

H6MMC22737

PROJECT IDENTIFICATION

Project Title: Project CASCADE

Grant Number: H6MMC22737

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Project Period: September 1, 2011 – August 31, 2014

Total Amount of Grant Awarded: \$843,092

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Frequently Used Acronyms

ABA	Applied Behavior Analysis
ABCD	Assuring Better Child Health and Development
ADDM	Autism and Developmental Disabilities Monitoring program
ASC	Autism Society of Colorado
ASD	Autism Spectrum Disorders
CASCADE	<u>C</u> ollaborative <u>A</u> ddressing <u>S</u> ystem <u>C</u> hange in <u>A</u> SD and other <u>D</u> evelopmental disabilities
CCB	Community Centered Board (serving people with developmental disabilities)
CDE	Colorado Department of Education
CDPHE	Colorado Department of Public Health and Environment
CO CANDO	(or CANDO) Colorado Collaborative for Autism and Neurodevelopmental Disabilities Options
CSHCN	Children/youth with Special Health Care Needs
CU SOM	University of Colorado School of Medicine
DD	Developmental Disabilities
EC	Early Childhood
EI	Early Intervention
HCP	Health Care Program for Children (Title V CSHCN program)
HCPF	(Colorado Department of) Health Care Policy and Financing
HIMAT	Health Insurance Mandated Autism Treatment (CRS 10-16 104 (1.4))
JFK	JFK Partners (University of Colorado School of Medicine LEND/UCEDD)
LEND	Leadership Education in Neurodevelopmental Disabilities
LSAE	<i>Learn The Signs. Act Early.</i> Centers for Disease Control and Prevention ASD campaign
PCP	Primary Care Provider
TA	Technical Assistance
UCEDD	University Center for Excellence in Developmental Disabilities

A. PURPOSE OF PROJECT

The 2011 application to the Maternal and Child Health Bureau (MCHB) for Project CASCADE (Collaborative Addressing System Change in ASD and other **DE**velopmental disabilities) was presented by the Autism Society of Colorado (**ASC**) and two partners: the University of Colorado School of Medicine **JFK Partners** (the Colorado LEND program), and the Colorado Department of Public Health and Environment (**CDPHE**), Children and Youth Branch (which houses **HCP**, the Title V Children with Special Health Care Needs (CSHCN) program). The **purpose** of Project CASCADE was to address MCHB's six outcomes for CSHCN and their families, which coincided substantially with many needs of Colorado children and youth with autism spectrum disorders (ASD) and other developmental disabilities (DD) and their families. Colorado ASD/DD service system needs were identified by the Governor's Autism Commission and addressed in the Commission's 2009 10-year strategic plan.¹

Some of the principal **needs and problems** of the Colorado population with ASD/DD as documented in the 2011 application included:

1. Information and support for families and service providers to forge effective partnerships to identify and meet the needs of children and youth with ASD/DD.
2. Medical homes access for support of comprehensive health care for children and youth with ASD/DD.
3. Earlier diagnosis of ASD/DD, as diagnosis in Colorado was occurring at a later age than the national mean age, delaying initiation of critical early intervention.

¹ *Report of the Colorado Autism Commission for Senate Bill 08-163, October 2009, may be accessed @ http://www.coddc.org/PDFs/CAC_final.pdf*

4. Fewer obstacles in securing financial coverage for services, which persisted despite the state legislative accomplishment of Health Insurance Mandated Autism Services (known as HIMAT).
5. A system of services organized for easy accessibility by families, in contrast to the silos and fragmentation families experienced.
6. Better preparation families and youth who have ASD/DD for transition to adult care, as well as better preparation of the providers of care to support transitions.

B. GOALS AND OBJECTIVES

1. Project CASCADE Goals & Objectives

Please note: A revised workplan submitted in fall 2011 made adjustments (primarily timelines) to address a 2011- 12 funding decrement. In the revision, the original Objective 3.2 (a Consumer Database/Registry of health care coverage) was recast as Objective 1.6 in Goal 1. The discussion hereafter reflects that adjustment.

- **Goal 1. To expand partnerships between professionals and families of children and youth with autism spectrum disorder and other developmental disabilities (ASD/DD),** addressed in: Objective (Obj.) 1.1 - to foster dialogue between parents and professionals regarding ASD/DD, using information/training sessions, fact sheets and live/webinar sessions; Obj.1.2 - to prepare local health department personnel for collaboration with families affected by ASD/DD; Obj. 1.3 - to prepare family/youth for policy leadership; Obj. 1.4 - to offer culturally/linguistically appropriate resources for diverse families; Obj. 1.5 - to bridge the gaps in the medical and education systems via a Med-Ed task group; and, Obj. 1.6 (added in 11/11 workplan revision) - to develop and monitor a Consumer Database/Registry of health

care and funding for information on the impact of Colorado's insurance mandate and other consumer experiences.

- Changes:* Some activities to these objectives were implemented by different partners as a consequence of changes in the core partnership structure and/or changes in leadership of those entities, as described below in **Obstacles and Compensatory Strategies**. This led to more reliance on technology vs. travel for outreach to rural communities. In addition, proposed product and fact sheets titles (i.e., *ABC's of Autism* and *Mythbusters*) were often replaced by titles reflecting specific content. A JFK Partners-HCP (JFK-HCP) quarterly webinar series implemented in Year 1 (and continuing) fostered improvement of family-professional partnerships by presenting core and emerging information on topics in ASD/DD. Speakers included health care and health science professionals, public health professionals, and family members and or individuals affected by ASD/DD. Live sessions at the Anschutz Medical Campus (AMC) were disseminated by webinar to 14 HCP regional offices and the Denver CDPHE Title V office. Individual presentations also served other CASCADE goals according to the specific content addressed (e.g., medical, home, transition). A Consumer Registry was not created due inability to develop a statewide data tracking system (see Goal 4) with which the Registry was expected to interact.
- **Goal 2. Improve access to a medical home**, addressed in: Obj. 2.1 –to infuse ASD/DD materials into trainings for local Medical Home implementation teams and Obj. 2.2 - to implement family-centered care, easy access, easy referrals (principles of Medical Home learning collaborative approach) in local communities.

- Changes:* Increasing use of technology by the CASCADE team and by the Colorado Medical Home Initiative facilitated dissemination of evidence and resources through Colorado Medical Home Forum meetings. Forums were decreased in frequency by the State, from monthly to alternate months, midway through the project period. As noted for Goal 1 (and addressed in **Obstacles and Compensatory Strategies**), the addition of Colorado Assuring Better Child Health and Development (ABCD) as a core partner strengthened the goal, as ABCD staff met with practices in communities throughout the state, encouraging the medical home approach.
- **Goal 3. Increase access to adequate health insurance and financing**, addressed in: Obj. 3.1 - to create provider and insurer resources on evidence for ASD treatment options, (*Obj. 3.2 - recast as Objective 1.6, Consumer Registry, as noted earlier*), and Obj. 3.3 - to analyze implementation of Federal and state health care laws and policies to inform consumers and the Colorado Division of Insurance.

- Changes:* In the absence of the Consumer Registry (Obj 1.6), ASC monitored implementation of federal and state policies, aggregated and responded to consumer complaints, but consumer data could not be elicited and tracked as methodically as originally planned. ASC issued *Action Alerts* throughout the state to acquire documentation of issues families confronted in acquiring services or insurance coverage for needed services (e.g., applied behavior analysis) to inform policy makers. (See **Obstacles and Compensatory Strategies**, below.)
- **Goal 4. Increase early and continuous screening in the medical home**, addressed in: Obj. 4.1 – to add systematic ASD screening to ongoing efforts in developmental screening in pediatric and family medicine practices statewide; Obj. 4.2 - to integrate

the electronic system (IDS) used by CDPHE with those of the Children's Hospital of Colorado and community pediatricians for centrally recorded data from autism screenings; Obj. 4.3 - to train pediatricians to score, interpret and communicate screening results and other information to families for increased participation in the care of their children with ASD/DD; and, Obj. 4.4 - to use the IDS application to track ASD/DD screening results, specialty/subspecialty care, and effectiveness.

Changes: CO ABCD strengthened the capacity of the project to make progress towards the adoption of standardized developmental/ASD screening & assessment practices and to deliver training to providers, complementing work by JFK Partners and the Colorado Medical Forum. As stated earlier, inability to establish the link with a statewide data tracking system prevented attainment of Obj. 4.2 and 4.4.

- **Goal 5. Improve organization of community services for easy use by families,** addressed in Obj. 5.1 - to update and disseminate the Care Coordination Plan and Care Coordination Toolkit to increase knowledge of and access to adequate care coordination.

