Ways of Nurturing Development through Enhancing Relationships: Community Partnerships for Young Children with Special Health Care Needs and their Families

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Implementation Phase Two Progress Report
June 2010-December 2010
The Colorado Trust’s Partnerships for Health Initiative
Implementation Phase Two Progress Report

Project Title: WONDERbabies

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Report Date: December 10, 2010

Report Time Period: June 1, 2010 – December 10, 2010

Colorado Trust Identification Number: 2006-047

Authorized Signature:
Project Summary - The project summary should address each of the following areas.

General Program Overview (3-5 pages):

Provide a brief description of your partnership, including the organizations that are involved. Please note if any new partners have been added since your last progress report and describe how they are involved.

The WONDERbabies Partnership for Health is a Colorado Trust funded initiative focused on building a system of care for babies and young children with special healthcare and developmental needs and their families. Through work in three target areas, systems issues, training and education, and data collection and evaluation, WONDERbabies' goal is to create an integrated, comprehensive system of care where “every door is the right door”.

The WONDERbabies Partnership includes representation from state departments (Colorado Department of Public Health and Environment, Health Care Program for Children with Special Needs; Department of Human Services, Early Intervention Colorado and the NICU Liaison Project), institutions of higher education (University of Colorado Denver, Departments of Psychiatry and Pediatrics; Irving Harris Program in Child Development and Infant Mental Health), stakeholder associations and organizations (CoAIMH - Colorado Association for Infant Mental Health; ABCD - Assuring Better Child health and Development), family leadership and parent advocacy groups (Family Voices Colorado; Grupo Vida; JFK Partners; Colorado Bright Beginnings), and service providers (The Children’s Hospital; ACT - Assessment and Consultation Team; ENRICH - Enrichment using Natural Resources In Communities and Homes; Anchor Center for Blind Children). No new partners have been added during this reporting period.

Provide an update on the progress your partnership has made toward achieving the goals specified in your grant proposal. How has your partnership made progress toward building both “trains” (any specific program you are implementing) and “tracks” (the infrastructure and resources that support programs).

Goal 1: Systems issues

WONDERbabies continues to work towards integration and coordination among stakeholders through participation in statewide task forces, advisory councils, and committees. With respect to both trains and tracks, our collaborative efforts yield trusting relationships among key partners and stakeholders that can further advance system building efforts. WONDERbabies is engaged in efforts that directly impact the lives of babies and young children with special healthcare and developmental needs and their families.

Participation in local and statewide initiatives enabled WONDERbabies to integrate the interests and needs of babies and young children with special health care needs into areas including the following:

- Creating medical homes for babies and young children with special health care needs that provide coordination of care, communication and planning among family, healthcare providers, community programs, insurance and other payment sources.
- Understanding the family perspective and experience when families have multiple points of entry and numerous service providers and complex needs that are not easily or adequately met within the current early intervention system.
Keeping cultural components in mind while collaborating and building systems that support people with disabilities as they transition throughout life.

WONDERbabies attended the Colorado Association of Funders’ Social Media training on August 24, 2010. This training featured sessions on how to most effectively use Facebook and Twitter to expand and engage your audience. At the WONDERbabies Quarterly Partnership Meeting on September 1, 2010, Partners discussed their use of social media to date. The Children’s Hospital is connected to over 6,900 “friends” and uses Facebook to share child and family stories, hospital events and news, common conditions and other health related information, and fundraising campaigns. The Colorado Association for Infant Mental Health and Family Voices Colorado use Facebook to share newsletters, articles, products, resources, as well as conference and meeting announcements, while Anchor Center for Blind Children uses Facebook to post photos of school graduations and field trips. WONDERbabies will create a Facebook page to share information with Partners, as well as spread the word to professionals and families about training opportunities and resources.

WONDERbabies Partner El Grupo Vida was also featured at the September 1st Quarterly Partnership Meeting. Maria Cabral spoke about El Grupo Vida’s activities, including a legislative conference, traumatic brain injury support group, and weekly computer classes free to families. El Grupo Vida worked with Family Voices Colorado (a WONDERbabies Partner) to do a systems overview training at Anchor Center for Blind Children (another WONDERbabies Partner). Partners discussed ways in which the system of care for babies and young children with special health care and developmental needs can be more coordinated. Suggested strategies include the following:

- Early Intervention Colorado providing speakers that can explain the early intervention systems at conferences for groups like El Grupo Vida and other family advocacy entities that help EIC with connections to families and referrals.
- For organizations with large Spanish speaking populations (e.g., at The Children’s Hospital 40% of babies in the neonatal intensive care unit are born to families that are Spanish speaking only), it will be important to fund efforts of groups like El Grupo Vida.

