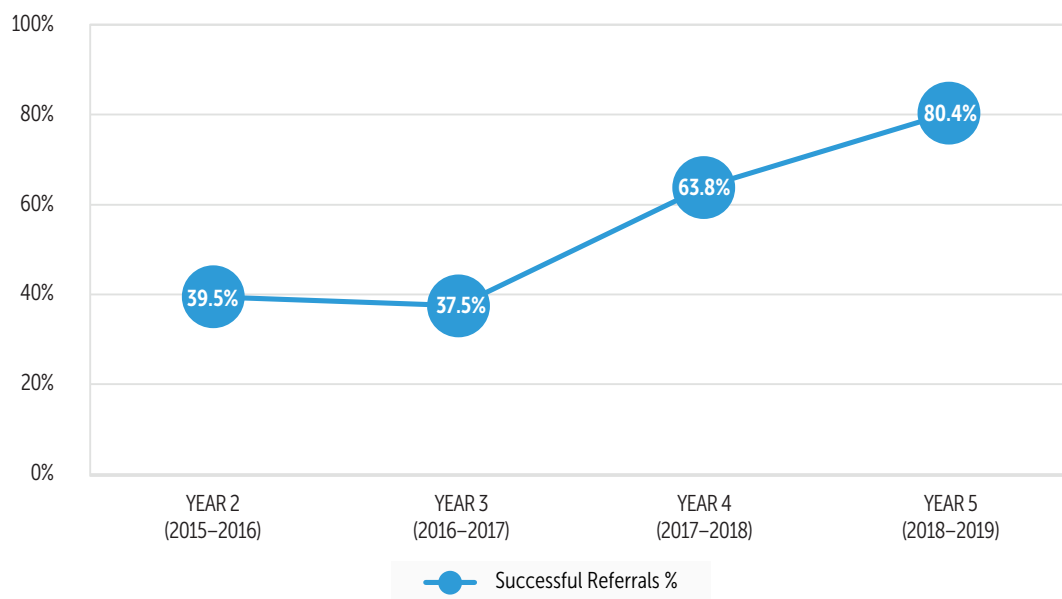
Care navigators, with support from COPL, have been key in promoting best practices in screening and referral in South

Adams County in Colorado. With each year, the Early Childhood Partnership of Adams County, care navigators, and other agency staff have worked to identify the barriers families face in following through on referrals. The Partnership has also made changes in data monitoring and reporting. As a result, all member agencies have refined their practice and implemented new approaches for engaging families and increasing equity. Over 4 years, the percentage of children who had a successful follow-through with an evaluation was 39.5%, 37.5%, 63.8%, and 80.4%, respectively (see Figure 1). The change from 2015–2016 to 2018–2019 represents an overall increase of more than 40.0%. In addition, over the 4 years, the majority of children who had a successful follow-through with an evaluation were Hispanic/Latino/a or of Spanish origin. The respective percentages were 73.4% (2015–2016), 69.7% (2016–2017), 67.5% (2017–2018), and 70.9% (2018–2019), which align with the demographics for South Adams County where Hispanics/Latinos/as or people of Spanish origin represent the majority population. Participating agencies have recognized the value of care navigation and, as a result, are approaching sustainability in various ways including use of Medicaid dollars, grants, and existing organization funding.

Acknowledgment

Collaborating partners for Colorado Project LAUNCH (COPL) include the Office of Early Childhood within the Colorado Department of Human Services, the Colorado Department of Public Health and Environment, the Early Childhood Partnership of Adams County, and JFK Partners at the University of Colorado School of Medicine. The authors thank Peter Dawson, MD, ZERO TO THREE Fellow, for his helpful contribution to an early draft of this article.

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Figure 1. Percent Successful Follow-Through With a Referral for All Children by LAUNCH Fiscal Year

of Medicine. Her specific interests include early language and communication development, parent–child relationships, family routines, and infant and early childhood mental health. Over the years, her research has involved families from diverse racial, ethnic, and socioeconomic backgrounds and their children who are typically developing, at risk, or with special needs. Dr. Kubicek is a ZERO TO THREE Graduate Fellow and served as council chair of the Academy of ZERO TO THREE Fellows from 2015–2017. She is a past president of the Colorado Association for Infant Mental Health and is active in state and national efforts to increase public awareness of, and foster professional development in, infant and early childhood mental health. She is the lead evaluator for the local evaluation of Colorado Project LAUNCH.

Lisa Jansen Thompson, MA, is the executive director of the Early Childhood Partnership of Adams County, CO. In this role, she is responsible for moving the community collaboration’s strategic plan into action and ensuring that local work is funded, coordinated, and well-connected to state-level early childhood systems-building efforts. She brings experience in collaborative strategy, implementation of evidence-based practice at a community scale, and project management. Lisa has been recognized for her early childhood leadership and systemic thinking and participates on several state-level initiatives. Prior to this position, Lisa was a program manager for early childhood mental health services for 3 years and an early childhood mental health therapist for 11 years.

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Stephanie Henderson, MSW, with the Early Childhood Partnership of Adams County, has been supporting screening and referral best practices, including care navigation, for more than 5 years. Prior to championing early childhood systems-building efforts, she worked directly with children, youth, and families in a variety of settings.

Rachel Hubbard, MA, is the young child wellness coordinator for Project LAUNCH at the Early Childhood Partnership of Adams County, CO. In this role, she has developed strong partnerships to support delivery of the five LAUNCH strategies, including screening and referral and care navigation. Prior to this position, Rachel was an early childhood/elementary school curriculum director for 5 years and an early childhood special education teacher for 3 years.

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