Changes: Two updates of the Care Coordination materials occurred, rather than the one planned, to incorporate more resources. Late in Year 2, JFK Partners was funded by the Colorado Department of Human Services Developmental Disabilities program to conduct a multi-part Dual Diagnosis Gap Analysis Project on services for Coloradans who have ASD/DD and concurrent mental health or behavioral disorders. The Colorado Autism Commission had identified the absence of such services as one of the most critical ASD issues. A subsequent study of Medicaid structural issues affecting Colorado children with behavioral issues and co-occurring ASD/DD

(Accessing Intensive Mental Health Services (AIMS) for Children Report: The Co-Occurring Disorder Dilemma), recommended a state-level study of service access for this ASD/DD subpopulation. Late in 2012, CASCADE funded a consultation on the issue by Dr. Joan Beasley of the University of New Hampshire, creator of the START model (Systematic, Therapeutic Assessment, Respite and Treatment) for the dually diagnosed. With support from CASCADE and CO CANDO (successor to the Colorado Autism Commission) and participation of some of the partners, JFK Partners conducted the Gap Analysis Study in Years 2 and 3. Activities and outcomes for the study hereafter will be reported under Obj. 5.2 - to conduct the Dual Diagnosis Gap Analysis.

- **Goal 6. Improve transition to all aspects of adult health care, work, and independence**, addressed in: Obj. 6.1 - to create a transition awareness campaign for parents and youth to be embedded into Colorado Medical Home Initiative and family outreach programs; and Obj. 6.2 - to increase state capacity for successful transition through training of pediatric and adult care providers.

Changes: In Year 3, the emerging Gap Analysis findings (Obj. 5.2) and the active participation in CANDO monthly meetings of an adult with ASD resulted in more attention of the transition-aged and adult population with ASD/DD. For example, JFK Partners conducted a daylong conference on transition-aged youth and adults and use of ABA for adaptive behaviors, and also offered four trainings for evaluation and interventions with adults with ASD/DD.

2. Obstacles and Compensatory Strategies

Two major obstacles to the full implementation of Project CASCADE were

personnel changes at ASC and CDPHE reorganization.

Personnel Changes at ASC

- Betty Lehman, ASC Chief Executive Officer (CEO) and original Principal Investigator (PI), left her position mid-year in Year 1. Subsequently, the ASC Board of Directors appointed John Miles, as CASCADE PI. Mr. Miles, recently retired from the position of Assistant Director of the Colorado Department of Human Services, Division for Developmental Disabilities, served as ASC policy advisor under Ms. Lehman prior to assuming the PI role.
- The ASC CEO position was not filled until Year 2, when veteran nonprofit professional James Buckles was hired to oversee ASC's strategic plan, daily operations, and financial oversight, providing the coordinated environment to facilitate implementation of CASCADE by John Miles. (Mr. Buckles subsequently left ASC late in Year 3 of CASCADE.)
- In Year 3, further resignations at ASC meant that the only grant supported ASC staff member to experience the whole of the project was John Miles, who has since returned to retiree status.

Organizational and Related Changes at CDPHE

- Early in Year 1, the CDPHE Title V program was significantly reorganized, impacting the HCP (CSHCN) program centrally and statewide. CASCADE plans for regional outreach through travel to HCP office visits were changed to delivery of content by JFK Partners and HCP in a series of interactive webinars (JFK-HCP Webinar series). Fourteen live, regional forums covering the State ultimately were conducted (11 as part of the Gap Analysis), but regional Community-Centered Boards

- (CCBs) were determined to be better hubs for the meetings.
- Also in Year 1, Dr. Vickie Thompson, Director of Newborn Screening Programs and a champion for the goals of Project CASCADE, resigned from CDPHE. The loss of Dr. Thompson compounded the uncertainty faced by the Project CASCADE leadership during several months of Year 1 and into Year 2. Dr. Thompson was also the chief CDPHE proponent for establishment of the centralized tracking system for screening through interventions of identified children.
 - Inability to establish linkage with an existing database system for tracking the progress of positive ASD screens, with feedback on outcomes to PCPs, was the major obstacle encountered in the project. CDPHE reorganization entailed delays and eventual awareness that the Integrated Data System (IDS), targeted for the ASD/DD add-on, would not be feasible. With renegotiation of the CDPHE contract in Year 2, Erica McKiever, MS, CDPHE EHDI Coordinator, was tasked with exploring alternative state IT systems for the ASD/DD tracking system. For some time, the CDPHE Colorado Immunization Information System (CIIS) seemed a likely option, although it too proved unworkable. Other paths to a solution included development of a Screening Brief in collaboration with the Blue Ribbon Policy Council to strengthen the statement for the data needs (Obj. 4.2) and exploration of other states' solutions. CDPHE did develop a report as part of its CASCADE contract to identify internal strategies and options for moving forward after the end of the grant period. Use of the Electronic Health Record (EHR) is currently under consideration.
 - In Year 2, ASC also contracted for Kelly Kast, MSPH, CDPHE Coordinator for Autism Projects, to conduct additional analysis of data from the CDC Autism and

- Developmental Disability Monitoring (ADDM) network to acquire more information about Colorado-specific ASD/DD prevalence and child characteristics (e.g., other diagnoses, IQ, intellectual disabilities, associated features, self-injurious, seizures, role of fear, sleep challenges).
- CDPHE contracted in Year 1 with Colorado Assuring Better Child Health and Development (ABCD) rather than hire a Screening Coordinator. Numerous CASCADE activities were designated for the Screening Coordinator, so ASC also contracted with ABCD. Thus, ABCD Executive Director Eileen Auer Bennett, MBA, joined the CASCADE partnership, overseeing implementation of ASD screening and referral, and physician participation/training objectives. The ABCD contract included Physician Outreach Coordinator Debra Efird, MD, a past JFK Partners LEND Fellow and parent of a child with ASD. Dr. Efird later became Colorado's CDC *Learn the Signs, Act Early* Ambassador, for the duration of the project, which further enriched CASCADE's screening, practice training, and outreach capacity.

C. METHODOLOGY

To address CASCADE goals and objectives, the key partners, ASC, JFK Partners, ABCD and CDPHE, implemented the project workplan activities, some of which were modified to address changing circumstances in the partnership (previously described), the state (e.g., some reorganization of state agencies), and the nation (e.g., implementation of the Affordable Care Act and the Colorado response). To leverage grant resources towards greater goal attainment, the partnership also actively supported, participated in, and worked through the statewide successor committee to the Colorado Autism Commission, that is, the Colorado Collaborative for Autism and Neurodevelopmental Disabilities

Options (CO CANDO, hereafter CANDO), an ad-hoc committee of the Colorado Developmental Disabilities Council.

1. Program Activities

Goal 1. To expand partnerships between professionals and families of children and youth with autism spectrum disorder and other developmental disabilities (ASD/DD).

Obj. 1.1. To foster dialogue between parents and professionals regarding ASD/DD using information sessions and fact sheets, CASCADE partners:

- Delivered *Autism 101* sessions on core and associated characteristics of autism and ways to support to individuals with autism. ASC conducted sessions at the Denver metro area headquarters (Lakewood, CO) monthly and in communities around the state (6-10 additional each year). At ASC's headquarters, sessions drew families, providers of services members of the community at large, donors, legislators, and state employees. Off-site sessions frequently were targeted towards specific populations (library systems, health care students, etc.) and usually were delivered with other agencies (e.g., state agencies and Community-Centered Boards (CCBs)) for outreach to more diverse locations and populations.
- Delivered *ABC's of Autism*. ASC delivered these topical presentations live and/or by webinar to increase urban, suburban and rural participation. The live sessions occurred at various metro Denver locations (e.g., Lakewood, Boulder, Denver) and elsewhere throughout the State (e.g., Colorado Springs, Fort Collins, various mountain communities).
- Developed and disseminated fact sheets. ASC developed (or co developed with others) fact sheets on key issues related to ASD/DD, with family/youth panel review.

ASC occasionally opted to purchase/duplicate a fact sheet from other sources when another agency released a high quality product. Dissemination was accomplished at resource fairs, community meetings, and ASC events, as well as via the ASC website.

Obj.1.2. To prepare local health department personnel for collaboration with families affected by ASD/DD, CASCADE partners:

- Conducted training sessions annually for State and regional HCP personnel. JFK Partners delivered quarterly ASD/DD webinars, conducted live on the metro Denver area Anschutz Medical Campus (AMC) and by webinar to the regional office staff across all 14 HCP programs and staff at CDPHE (the presentations were open to others as well). Live webinar access included question and answer engagement from remote sites.
- Made available to HCP an autism consultant (social worker and parent Val Saiz, LCSW) to address inquiries/referrals regarding or from individuals and families affected by ASD/DD and practices pertinent to the population.
- Facilitated three regional summits Years 1 and 2. CCBs were the main entry point to assemble an array of community stakeholder to help equip families and service providers to work together in local planning for children with ASD/DD. In Years 2 and 3, 11 additional Colorado regional community forums were conducted in the Dual Diagnosis Gap Analysis Project.