The discussion centered around how organizations within the WONDERbabies Partnership, as well as within Colorado’s system of care for babies and young children with special health care and developmental needs can leverage their assets to better meet the needs of children and their families. With efforts like the ones detailed above, organizations can successfully accomplish their goals and support and promote each other’s efforts at the same time.

Goal 2: Training and education

Our second target area involves increasing awareness and capacity of the system to meet the needs of babies and young children with special health care needs and their families. The following are selected examples of training and education efforts in which WONDERbabies has been involved during this reporting period:

- Presented “Developmental Screening in Pediatric Primary Care” at The Children’s Hospital, Denver (50 participants) on August 23, 2010
Presented “Transition to Parenthood” at The Children’s Hospital, Denver (20 parent participants, 2 professionals) on October 13, 2010

Hosted Fussy Baby Network meeting in Denver (35 participants from six sites across the country) on October 13-14, 2010

Presented “Talking about Toddlers” at The Children’s Hospital, Denver (75 parent participants, 3 professionals) on October 19, 2010

Presented “This is Infant Mental Health” at the inaugural meeting of the Blue Ribbon Policy Council (30 participants) on October 29, 2010

Presented Infant Assessment lecture to Psychology Interns at The Children’s Hospital, Denver (6 participants) on November 2, 2010

Presented Social Network Analysis lecture to School of Public Affairs students (17 participants) on November 4, 2010

Presented “Closing the loop: Improving quality of screening, identification, referral and outcomes related to developmental screening through a multi-directional collaboration” at the American Public Health Association 138th Annual Meeting in Denver on November 10, 2010

Presented Family Infant Relationship Support Training Program (FIRST-3R) in Aurora, CO (5 parent participants, 50 professionals) on November 18-19, 2010

On December 1, 2010, WONDERbabies hosted our 3rd Annual Stakeholders’ Community Forum, “Developing Health Homes for Children Enrolled in Early Care and Education Settings.” The Forum featured keynote speaker Dr. Julie Novak, who discussed a Health Home model that used community collaboration in San Antonio, Texas, as well as foundational evidence-based successful programs. In the afternoon, Dr. Danielle Varda presented the WONDERbabies social network analysis research and data on Colorado’s system of care for babies and young children with special health care and developmental needs. Seventy people registered to attend the Forum. Registrants came from all over the State, and included early interventionists, social workers, psychologists, nurses, and administrators. The Colorado Department of Public Health and Environment (CDPHE) sponsored the Forum, providing scholarships to public health professionals and helping to offset conference expenses.

Of the participants attending the Forum, 48 completed evaluations. Both Drs. Novak and Varda were each rated 5.8 (out of 6) on their knowledge of the subjects they presented on (health homes and social network analysis, respectively). The Forum overall was rated a 3.36 (out of 4). Participant comments included:

- “Presenters were great; they both presented information in new ways.”
- “I liked best the new concepts and ideas for furthering programs, especially in terms of making them family-centered.”
- “I liked the variation in presentation from systems overview to very specific discussion about practical application.”
- “Dr. Varda was effective at helping me understand our complex system.”
- “Hearing the stories of collaboration was wonderful!”
**Goal 3: Data collection and evaluation**

The WONDERbabies Partnership for Health established measurable indicators, developed evaluation surveys for education and training opportunities, and elicited cooperation in sharing data among Partners. Standardized evaluation forms for trainings and educational opportunities can be used to measure change in service provision, practice, and systems work and engage participants in developing future trainings.

The WONDERbabies website continues to expand (www.wonderbabiesco.org). In this reporting period, our website has received an average of 380 daily hits (a 75% increase since the last reporting period), with a total of 111,327 hits since our launch two years ago. The most popular pages are currently our Publications & Materials page, with the Getting to Know Your Baby booklet as the most downloaded resource, followed by WONDERbabies Partner, Dr. Joy Browne’s resources on chemosensory, auditory and sensory development in newborns. The Upcoming Events and Education & Training pages are updated weekly with events that would be of interest to families and providers from across the state, including relevant local and national conferences and trainings.

Since the last reporting period, we have analyzed, interpreted, and presented the data from the statewide social network analysis conducted in the spring of 2010. The first presentation was made to WONDERbabies Partners and a group of invited early childhood systems stakeholders at the June 2010 Partnership meeting. Over the summer we successfully piloted the personal network survey with a group of families and have summarized these data and included them in presentations and a manuscript that is currently under review. Please see the “Supplemental Data” document for a summary of the social network data to date. Additionally, we submitted a three year grant to the Health Resources and Services Administration (HRSA) in October, 2010, to engage in statewide social network analysis and strategic collaborative management. We continue to partner with community organizations to further this work. We submitted an Improving Translational Research proposal through Community-Academic Partnerships grant to the Colorado Clinical & Translational Sciences Institute in collaboration with Arapahoe County Early Childhood Council in November, 2010. We are currently working with Family Voices on a federal grant submission that will include ongoing personal network data collection to help improve our understanding of family experiences within the system of care for babies and young children with special health care and developmental needs.

**Indicate if any major activities in your Phase Two work plan have been changed, added or deleted. If changes were made, explain how these changes will improve the effectiveness of the partnership.**

Since the last reporting period, no major activities have changed. We are delighted to report on the additions below as they have potential to significantly enhance the ongoing efforts of the WONDERbabies Partnership for Health Initiative.

- **Addition:** The Center for Family and Infant Interaction has updated materials and training content using the BABIES Model in order to improve the quality of education of families and enhance workforce capacity. Please see the handout describing different programs and educational offerings. Over the next 12 months materials will continue to be revised and updated.

- **Addition:** The Center for Family and Infant Interaction has developed a Learning Collaborative that is being conducted for North Metro and is funded by the Temple Fund.
Hoyne Buell Foundation and Rose Community Foundation. This year-long training effort will ensure that a cohort of providers working with fragile infants, young children, and their families is thoroughly trained and prepared to address the complex needs of this vulnerable population. In addition to monthly didactic content, case review, and clinical application, the learning collaborative model offers reflective processing opportunities. Reflective processing enables professionals to integrate and consolidate what they are learning and consider the impact of their experience on the families and children they serve. Learning collaboratives have been shown to be effective mechanisms for training and sustaining highly skilled professionals and enhancing workforce capacity.

**Addition:** The Colorado Department of Public Health and Environment became a sponsor of the annual Stakeholder’s Community Forum this year. CDPHE provided scholarship funding for public health professionals to attend the conference and provided additional funding to offset the costs of the meeting. We are hopeful that the Forum will be a self-sustaining educational opportunity for stakeholders with a vested interest in babies and young children with special health care and developmental needs for many years to come.
Provide baseline and follow-up data for the indicators in your Phase Two proposal. If you are proposing new indicators for Phase Two, please include a description of the new indicator(s) and baseline data.

**Partnerships for Health Indicator Chart**

| Indicator 1: Increase proportion of healthcare organizations providing patient and family education and technical assistance. |
|---|---|---|---|
| **Time Period** | **Number of organizations* (% of total organizations)** | **Number of presentations/technical assistance** | **Number of participants** |
| July – December 2005 (pre – WB) | 1 (4%) | NICU Project 1-4 contacts per family | 303 |
| January – July 2006 (strategic planning) | 2 (8%) | 1 Presentation & NICU Project 1-4 consults per family | 378 |
| August – December 2006 | 4 (17%) | 1 Presentation & NICU Project 1-4 contacts per family | 422 |
| January – July 2007 | 2 (8%) | 1 Presentation & 1-4 NICU project contacts per family | 491 |
| August 2007 – January 2008 | 11 (46%) | 10 Presentations/TA & 1-4 NICU project consults per family | 979 |
| February – June 2008 | 16 (52%) | 10 Presentations/TA & 1-4 NICU project consults per family | 682 |
| July – December 2008 | 10 (42%) | 22 Presentations/TA & 1-4 NICU project consults per family | 1,267 |
| January – June 2009 | 11 (46%) | 38 Presentations/TA & 1-3 NICU project consults per family | 595 |
| July – December 2009 | 13 (81%) | 8,806 Presentations/TA & 1-3 NICU project consults per family | over 1,151 |
| January – June 2010 | 14 (88%) | 9,099 Presentations/TA & 1-3 NICU project consults per family | 14,684 |
| July 2010 – December 2010 | 12 (75%) | 6,159 Presentations/TA & 1-3 NICU project consults per family | *8,144 |

*Please note: This amount does not include additional family members that were present at Colorado Bright Beginnings visits, so only one family member per visit (n = 5,604) was included in this figure.
Indicator 2: Increase proportion of local public health agencies providing continuing education to develop competency in essential public health services for their employees.