Obj. 1.3. To prepare family/youth for policy leadership and advisement, CASCADE partners:

- Recruited/involved parents/youth for policy leadership and advice, including on state policies issues that impact their own lives. ASC's and partners' actions included

singular events such as recruitment of families for grassroots advocacy events (e.g., Year1 *Colorado State Capitol to Speak Up for Kids*; youth self-advocacy in a Colorado Consumer Health Initiative *Health Care Day of Action*), and participation of five young self-advocates with DD in the Colorado State team for the Administration for Developmental Disabilities 2012 Self-Advocacy Summit in Seattle, WA, to establish the fundamentals of a Colorado state action plan for self-advocacy. ASC networked with families and self-advocates using family-friendly programs (e.g., ASC's *Family Pizza Night Out*, *Sensory Family Films*, both in several locations) to support engagement, policy involvement and responsiveness to appeals for information on policy issues.

- Developed in Year 2 and delivered the *Understanding Public Policy Series* to inform and engages young self-advocates, parents, and other members of the community in ASC's public policy program. The four 90-minute workshops included: a) *Government 101* (roles of federal and state government, identifying legislators and key policy issues, and sharing one's story); b) *Private Insurance 101*(HIMAT benefits, healthcare reform, and the ACA); c) *Public Insurance 101*(Medicaid/expansion, Children's Health Plan Plus, how to qualify for and receive benefits, and implications for those affected by ASD); and, d) *Special Education 101* (Colorado special education, Individualized Education Program, out of district placements, and the twice exceptional student). ASC created "*Understanding the Role of Government*" information sheet and "*How to Share Your Story*" for this series.
- Recruited and trained Shannon Zimmerman, parent of a child with autism, to co-chair the ASC Policy Committee, foster family/youth leadership skills, and represent

ASC and family policy interests in state and community meetings in Years 2 and 3.

Obj. 1.4. To provide culturally/linguistically appropriate resources for diverse families, CASCADE partners:

- Linked the Project website (CO CANDO.org) to and disseminated downloaded copies of *CDC Learn the Signs, Act Early (LSAE)* materials in multiple languages at resource fairs and community events. During the project the website was revised to include a Spanish language link to El Grupo Vida (a family group for Spanish-speaking and -culture families of CSHCN).
- Delivered *Autismo 101* to Spanish-speaking childcare providers.
- Translated selected fact sheets into Spanish (occurred primarily in Year 1, prior to resignation of ASC's Spanish-fluent staff member).
- Delivered technical assistance on screening for ASD/DD to Salud, a health center that serves a Spanish-speaking population (by JFK Partners, Years 1-2).
- Hired a parent leader Shannon Zimmerman (at ASC) who is conversationally fluent in Spanish.
- Organized a CANDO quarterly statewide meeting (hosted live and disseminated via webinar by JFK Partners) "Crossing the Divide: Cultural & Linguistic Perspectives in Treatment of ASD," which was delivered in September 2014.

Obj. 1.5. Bridge gaps in the medical and education systems (via a Med-Ed task group), CASCADE partners:

- Worked through CANDO to deliver guidance on discrepancies between the medical and education systems that impeded families' acquisition of needed ASD/DD services. CASCADE supported the merger of the CDE Autism Education Task Force

with the CANDO education sub-committee to ensure coordinated actions and outcomes. JFK Partners brought faculty members Susan Hepburn, PhD, and Kristen Kaiser, MA, into the monthly CANDO meetings in 2012, to coordinate CASCADE/CANDO goals with their ED ID project (improving autism identification among rural and mountain school personnel). Dr. Hepburn, Ms. Kaiser and Melinda Graham (Colorado Department of Education (CDE) Autism Consultant and CANDO member) co-authored Colorado's *Guidance for Educational Identification of Autism Spectrum Disorders* manual for CDE. The guidelines informed statewide trainings to make available ASD educational services independent of a medical diagnosis.

- Organized Ed ID presentations through CANDO quarterly meeting (hosted and webcast statewide by JFK Partners) to inform service providers, educators and families of the updates in educational identification of ASD/DD and implications for families and educators.

Obj. 1.6. Develop and monitor a Consumer Database/Registry of health care and funding for information on the impact of Colorado's insurance mandate and other consumer experiences, CASCADE partners:

- Initiated alternative measures to acquire consumer data in support of efforts to inform policy development and implementation when the Registry could not be created. These included issuing *Action Alerts* throughout the state to acquire documentation from families to address emerging policy/insurance issues and participation in collaborative forums to advise related state actions (see Collaboration later in this section).

Goal 2. Improve access to a medical home that coordinates and co-manages care with

pediatric subspecialties and other services.

Obj. 2.1. To infuse ASD/DD materials into trainings for local Medical Home implementation teams, CASCADE partners:

- Established a core group in Year 1 to influence infusion of ASD/DD information in state and local medical home initiatives. The group included JFK Director Dr. Robinson, ABCD Physician Outreach Coordinator Dr. Debra Efird, and Denver HCP Social Worker Val Saiz. Dr. Robinson served on the Steering Committee of the Colorado Medical Home Initiative and as a member of the planning group, assuring attention to ASD/DD issues in the CO Medical Home throughout the project.
- Selected 2007 AAP best practices as the standard and correlated them with Colorado Medical Home Initiative materials (performed by Dr. Debra Efird).
- Participated regularly in Medical Home Forums.
- Disseminated ASD/DD information and materials to medical home teams via the Colorado Medical Home meetings held live in Denver and accessible in communities throughout the state (initially by phone and soon thereafter by webinar). In April 2012, Colorado prevalence information from the ADDM network, as well as screening, diagnostic and intervention materials. In June 2013, health systems, youth engagement, and care transitions and the medical home model were presented by speakers Dr. Laura Pickler, MD, MPH, (a medical home advocate for underserved children and adults), CDPHE professional and family staff, and a speaker on youth experiences.
- Linked the CANDO website to the Colorado Medical Home.
- Integrated the CDC LSAE campaign goals and materials and medical home

concepts in practices visits Years 1-3 (by ABCD and Dr. Efirid).

Obj. 2.2. To implement family-centered care, easy access, easy referrals (principles of Medical Home learning collaborative approach) in local communities, CASCADE partners:

- Provided training and technical assistance (TA) to pediatric and family practices in local communities, including medical home implementation (by ABCD).
- Facilitated small group exchanges in selected Medical Home meetings on issues pertinent to local constituencies, which participants could share with local providers.
- Conducted Referral Roadmap Trainings with 10 local public health teams on MCH health priorities of increasing screening and referral and/or medical home, and with 11 early childhood (EC) councils that identified screening and referral as their health integration priority (Years 2 and 3, by ABCD Colorado).

Goal 3. Increase access to adequate health insurance and financing.

Obj. 3.1. To create provider and insurer informational materials on evidence for ASD treatment options, CASCADE partners:

- Completed an environmental scan of provider/insurer information materials and mechanisms related to best practices in ASD interventions.
- Tracked input from Colorado providers, feedback from family experiences, and actions in other states (by ASC).
- Participated as expert sources (JFK Partners faculty Drs. Robinson and Judy Reaven) on the status of Medicaid funding for autism services for the report, *Assessing Intensive Mental Health Services (AIMS) for Children Report: The Co-Occurring Disorder Dilemma* (by Steve Harvey, Esq, JD, MA). The report

contributed to the CO-CANDO and CASCADE decision to pursue the Gap Analysis project in Years 2 and 3. (See earlier discussion of Dual Diagnosis Gap Analysis.)

- Conducted literature searches on evidence-based treatments (by JFK Partners faculty) and the variety of services persons with ASD/DD require, their variability in reimbursable services from state to state to inform discussions on medical necessity within CANDO and with the Colorado Department on Health Care Policy and Finance (HCPF), insurers, and providers.
- Presented *Implications of the Affordable Care Act on HIMAT (Colorado's Autism Insurance)* to public health professionals, in a 2013 HCP-JFK Partners webinar *Update on Autism Spectrum Disorders* (by PI John Miles and JFK Partners).
- Solicited and assembled consumer/provider feedback on issues in acquiring insurance coverage of ASD/DD services (ASC and members of CANDO).
- Worked in variety of collaborative structures to inform policy makers and to advise policy recommendations (by ACS) (discussed under Collaboration section).
- Provided the forum in CANDO meetings for statewide presentation/reports on the status of legislation and health policy developments influencing insurance, waivers and others supports (Years 1-3).

Obj. 3.2 – *deleted from Goal 3, and addressed earlier as Objective 1.6.*)

Obj. 3.3. To analyze implementation of Federal and state health care laws and policies to inform expert opinion and resources to Colorado Division of Insurance and others, CASCADE Partners:

- Reviewed implementation of federal and Colorado laws impacting access, coverage of services for ASD/DD care, and a survey by the Colorado Coalition of

Autism Professionals (ASC task force included an attorney, a paralegal, a licensed psychologist, an ABA therapist, and then-PI Betty Lehman) in preparation for a 2011 statewide HIMAT webinar.

- Deferred development of Year 1 recommendations in consultation with the Colorado Division of Insurance staff, pending ACA implementation.
- Developed the fact sheet *Fast Facts about the Affordable Care Act & Autism Coverage in Colorado* and posted it on the website in Year 2 (by ASC).
- Monitored Colorado's Health Reform Implementation (Connect for Health Colorado insurance marketplace), tracking insurance emails and alerts and monitoring the status of legislation at the state and federal levels all three years (ASC).
- Discussed with Health Care Policy and Financing (HCFP) the inclusion of an ABA benefit in Medicaid state plan, prompting formation of an HCPF internal workgroup in Year 2 (ASC).
- Monitored and commented upon implementation of the ACA and creation of the Colorado Insurance Exchanges and the Essential Health Benefits.
- Worked with the Division of Insurance and legislators on (i) HB13-1266 Insurance Alignment Federal Law, (ii) definition of "habilitative", and (iii) non-monetary conversion of EI and ABA treatment in HIMAT.
- Contributed resources on autism to multiple *Children's Buy-In Outreach Sessions*, conducted statewide by Family Voices Colorado and the HCPF in 2012 (ASC).
- Collected examples of problems experienced by families that resulted in a delay in services and/or denials to present in collaborative discussions.
- Worked with the Division of Insurance to determine effectiveness and efficiency

of the appeals system (ASC).

- Led collaborative advocacy effort for adequate coverage of ABA in the nonmonetary conversion from dollar limits to minimum session requirements in Colorado's ACA compliant health insurance plans (ASC).

Goal 4. Increase early and continuous screening in the medical home.

Obj. 4.1. To add systematic screening for ASD to ongoing efforts supporting developmental screening in pediatric and family medicine practices statewide, CASCADE partner CO ABCD (unless otherwise noted):

- Accumulated data on frequently used screening tools in Colorado and the barriers practices cited to routine developmental screening.
- Conducted at least 3 onsite visits per practice to introduce, implement and follow-up of developmental screening some months later to a varying number of practices/yr.
- Delivered TA and training to promote the Modified Checklist for Autism in Toddlers (M-CHAT) in practice visits around the state.
- Promoted the CDC LSAE during outreach practice visits by ABCD Physician Outreach Coordinator, Dr. Efird (and CO LSAE Ambassador).
- Presented a resource table on ABCD and LSAE campaigns at the Colorado American Academy of Pediatrics 2012 meeting (by Dr. Efird).
- Offered 2012 and 2013 Continuing Medical Education (CME) trainings for practicing family physicians, pediatricians, primary care physician assistants and nurse practitioners (ABCD).
- Presented autism awareness and screening information to early childhood educators four times (twice each in Years 1 and 2) (by JFK Partners). The

presentation addressed the definition of autism, described screening, and covered an overview of interventions. LSAE materials were disseminated as well.

- Offered monthly ADOS-2 Booster Sessions all three years to clinicians to improve ADOS administration skills and scoring accuracy through live administrations, video tapes, and case examples (by JFK faculty, Dr. Terry Katz). In Year 2, the 2nd edition of the ADOS was introduced in three additional half-day sessions.
- Conducted a provider survey of psychiatrists and clinical psychologists to identify training needs and assess state capacity for ASD/DD diagnosis and treatment across the life span (BY CDPHE and CANDO, funded by CASCADE).
- Co-facilitated monthly Model Community Framework meetings with 9 local public maternal child health teams and with 8 early childhood councils (Year 3).
- Conducted *ASQ/ASQ-SE in a Coordinated System* trainings in 2 communities (Year 3).
- Assisted 14 communities in identifying a community goal related to child development (Year 3).

Obj. 4.2. To integrate the electronic system (IDS) used by CDPHE with that of the Children's Hospital of Colorado (CHC) and community pediatricians for centrally recorded data from autism screenings, CASCADE partners:

- Were unable to deliver the planned activities to link a central system with the CHC systems and systems in use at practices. Therefore, associated trainings of practices to use the system were not implemented.
- Developed a Screening Brief in collaboration with the Blue Ribbon Policy Council for Early Childhood Mental Health (co-chair, JFK Partners' Sarah Davidon)

to strengthen support for a centralized data system on the volume and completeness of screening and follow-up on developmental, social emotional, and autism issues.

Obj. 4.3. To train pediatricians to score, interpret and communicate screening results and other information to families to increase parent participation in the care of their children with ASD/DD, CASCADE partners:

- Conducted pediatrician training in helping families understand screening outcomes and next steps in aforementioned practice visits.
- Offered a Continuing Medical Education (CME) training (October 2012) on screening, referral, evaluation and services (by ABCD, featuring JFK Partners' Dr. Judy Reaven). In the associated resource fair, *Milestone Moments* materials were disseminated for participants to take back to their practices (by Dr. Efird).
- Funded customization and reproduction of *Milestone Moments* for widespread dissemination (by CASCADE), especially to health programs that serve diverse and refugee populations, as well as through home visiting programs (e.g., the CO Nurse-Family Partnership) (by Dr. Efird), in Year 2 and 3 (ASC).

Obj. 4.4. Use the IDS application to track ASD/DD screening results, specialty/subspecialty care, and effectiveness of care, CASCADE partners:

- Were unable to conduct planned activities due to inability of the collaborative partners to identify with the State a suitable alternative to the CDPHE IDS platform.

Goal 5. Improve organization of community services for easy use by families.

Obj. 5.1. To update and disseminate the Care Coordination Plan and Toolkit to increase knowledge of and access to adequate care coordination, CASCADE partners:

- Revised the Care Coordination Plan and Toolkit twice to address and incorporate

more resources on tools to measure care coordination (JFK Partners). The Toolkit was designed to help practices and providers measure care coordination outcomes by cross walking Toolkit outcomes with the Medical Home Index survey (JFK Partners in collaboration with the Colorado Care Coordination Community-of-Practice).

- Delivered a 2012 national (AUCD) webinar presentation on issues in standardization and definition of care coordination used in Colorado (by JFK Partners faculty Ms. Davidon).
- Provided technical assistance to align CASCADE care coordination activities with the Colorado Care Coordination Community-of-Practice regarding roll out of ACA in the state (JFK Partners).
- Introduced the Plan and Toolkit to the CO Dept of Human Services for collaboration with their System of Care initiative in the Office of Behavioral Health, the CO Medical Home Collaborative, and CDPHE HCP (JFK Partners faculty Ms. Davidon).
- Delivered *Care Coordination Update*, a 2012 Colorado JFK-HCP webinar featuring Christopher Stille, MD, MPH, principal investigator for a HRSA-funded R40 project, P3RC: Parent-Provider Partnerships for Referral Communication in the Medical Home (JFK Partners & CDPHE).
- Embedded the plan and toolkit in the Project LAUNCH initiative that was awarded to the Colorado Department of Human Services/Office of Early Childhood, in Year 3 (JFK Partners in collaboration with the Office of Early Childhood).

Obj. 5.2. To conduct the Dual Diagnosis Gap Analysis, CASCADE partners (JFK Partners, unless otherwise noted):

- Sought and achieved Colorado Multi-Institutional Review Board approval for administration of the study.
- Appointed a Gap Analysis Steering Committee that included CASCADE PI John Miles and others associated with CASCADE and CANDO.
- Organized and facilitated 11 regional forums throughout the state to identify resources and service gaps and challenges. Community meetings included a broad spectrum of stakeholder groups: families, self-advocates, CCBs, Behavioral Health Organizations and mental health programs and providers, local public health agencies, hospitals and medical providers, law enforcement, education, child welfare, residential care facilities, respite providers and others.
- Compiled and analyzed a catalogue of relevant statutes, policy and regulations to reveal inconsistent/conflicting policies.
- Established and monitored a website survey with English and Spanish language versions for families/individuals, professionals, and the general public regarding access to appropriate services and supports for dually diagnosed individuals.
- Developed a website to host the surveys, create access to videos that offered context for the study.
- Presented status reports in CANDO meetings.
- Presented the draft policy analysis and recommendations in a May 2014 meeting of state agency leaders, including: CDE; Department of Human Services, Offices of Community Access and Independence, Child Welfare and Behavioral Health; CDPHE and HCPF.
- Completed a summary report of the findings for submission to the funder that

identified gaps in waiver services regarding mental health crisis intervention and outline recommendations. (The draft report was completed and submitted to the funder shortly after the end of CASCADE and revised 12/14.)

Goal 6. Improve transition to all aspects of adult health care, work, and independence.

Obj. 6.1. To create a transition awareness campaign for parents and youth that can be embedded into Colorado Medical Home Initiative and family outreach programs, CASCADE partners:

- Assembled a planning group that supported delivery of a transition live presentation and webinar in Year 1(ASC).
- Hosted and supported a 2012 statewide CANDO meeting/webinar presentation that featured the Colorado Division for Developmental Disabilities (DDD) and Division of Vocational Rehabilitation (DVR) state assessment of employment for people with disabilities, which CANDO sub-committees (including CASCADE partners) reviewed to identify strategies for the campaign to address unmet needs, families concerns, and systemic barriers to transition to adult activities and systems (JFK Partners & ASC).
- Purchased the Family Voices *Transition Guide* for dissemination (in lieu of finalizing a draft ASC transition fact sheet) (ASC).
- Hosted and supported a 2013 statewide CANDO meeting/webinar with presentations on transition to adult life as a person with ASD/DD. Presentations identified diagnostic, services, health, educational, vocational and interpersonal challenges, and means to overcome them (JFK Partners & ASC).
- Joined Metro Interagency Transition Team in Year 3 to identify challenges, share

resources with other organizations and create a comprehensive resource fair for families (ASC).