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Number of organizations* (% of total organizations)</th>
<th>Number of presentations/technical assistance</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>July - December 2005 (pre – WB)</td>
<td>0 (0)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>January – July 2006 (strategic planning)</td>
<td>4 (17%)</td>
<td>4</td>
<td>180</td>
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<tr>
<td>August – December 2006</td>
<td>4 (17%)</td>
<td>3</td>
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<tr>
<td>January - July 2007</td>
<td>8 (33%)</td>
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<td>10 (42%)</td>
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<td>January 2009 – June 2009</td>
<td>11 (46%)</td>
<td>65</td>
<td>2711</td>
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<tr>
<td>July 2009 – December 2009</td>
<td>13 (81%)</td>
<td>67</td>
<td>2519</td>
</tr>
<tr>
<td>January – June 2010</td>
<td>14 (88%)</td>
<td>142</td>
<td>1692</td>
</tr>
<tr>
<td>July 2010 – December 2010</td>
<td>12 (75%)</td>
<td>*33</td>
<td>*1664</td>
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*These figures do not include the work of Colorado Bright Beginnings. Although they do provide training on child health and development topics to all new volunteers and partner agencies, their current data tracking system does not allow them to track this data statewide.

Organizations are only counted once per time period regardless of the number of presentations/opportunities they provide within that period.

The data reported for our current reporting period (July 2010-December 2010) includes only our 16 active partners: Anchor Center for Blind Children, Assessment and Consultation Team (ACT), Assuring Better Child health and Development (ABCD), Center for Family and Infant Interaction, Colorado Association for Infant Mental Health (CoAIMH), Colorado Bright Beginnings, Colorado Department of Public Health and Environment (CDPHE), Early Intervention Colorado, El Grupo Vida, Family Voices Colorado, Irving Harris Program in Child Development and Infant Mental Health, JFK Partners, NICU Project, The Children’s Hospital, University of Colorado Denver, and WONDERbabies.
Data from previous reporting periods includes organizations, agencies, and programs that are no longer active WONDERbabies Partners. These are: Harambe, Colorado Department of Education, Wyoming Public Health Association, Colorado Public Health Association, Colorado Society for Public Health Education, Public Health Nurses Association, Parent-to-Parent, Peak Parent, Community Parent Resources, ARC, Zero-to-Three, and March of Dimes.

Please note the data collected above reflects information we were able to obtain from our Partners and from Public records. The organizations are likely to have been involved in other relevant activities that have not been tabulated because we were unable to access the data.

Insights and Lessons Learned (2 – 4 pages)
1. Discuss how the collaborative process is improving in Phase Two.
2. What are the biggest challenges to accomplishing permanent changes in the infrastructure or system that your partnership seeks to improve? Consider local, state and federal policies, economic issues, relationships between organizations and people, local beliefs and attitudes, etc.

The collaborative process continues to evolve for WONDERbabies. Partners represent a broad array of stakeholders and organizations working with babies and young children with special health care and developmental needs across the continuum of care and across the four domains of the Early Childhood Colorado Framework. Over the course of the Partnership, relationships among the Partners have solidified to the point where Partners count on one another to participate in activities (e.g., present at each other’s meetings, participate in data collection and evaluation efforts, work together to obtain funding) that function to strengthen individual Partners and simultaneously bolster and advance the efforts of the Partnership as a whole.

For example, Partners routinely write letters of support for each other when funding opportunities emerge. One of the Partners, the Assuring Better Child Health and Development Project (ABCD), successfully secured a three year grant from the Colorado Health Foundation having called upon various Partners to write letters of support. ABCD also facilitates the CCTSI grant submission that, if funded, would further advance the strategic collaborative management efforts in Arapahoe County.

Partners have also routinely assisted in data collection and evaluation efforts (e.g., completing the Tri-West surveys, responding to the social network survey). Most recently, Partners help identify families for the personal network pilot data collection. Over time, Partners have become increasingly willing to share data and resources in order to leverage information to obtain additional resources, services, and supports for the WONDERbabies population.

The social network data have been extremely informative in guiding WONDERbabies efforts. The data were first presented to the Partners during a quarterly meeting. Partners had time to consider and synthesize what the preliminary data offered about the existing system of care. Further analyses have been conducted and presented to various audiences including, most recently, to the participants at the Stakeholder’s
Community Forum. Partners have used pieces of the social network data in their work at their own organizations. Additionally, Partners have requested information and additional details that can be used to advance their work in their organizations/communities. For example, the early childhood group at CDPHE conducted an internal social network analysis that was modeled after the one that WONDERbabies developed. We continue to expand and facilitate applications of the methodological approach developed for WONDERbabies to other aspects of the system of care and to other systems of care more broadly.