Obj. 6.2. To increase state capacity for successful transition through training of pediatric and adult care providers, CASCADE partners:

- Hosted and delivered a 2012 JFK-HCP webinar on transition to the adult health care system. Speakers were Dr. Laura Pickler, a child/youth development specialist at the Children's Hospital Colorado Special Care Clinic, CPDHE staff, and a young self-advocate (JFK Partners & CDPHE).
- Organized and facilitated regional community-based summits in Grand Junction (Year 1) and in Colorado Springs and Glenwood Springs (Year 2) (ASC, JFK Partners in collaboration with CANDO). The summits addressed local assessments and planning for ASD/DD needs and resources, and included participation of local agencies and provider groups that address transition (health care, employment, residential and direct service supports) to support the local networking that facilitate the full range of successful transitions from pediatric to adult services.
- Helped organize a 2013 live/video Medical Home Community Forum on Care Transitions, through JFK Partners Director Dr. Robinson's Steering and Planning Committee roles in the Medical Home Initiative (JFK Partners & CDPHE).
- Delivered *Supporting Youth with Autism Spectrum Disorders as They Transition from Adolescence to Adulthood* (October 2013), a JFK Partners conference featuring Peter F. Gerhardt, EdD, on evidence-based practice, ABA, and adaptive behavior in community inclusion, employment, sexuality, and quality of life. The presentation was for clinicians, school personnel, community providers, and parents of and

individuals with developmental disabilities.

2. Collaborative Relationships and Partnerships with Key Stakeholders

As a project intended to have statewide impact, collaboration with a broad range of stakeholders throughout the state was critical in attaining CASCADE goals. Starting with the core partnership of lead agency ASC, JFK Partners, CDPHE and, ABCD, through the majority of project activities (policy, system and community-focused) collaborative relationships were fundamental. In the principal instance where collaboration was not feasible (i.e., as CDPHE reorganized), the anticipated outcome was compromised (i.e., CASCADE lost ground in connecting ASD/DD tracking with a centralized information system). Typically, however, collaboration was successful, with the partnership and with a broad array of stakeholders.

The key collaboration outside the core partnership team was with CANDO, the statewide ad hoc committee of the Colorado Developmental Disabilities Council (successor to the Autism Commission). CANDO included family members and self-advocates, as well as many diverse agencies (e.g., the CO DD Council; The Legal Center for People with Disabilities and Older People (CO P&A); CO Respite Coalition; Marion Downs Hearing Center; CO West Regional Mental Health Center, Inc.; mental health payer ValueOptions, Inc.). CASCADE provided technical assistance to carry forward the commitment and energy of the CANDO membership to help address the overlapping goals of the State's 10 year plan with CASCADE, thereby expanding the network and resources of the federally funded project. The CASCADE PIs (Betty Lehman and John Miles) and JFK Director Corry Robinson were members of the small CANDO Executive Committee. In fact, Dr. Robinson co-

chaired CANDO, which further facilitated alignment of actions to pursue the shared goals. ASC hosted monthly meetings of the CANDO Committee Chairs (later co-hosted with JFK Partners at the Anschutz Medical Campus (AMC) as membership grew). JFK Partners hosted the CANDO full membership quarterly meetings at AMC and provided technological support for interactive webinar delivery throughout the entire state.

Dr. Robinson drew upon JFK faculty expertise to enhance co-chaired CASCADE/CANDO goal attainment. For example, JFK's Dr. Susan Hepburn, an autism specialist and scientist joined the monthly CANDO meetings as the need arose for informed discussion of medical necessity in ASD/DD treatments. In Year 3, Dr. Audrey Blakely-Smith was enlisted to train psychiatrists and psychologists in adult ASD evaluation and treatment, a response to a CASCADE-funded CDPHE/CANDO survey of provider capacity and training needs. Similarly, PI John Miles saw the opportunity to leverage CDPHE resources by funding a subcontract for Kelly Kast, MSPH, CDPHE Coordinator of Autism Services, to delve more deeply into ADDM data to better understand prevalence and child characteristics of ASD in Colorado, adding a new dimension to that side of the core partnership.

ASC's own contacts and activities to follow and influence policies affecting children with ASD were supplemented in the CANDO collaboration. Key state players in advocacy for the ASD/DD and CSHCN populations, such as The Arc of Colorado Executive Director Marijo Rymer, kept the committee well informed of policy issues, legislative status and implications of bills, and state rulemaking. One closely followed issue was the 2013 alignment with statutory definition of the

Developmental Disabilities Definition and Determination Rules (which define eligibility for state services) by the Colorado Department of Human Services (CDHS) Division for Developmental Disabilities (DDD). The changed rules define DD in relation to significant intellectual impairment OR significant adaptive behavior, whereas previously, low IQ was essential for eligibility--a crucial achievement of years of work by many CANDO members and agencies, CASCADE principals, self-advocates, families, and others. The revised definition was a significant achievement as the definition is more inclusive of people with ASD who will now have greater access to state-funded long term community-based services. However, Ms. Rymer reported to CANDO that the breakthrough rules were written leaving families to pay substantial costs for required assessments by default, as the DDD, CCBs, and schools were not responsible. ASC wrote to the State Board of Human Services on behalf of affected families affected, which resulted in CDHS' reconsideration of options for using a newly appropriated \$3 million for determinations of a developmental disability and wait list management.

Other collaborations enabled CASCADE to capitalize upon existing resources, infrastructure, and relationships. Some offered pathways to overcome challenges to activities and others opened new opportunities for pursuing the project's mission.

As CDPHE reorganized Title V impacted HCP (CSHCN) offices throughout the state, JFK Partners and ASC piloted an alternate approach for community-level forums by reaching out to Community Centered Boards (CCBs, regional, single entry points for DD services). In 2012, Dr. Robinson joined the Focus on the Future Workgroup convened by Alliance, the statewide nonprofit association of CCBs and

Service Provider Organizations, to address long-term planning of community-based DD services. Membership in the Workgroup helped gain the participation of CCBs in 11 regional meetings of the Dual Diagnosis Gap Analysis.

PI John Miles and ASC staff worked to address gaps in insurance coverage and other financing of services with key state agencies (e.g., HCPF, Division of Insurance Consumer Insurance Council, and CMS) and in partnerships with Colorado policymakers, health insurance companies and managed care organizations, provider organizations, employers, families, and several advocacy and community-based groups. Collaboration with the Division of Insurance for adequate ABA (Applied Behavior Analysis) coverage resulted in the nonmonetary conversion from dollar limits to minimum session requirements in Colorado's ACA-complaint health insurance plans. Additional legislation on this issue will be introduced in 2015 to further expand coverage of ASD services. ASC worked with the Colorado Coalition of Autism Professionals to educate families and professionals about interventions and insurance, and collaborated with the local Autism Societies (Boulder and Larimer Counties) and several CCBs to expand family outreach and family and staff ASD policy education.

ASC Policy Director Kim Tenure served on the Steering Committee for the Colorado Consumer Health Initiative, worked with Family Voices Colorado to promote community awareness on accessing the Medicaid Buy-In Program for Children with Disabilities (Children's Buy-In), and worked in Year 3 with the Metro Interagency Transition Team (MITT). She also worked with: the Children's Disability Advisory Council; All Kids Covered; Great Futures Coalition; Early

Childhood Leadership Council; CO Interagency Coordinating Council; CO Special Education Advisory Committee; and CO Health Benefits Exchange. Ms. Tenure reached out to for-profit entities such as a local pizza chain and a movie theater franchise to open venues for ASC family events. These events in turn built bonds of trust with ASC that fostered family engagement and collaboration.

CASCADE collaboration with families was also facilitated by contracts with parents of children with ASD or other DD conditions. Parent and social worker Val Saiz, LCSW, supported families at HCP offices and fostered collaboration of CASCADE with the Colorado Respite Coalition (which she co-founded). Shannon Zimmerman, co-chaired the CANDO Early Intervention committee, engaged in policy work on public insurance, and interfaced directly with families. She served on the Colorado Special Education Advisory Council and represented ASC in the Parents Encouraging Parents (PEP) Conferences.

The CASCADE partners worked with numerous state and local agencies to implement grant-related activities. Some of these programs included: Early Intervention CO; the Colorado Department of Education (CDE); and, large school systems in the Denver metro area and rural and mountain districts. JFK Partners faculty, Sarah Hoover, MA, co-chaired the Blue Ribbon Policy Council for Early Childhood Mental Health and coordinated converging goals.