Current challenges include thinking through durability and sustainability for the WONDERbabies Partnership as the formal funding period comes to an end. We have been dialoguing with Partners during quarterly meetings and with system stakeholders between quarterly meetings about the evolution of WONDERbabies and how it will evolve in the coming years. Financial constraints continue to be one of our primary challenges. Asking overtaxed Partners to provide time and effort without compensation is a tremendous challenge. Partners are willing to bring their resources to the table if they feel that these resources will be leveraged into something more substantial. However, the most substantial “resources” for our target population exist at the State Department levels. Unfortunately, State programs are not yet willing to reconsider how to distribute their resources in a way that is more consistent with meeting child and family needs. We continue to strongly advocate for establishment of funding priorities and service delivery models that are consistent with population needs.

Our core group of Partners has remained consistent over the past 24 months. Our Partners continue to be stretched thin as a result of losing resources and positions at their agencies. The focus of quarterly meetings is on productive agendas that provide information, allow for conversations, continue to foster relationship development, and advance Partnership activities and goals.

Ultimately, our goal is to firmly establish WONDERbabies within the early childhood system in Colorado so that the needs of babies and young children with special health care and developmental needs are included in existing and yet to be developed policy, service delivery, and advocacy efforts. Dr. Talmi is a member of the Early Childhood Councils Advisory Team (ECCAT), serving on the data and evaluation subcommittee of that group. She is also on the State Assuring Better Child Health and Development Team and serves on the Data subcommittee for that group. Dr. Talmi participates in the quarterly State Early Childhood Framework meetings and contributed to the development of the “framework in action”. Most recently, Dr. Talmi was invited to join the Blue Ribbon Policy Council, a group of stakeholders and leaders in the field of Early Childhood Mental Health. Mandi Millar represents WONDERbabies on the Medical Home Advisory Group through CDPHE. Such activities help us infuse WONDERbabies goals into the strategic planning process as many young children with special health care and developmental needs across the early childhood system. These efforts are ongoing and require time and participation in state partnership activities on a regularly basis. Without further funding for staff time, it may be difficult to sustain this level of participation.

One key lesson that WONDERbabies has learned is to not focus on the numbers at our table but rather, on the relationships we form among Partners and other key stakeholders. These relationships have advanced our mission and vision exponentially. We have been able to leverage resources, get invited to many tables, and be represented and
many other tables as a result of relationships among the Partners. We have also noticed the impact of braided representation in that at times when WONDERbabies is not at the table, one of our Partners or a close collaborator will often raise issues that are central to our work. Our collaborative efforts extend far beyond the Partnership itself and are being weaved into the system of care.

Perhaps our biggest lesson has been in the time scale necessary for systems change. Coordination, integration, and communication are challenging enough within systems. Across systems the barriers seem insurmountable at times. We are fortunate to be in a State that focuses on early childhood issues. Numerous parallel efforts exist to improve systems of care for young children and their families. WONDERbabies plans to facilitate the emergence of tracks that guide the establishment of a comprehensive system of care for babies and young children with special health care and developmental needs through our ongoing efforts over the next 18 months.

Technical Assistance
1. Usefulness of technical assistance
   a. Has the technical assistance you received from the coordinating agency, the Center for Public-Private Sector Cooperation, been useful in helping your partnership work? What made the technical assistance useful? If not, please explain.
   b. Are there any specific technical assistance or training needs that you anticipate over the next six-month period?

   Facilitation continues to be vital in supporting our Partnership efforts. Our collaboration with Dr. Danielle Varda has allowed us to advance our understanding of the system of care with empirical data. Beyond data gathering, this work has allowed us to operationalize and measure the success of our Partnership in changing the system of care. Beverly Buck has been instrumental in supporting our efforts and advancing WONDERbabies goals and priorities. In addition to regularly attending and co-facilitating Partnership meetings, Beverly regularly sends us information and materials that are relevant to the Partnership (e.g., funding opportunities, research articles). Her dynamic presence at our quarterly meetings helps engage Partners and propel us forward. Beverly has facilitated numerous invaluable connections on behalf of WONDERbabies and continues to encourage us to wear our WONDERbabies glasses.

Products and Media Coverage
1. If you have produced any reports, news releases, brochures or other print or electronic publications related to this partnership, please provide a brief summary or the website link to those materials.
2. If you received any media coverage during the reporting period, please provide a summary of that information.

WONDERbabies Brochure
Report for Children’s Advisory Council
Colorado Bright Beginnings Community Resource Guide
Giving Your Child a Bright Beginning Parenting Handbook
Video: Young Children in Foster Care