Leveraged relationships and resources were essential to the undertaking the Dual Diagnosis Gap Analysis in Years 2 and 3. Collaborations with participants in the 11 regional forums conducted in this project varied by region, but included: families, self-advocates, CCBs, Behavioral Health Organizations and mental health programs

and providers, local public health agencies, hospitals and medical providers, law enforcement, education, child welfare, residential care facilities, respite providers and others. Study administration also required input of members of a diverse Steering Committee, including Corry Robinson and several JFK faculty, CASCADE PI John Miles and ASC staff, and family members affected by ASD (with and without professional affiliations). The Committee also included representatives of: a) Alliance; b) Behavioral Healthcare, Inc.; c) Colorado Behavioral Health Care Council; d) HCBS-DD Waiver Coordination, Colorado Department of Human Services, Division of Intellectual and Developmental Disabilities; e) Prevention and Interagency Collaboration Unit, Colorado Office of Children, Youth and Families; and, f) The Arcs of Colorado, of Arapahoe and Douglas Counties, and of Jefferson, Clear Creek and Gilpin Counties.

Throughout the project, one or more of the CASCADE core partners (ASC, JFK Partners, CDPHE and ABCD) maintained communication:

- Weekly - for close collaboration to implement grant activities, with: CDPHE ADDM (ASD/DD Surveillance); Children's Hospital CO; CO Consumer Health Initiative; Family Voices CO; and, Great Futures Coalition.
- Bi-monthly - for collaboration to implement grant activities, with: All Kids Covered CO; Children's Disability Advisory Council (to CO HCPF); CO Division of Insurance, Consumer Insurance Council; Denver Regional Mobility Access Council; Marion Downs Hearing Center; and Strive (CCB).
- Monthly - for coordination of grant activities or exchange of related information, with: Alliance; The Arc of CO; Autism Society of Larimer County; Colorado

- Behavioral Health; CO Coalition of Autism Professionals; CDE; CO Department of Human Services, Division of Vocational Rehabilitation; CO DD Council; CO Health Benefits Exchange (now known as Connect for Health Colorado); CO Interagency Coordinating Council; CO Medical Home Coalition; Developmental Pathways (CCB); Early Intervention Colorado; HCPF; Imagine! (Boulder CCB); Paraprofessional Research & Resource Center; Region VIII Department of Aging; and, The Legal Center for People with Disabilities and Older People (Colorado P&A).
- At least quarterly - for exchange of related information or to implement an activity related to CASCADE's mission, with: Advocacy Denver (Arc of Denver); Cherry Creek Schools; CO Special Education Advisory Committee; Down-Syndrome Autism Connection; Early Childhood Leadership Council; ValueOptions (mental health).

EVALUATION

Process evaluation documented timely implementation of proposed activities, and delivery of promised resources. Project CASCADE evaluation presumed effectiveness is the cumulative achievement of short and medium term objectives that support attainment of long term goals and impact. In addition to the accumulation of specific assessments and data, progress of the partnerships in moving forward the Colorado State plan and CASCADE goals also was monitored in CANDO meetings.

As a three year project, evaluation of program impact was limited to assessment of short- and intermediate term impact. Short-term impact focused on acquisition of knowledge or skills, gained through exposure to training, technical assistance, and informative materials, and assessed in evaluation questionnaires. Ratings and open ended

feedback received in response to CASCADE partners' performance of these activities were consistently indicative of at least (and typically more than) reasonable success in achieving the targeted numbers and the intended outcomes of activities and objectives.

Evaluation of intermediate outcomes addressed the degree to which objectives and activities substantially increased, for example, the state capacity for screening, diagnosis and treatment of ASD/DD, assessed in screening rates in follow-up with practices.

Attainment of key systems changes intended to improve access to, comprehensiveness, coordination, affordability and organization of ASD/DD services was another aspect of evaluation of intermediate outcomes. The report of the major results and project outcomes, which follows, describes the degree to which goals, such as improved developmental screening were attained, through report of accrued data and report of hallmarks of the system changes (e.g., changes to waivers and pervasive state agency policies). For systems changes in particular, CASCADE core partners were either catalysts or long-term, working advocates in broader collaborations for these changes.

Longer term impact is generally defined as discernible in 5-10 years. For CASCADE, the mission was to contribute meaningfully to the improved the health and quality of life of Coloradans affected by ASD/DD. Some evaluation of longer-term project impact presupposed establishment of the central data tracking system to obtain data on the cumulative outcomes for (unidentified) individual children. So long as that goal remains elusive, the cumulative effects of the project may be best approximated in cross-sectional data comparisons (e.g., in changes in early intervention referral rates, in CO ADDM data in years to come), versus the desired longitudinal data a centralized system would offer. A proxy indicator of the project's long term impact also may be

identified in the persistence of project activities beyond the grant funding. As the later Sustainability section on this topic reveals, although a few goals were not equally achieved, Project CASCADE has made a major contribution to continuing implementation of the Colorado State Plan for improved autism services.

D. RESULTS/OUTCOMES/LESSONS LEARNED (Positive & Negative)

Results and outcomes are reported immediately below by CASCADE Goal. Key outcomes, such as systems changes and screening rates, are presented in bold type, as are barriers to success. Lessons learned are reported at the end of this section.

Goal 1. To expand partnerships between professionals and families of children and youth with autism spectrum disorder and other developmental disabilities.

- **More than 1,000 individuals were informed of core and associated characteristics of ASD** in ASC's *Autism 101* sessions. Recipients included, e.g., self-advocates, families, foster parents of children with ASD, community members, Boy Scouts employees, child caregivers,, CDE investigators, legislators, library staff, nurses, respite providers, special educators, students in allied health fields, and others.
- **Each of the three years, at least 200-250 families, youth, and professionals learned to understand law, policy implications and appropriate services, including insurance coverage, and adaptive skills related to ASD/DD** in ASC's *ABCs of Autism*, in varying topics delivered live (some also by webinar) in locales throughout the state. Topics included: Colorado HIMAT legislation; Juvenile Justice; Transition; IEPs; Financial/Futures Planning; Early Language Development and Communication skills; Applied Behavior Analysis; Autism Coverage and the ACA. Several fact sheets were developed or purchased for dissemination at these sessions,

- resource fairs and other events. Approximately **15,000 fact sheets and brochures were disseminated statewide** topics such as basic autism facts, HIMAT, transition, the ACA and Autism Coverage in Colorado, and the Children's Medicaid Buy-In. In excess of **10,000 CDC Milestone Moments booklets were disseminated.**
- **40 -70 live audience members (professionals and families) and 90+ remote participants² in each of 11 quarterly JFK-HCP webinars acquired knowledge on ASD/DD.** Topics included, e.g.: screening and referral; updates on ASD prevalence, insurance and coverage of services, ACA and HIMAT, co-occurring conditions, DSM V criteria for ASD, care coordination; transitions, social-emotional/mental health services; family leadership; and benefits for Colorado's CSHCN.
 - **3 areas, Grand Junction (western), Colorado Springs (southern), and Roaring Forks Valley (mountain communities) developed ASD/DD action plans or strategies** in community forums facilitated by ASC and JFK staff (Years 1 & 2).
 - **70 family members and advocates learned grassroots advocacy skills** in the 2012 *Speak Up for Kid* campaign at the State Capitol.
 - **140 families acquired understanding, and some leadership skills,** in the *Understanding Public Policy Series* (by ASC).
 - **Systems change was achieved in accessing education services for children with ASD** at CDE through the collaborative activities of CASCADE and CANDO with CDE (e.g., merger of the CDE Autism Education Task Force merged with the CO-CANDO education sub-committee, co-authorship of the state guidelines for education

² Since it is unknown how many attendees viewed webinars at each Adobe connection, it is difficult to accurately estimate total number informed during the JFK-HCP series. Also, a cumulative number is not reported for the 11 webinars since an unduplicated count could not be obtained (i.e., many HCP staff and some JFK participants attended multiple sessions.)

- identification of autism).
- **5 rural and mountain school districts acquired knowledge in identifying and addressing ASD/DD challenges in school settings** via coordination of CASCADE with JFK faculty and CANDO Chair for Screening and Evaluation Committee Dr. Susan Hepburn (PI for Improving Educational Identification in Rural Communities, funded by Autism Speaks).
 - Development of a Consumer Database/Registry was unsuccessful due to **barriers in establishing a centralized data tracking system.**

Goal 2. Improve access to a medical home that coordinates and co-manages care with pediatric subspecialties and other services.

- **2007 AAP evidence-based best practices informed best practices for ASD/DD in the Colorado Medical Home Initiative** (by Debra Efird, MS, LSAE Ambassador).
- **Health care providers and medical home teams acquired updated information on ASD/DD in Colorado Medical Home Forum presentations** organized or delivered by CASCADE partners live and through distance technology throughout the state for community systems building (unduplicated counts not available).
- **At least 113 community pediatric and family medicine practices** received medical home support in ABCD practice visits.
- **10 local public health teams and 11 early childhood councils** received technical assistance regarding the medical home in ABCD Referral Roadmap Training (Years 2 and 3).
- **Public health practitioners in 14 regional health departments** learned concepts for medical home support of transitions, family leadership and family-centered care in

- JFK-HCP webinars.
- **Colorado Care Coordination Resource Guide was cross-walked with the Colorado Medical Home Standards** to include links to validated tools such as the Medical Home Index, with dissemination in trainings and archived webinars.

Goal 3. Increase access to adequate health insurance and financing of services.

Improvements to adequacy of health insurance and financing for services during the project were impacted by actions of the CASCADE partners and their collaboration with others (agencies and families) during the project.

Key systems and funding changes that affect access/insurance/coverage of ASD/DD services in which the partners were active with collaborators included:

- **Increased funding for the Supported Living Services (SLS) waiver** (services for adults with developmental disabilities) eliminated the waiting list and the **Children's Extensive Support (CES) waiver** (Medicaid-funded services and supports to children with developmental disabilities or delays with intensive behavioral and/or medical needs who are at high risk of out-of-home placement) to eliminate the waiting list.
- **Revision of the Children with Autism waiver** (Medicaid benefits for behavioral therapy for children under age five years)
- **Colorado Division for Developmental Disabilities *Developmental Disabilities Definition and Determination Rules* were made more inclusive of people with ASD, i.e., including individuals with higher IQs who have significant adaptive behavior impairment. ASC communications about evaluation costs defaulting to families are under consideration by CDHS regarding disposition of state funds.)**

- **Colorado legislation** (Colorado House Bill 13-1266) **brought HIMAT into compliance with the ACA** by aligning state and federal rules. The bill gave the Commissioner of Insurance rule making authority to convert the monetary limits in Colorado Mandates. ASC and partners (The Arc of Colorado, The Arc Arapahoe and Douglas, Colorado Consumer Health Initiative, Autism Society of Boulder County, Autism Speaks, and many parents) informed the Division of Insurance (DOI) that the conversion was faulty, achieving change in the language from “maximum” to “minimum” in those conversions (i.e., DOI received more than **50 emails from parents mobilized by ASC** to tell their stories, most using an ASC template letter):

From:	To:
\$34,000/ year from child 0-through age 8 (up until 9 th birthday)	“in twenty-five (25) minute increments, established by rule is five hundred fifty (550) visits for a child through age 8”
\$12,000/ year from 9-through age 18 (up until 19 th birthday)	“one hundred eighty five (185) visits for a child aged nine (9) up to age nineteen (19)”

Goal 4. Increase early and continuous screening in the medical home to achieve early detection, diagnosis and treatment for ASD/DD.

- **The percentage of Colorado practices using a standardized developmental screening tool rose steadily throughout the project).**

Colorado Practices Using Standardized Developmental Screening Tool: ABCD database (approximate N = 750) (ABCD Database, 2014)				
	6/12	6/2013	8/14	% M-CHAT use: 8/14
All Practices (Family + Peds)	n/av	44%	46%	11%
Family Medicine	n/av	31%	33%	4%
Pediatrics	70%	88%	92%	32%

- **10 practices completed CME training by ABCD on implementing a standardized developmental screening tool (MCHAT, ASQ, ASQ-SE), from 9/1/13 – 12/31/13.**
- **The most frequently cited barriers to standardized developmental screening** were: lack of awareness of screening recommendations, lack of “buy-in” to current recommendations, use of a non-evidence based tool as part of an Electronic Medical Record (e.g., EMR Milestone Checklist) and related EMR issues.
- **Primary care physician referral to Early Intervention from was static (66-69%).** **Barriers to successful referral for evaluation** cited were: lack of understanding of referral process; lack of a standard office procedure for these referrals; families not understanding the importance of the referral; incorrect contact information.
- **Association with the MCHB SIG project and ability to award CME increased ABCD credibility among practices.** ABCD “Lunch and Learn” in-office Category 1 CME credit used with 4 practices (April-August 2014) resulted in either implementation of /improved screening processes, or improved referral processes.
- **In Larimer, LaPlata, Adams and Pueblo counties, local community work-groups conducted physician outreach for screening and referral best practices** resulting from ABCD Referral Roadmap Training and Model Community Framework training.

Goal 5. Improve organization of community services for easy use by families.

- **The Care Coordination Toolkit and Plan** was
 - o **rolled out to the CO Dept. of Human Services** for collaboration with the System of Care initiative in the Office of Behavioral Health, the CO Medical Home Collaborative, and CDPHE HCP and presented nationally in an Association of University Centers on Disability (AUCD, 2012).

- **included in Colorado's Project LAUNCH initiative** (Colorado Department of Human Services/Office of Early Childhood) as a measure of care coordination and integrated care (in LAUNCH pilot community, Adams County, 2014-15).
- **The Dual Diagnosis Gap Analysis resulted in:**
 - **Legislative recognition of the challenges faced by Coloradans with ASD/DD and who need behavioral health services**, by acquiring State funding for the study.
 - **Mobilization of community forums across the state for support of future legislative changes in access to and the delivery of long term and crisis intervention services for the dually diagnosed population.**
 - **An agenda of recommendations for actions to improve access to and organization of appropriate services for people with ASD/DD and behavioral challenges that are grounded in evidence acquired with public funding.** (See full report in JFK Partners section of Publications and Products Appendix.)
- **New Colorado Respite Coalition (CRC) regional coalitions were established in Grand Junction and Colorado Springs** in 2013-14 (CASCADE subcontract with CRC co-founder Val Saiz, LCSW).

Goal 6. Improve transition to all aspects of adult health care, work, and independence.

- **203 medical practices acquired increased knowledge of transition care** for youth with ADD/DD.
- **255 families acquired skills to support youth transitioning to adult services.**
- **At least 180 youth acquired knowledge to facilitate their transitions** to adult health care and employment or educational opportunities.

- **Increased funding for the Supported Living Services (SLS) waiver (services for adults with developmental disabilities)** eliminated the wait list and improved the transition from school to adult services.
- **Increased focus on transition and adult life with ASD/DD in CO CANDO** resulted from stronger self-advocate participation at the committee level (Years 2 & 3), prompting several JFK trainings on adult evaluation and interventions for providers (informed by a CASCADE-funded survey), and transition-adult focused presentations to the quarterly CANDO whole membership meetings.

LESSONS LEARNED

The principal lessons learned in implementing Project CASCADE are:

1. The importance of unifying entities to provide leadership to achieve widespread change. In this effort, CASCADE funding contributed substantially as such an entity, as did CO CANDO, with its roots in the Autism Commission, and JFK Partners, which has numerous ASD related activities, including LEND, co-leadership of CANDO and technological capacity to support for messaging throughout the state.
2. The criticality of multi-system commitment to common objectives. The complexity of data collection and analysis regarding the needs of people with ASD that cross over many systems, all with different data systems and reporting requirements, could not be overcome during the project period. Many parties shared the interest in a centralized data tracking system for ASD/DD but tackling the realities to achieve it was not a common objective.
3. Integrating ASD data collection within other existing data systems, such as an Electronic Health Record (EHR) is the only feasible approach for Colorado.

4. The long term, sustainable success of any program must include strong self-advocate and parent/family involvement. The passion and needs of families and self-advocates fuels their professional partners to work towards their shared goals, and families' wisdom corrects missteps in the process.

E. PUBLICATIONS/PRODUCTS (See Appendix for copies of products)

The following codes identify target audiences (in parentheses after product name):

All	ED (Educators)	OP (Other Providers)
AD (Advocates)	F/P (Families/Parents)	Public
ECE (Early Care & Education)	HP (Health/Mental Health Providers)	SA (Self-Advocates)

ABCD materials (items 1-8): *For copies, contact Eileen Auer Bennett, Executive Director, 8801 E. Hampden Ave., Suite 106, Denver, CO 80231, 720-748-7702, info@coloradoabcd.org.*

1. *Optimizing Developmental Referrals in the Primary Care Setting (brochure)* (HP)
2. *Algorithm to help families access healthcare and special education/early intervention services.* (F/P, OP, HP, AD, ECE, Public)
3. *Brief Summary of Autism Screening Recommendations for Primary Care Physicians* (HP)
4. *Consensus Statement on Screening for Autism Spectrum Disorders in Colorado* (HP)
5. *Billing for Developmental Screening* (HP)
6. *Optimizing Developmental Referrals in Primary Care Practice Improvement/ Quality Improvement Project (first visit)* (HP)
7. *Implementing Developmental Screening & Optimizing Referrals in Primary Care* (HP)
8. *ABCD Colorado Project CASCADE Activity Summaries:2013-2014* (All)

ASC Materials (items 9 - 27)

9. *Action Alert: Applied Behavior Analysis Service Utilization* (F/P, OP)

10. *Ambassador Final Repport:2013-14 (AD, HP, OP)*
11. *Autismo 101 (F/P, SA, HP, OP, ECE, Public)*
12. *Autism and Access to Health Insurance (F/P, Employers)*
13. *Essential Health Benefits (EHB) Benchmark Plans for Colorado (All)*
14. *Children with Disabilities, Medicaid Buy-In Program (F/P, SA, Public)*
15. *Facts About Autism (All)*
16. *Fast Facts about the Affordable Care Act & Autism Coverage in Colorado (All)*
17. *Health Insurance Mandated Autism Treatment (HIMAT) 2011 Seminar (All)*
18. *How to Share Your Story (F/P, SA)*
19. *Information on Auditory Processing (All)*
20. *Introduction to Understanding Private Insurance (F/P, SA, Public)*
21. *Overview of HIMAT (All)*
22. *Recap of Audessey Conference (F/P, SA, ED, HP, OP, AD, ECE, Public)*
23. *Resources for Colorado Transitioning Youth (F/P, SA, AD, ED, HP, OP)*
24. *Sample Session Evaluation (All)*
25. *Say What? Understanding Insurance (F/P, SA, Public)*
26. *Understanding the Role of Government (F/P, SA, Public)*
27. *Sample ASC Program Announcement (All)*

ASC also developed and revised the CO CANDO website, which later was adapted to a new platform (still being updated) by JFK Partners (@ www.coloradocando.org).

CDPHE Materials (items 28 & 29)

28. *ASD Provider Survey (AD, ED, HP,OP)*
29. *Project CASCADE: Data Systems Development (AD, ED, HP,OP)*

JFK Partners Materials (items 30 -35): *For copies, contact Cordelia Robinson*

Rosenberg, PhD, RN, Director, JFK Partners, U. of CO School of Medicine, C234, 13121

E. 17th Ave., Aurora, CO 80045, 303-724-7680, Cordelia.Rosenberg@ucdenver.edu

30. *Analysis of Access to Mental Health Services for Individuals who have Dual*

Diagnoses of Intellectual and/or Developmental Disabilities and Mental and/or

Behavioral Health Disorders (Gap Analysis) (All)

31. *Changes to Colorado Rules Regarding Definition of Developmental Disabilities (All)*

32. *Colorado Care Coordination Resource Guide: 2013. (All)*

33. *Data Collection for Developmental, Social Emotional and Autism Screening in Early*

Childhood (OP, ED, HP, AD, ECE)

34. *Guidelines for the Educational Evaluation of Autism Spectrum Disorder JFK*

Partners and Colorado Department of Education (ED, F/P)

35. *Social-Emotional Mental Health Navigation Guide Q & A (All)*

In addition to support of the CO CANDO website, JFK Partners co-/developed two other websites during the project: the *Early Childhood Social-Emotional/Mental Health Navigation Guide* (@ <http://tinyurl.com/ECMH-Navigation-Guide>) to locate services, inform strategic planning, and assist appropriate referrals for services related to social-emotional and mental health in early childhood; and with the Colorado Respite Coalition, the *Colorado Respite Locator* (http://www.coloradospitecoalition.org/respite_locator).

During the SIG funding period, JFK Partners also organized and/or delivered and archived more than 30 webinars in conjunction with, or overlapping, its role as CASCADE and CANDO partner. In addition to the 2011 HIMAT webinar with ASC, five series are available as this report is written, including: a) the JFK-HCP series (11

during the grant, plus one following); b) Adults with Autism Spectrum Disorders Webinar Series (4 sessions); c) Early Childhood Mental Health (2 of 6 are specific to ASD); d) Educational Identification (of ASD); and, e) CO CANDO full membership meetings (from 9/13, earlier meetings were presented live with call-in numbers and emailed PowerPoints, and were not preserved as webinars). Archived webinars and handouts (not included in the Attachment to this report) may be viewed/retrieved @ <http://www.ucdenver.edu/academics/colleges/medicalschool/programs/JFKPartners/educationtraining/Pages/Archived-Webinars.aspx> by clicking on the title of interest.

F. DISSEMINATION/UTILIZATION OF RESULTS

Throughout the course of the project products, developing findings and results were disseminated statewide in CONDO meetings, and, primarily, through the websites of three of the partners (specifically ABCD, ASC and JFK Partners ASC) and the CO CANDO website, developed/revised by ASC and JFK Partners. The website addresses (and project results emphasis) are:

<http://www.coloradoabcd.org/> - developmental screening and practice resources

<http://autismcolorado.info/> - public/private ASD insurance coverage (e.g., ACA , HIMAT, Children's Medicaid Buy-In)

<http://www.ucdenver.edu/academics/colleges/medicalschool/programs/JFKPartners/Pages/JFK%20Partners.aspx> – archived webinars and materials; Gap Analysis

<https://www.colorado.gov/pacific/cdphe/medical-home-systems-development>

<http://www.coloradocando.org/> - Colorado State Plan

The key developments in the progress on the implementation of Colorado State plan were shared in quarterly CANDO live meetings and by webinar across the state, as they

occurred (e.g., CDE Autism Guidelines, Dual Diagnosis Gap Analysis survey and forum findings and recommendations). The Colorado Care Coordination Resource Guide disseminated was to key state offices and also nationally in an AUCD webinar, and several products (e.g., ABCD Referral Algorithm) were shared in annual grantee meetings and the 2012 peer-to peer collaborative.

G. SUSTAINABILITY

Many aspects of Project CASCADE can be sustained and enhanced by the partners going forward. ASC will continue to monitor evolving policy implementation regarding coverage of ASD services in Colorado public and private insurance and to apprise families of these developments and elicit their feedback as challenges are encountered. ASC also will continue to promote family professional partnership by delivering ASD information to the community in resource fairs and *Autism 101* sessions (e.g., future sessions are scheduled for school districts, library systems, the Denver History Museum, a Douglas County Childcare organization, and North West Police Departments).

CDPHE recently completed an IT systems assessment that included recommendations for tracking the progress of positive ASD/DD screens (through intervention) in a centralized system through EHRs. CDPHE also will continue to host Forum meetings and provide staff to the Colorado Medical Home Initiative, affording continuing work in promoting medical homes for children, youth and adults with ASD/DD.

JFK Partners remains committed to support of CO CANDO. JFK Partners is updating the CO CANDO website and Dr. Robinson co-chairs the committee and continues to organize and host quarterly full committee meetings at AMC and webinar delivery across Colorado. Post-MCHB funding, the September and December 2014 sessions included

Cultural and Linguistic Perspectives in Evaluation and Treatment of ASD/DD and updates on crisis services for people with ASD/DD, a proposed Children with Autism Waiver Expansion; educational identification and services for ASD/DD, and the Gap Analysis. Dr. Robinson continues to lead the final GAP Analysis Report team and remains committed to following the State response. JFK Partners will also respond as needs are identified for professional continuing education of providers of ASD/DD services. JFK and CDPHE have no plans to discontinue JFK-HCP webinars. Most recently, the topic was *Benefits for Colorado's Children with Special Health Care Needs* (October 2014). Finally, in September, JFK Partners began participation in a new R-40 grant (PI, Carolyn DiGuseppi, MD, MPH, PhD) to work with Denver Health and Rocky Mountain Human Services (a major metro CCB) to institute M-CHAT-R screening, and follow through to enrollment and maintenance in service.

ABCD was well positioned through its work in CASCADE to transition several medical education and quality improvement activities with funding from National Jewish Health. ABCD completed an application to National Jewish Health and the American Board of Pediatrics for a joint CME/QI project. Twenty pediatricians in three large practices will apply a set of Quality Standards determined by community workgroups to be essential to any entity making a referral (i.e., faxing the state referral form for Early Intervention and Child Find referrals; giving families written referral information; making any medical referrals simultaneously; following up with families within 2 months); and, tracking all referral outcomes. Additional practices are interested, so ABCD applied to COPIC Foundation for funding to expand the pilot to 20 practices. They plan also to apply with the local chapter for additional funding from the American

Academy of Pediatrics. ABCD continues to offer “Lunch and Learn” in office Category 1 CME credit to interested practices and to deliver practice visits for TA on developmental delays, autism, and referral to Early Intervention and Child Find. ABCD also is:

- Supporting communities to identify TA needs in the essential roles in the ABCD model community framework, and training local community partners as TA leaders;
- Participating in CO-CANDO;
- Partnering with Dr. Deb Efird in physician outreach efforts specific to M-CHAT;
- Modifying the ABCD database to track comprehensive screening and referral in primary care; and,
- Completing a *Meeting Milestones Initiative* in Grand County, CO, to inform an electronic screening and referral platform.

States vary greatly in the systems, laws, and stakeholder alliances that are in place regarding the ASD/DD community. Given this context, the major replicable aspect of Project CASCADE is most likely the partners’ use of grant-resources to leverage limited funding by promoting statewide collaboration of their public and voluntary agencies, families and their representatives, self-advocates, and ASD/DD educational resources (e.g., LEND/UCEDD, ABCD and similar programs) to meet ASD/DD goals.

H. SUMMARY OF DISPOSITION OF PROPERTY

Grant funds were used for ASC personnel, contract personnel, and consultant costs and operating expenses. Funds in the amount of \$4,000 were charged to the grant in Year 2 for printing of copies of the CDC *Milestone Moments* booklets that were disseminated fully during the project. No equipment with a fair market value of \$5000 or more was purchased, nor do property/supplies with an aggregate value of \$5,000 remain.