

**MATERNAL AND CHILD HEALTH BUREAU (MCHB)
SPECIAL PROJECTS OF REGIONAL AND NATIONAL SIGNIFICANCE (SPRANS)**

FINAL REPORT AND ABSTRACT

Project Identification

Project Title: Healthy Tomorrows Partnership for Children Program - Achievable Innovative Medical Home Initiative

Project Number: H17MC25738

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Total Amount of Grant Awarded: \$235,191

Purpose of Project and Relationship to SSA Title V Maternal and Children

The major purpose of this project was to create a medical home that provides developmentally-centered, continuous, coordinated and comprehensive care specifically tailored to serving children with intellectual and developmental disabilities (I/DD) and medical complexities, and their families. This project, called the Achievable Innovative Medical Home Initiative (AIM HI), was implemented through The Achievable Foundation, a Federally Qualified Health Center (FQHC) in Culver City, California. The AIM HI initiative serves children ages 0 to 18 years, and their families, throughout 30 adjacent zip codes in Los Angeles County (LAC). The majority of the target population come from low-income households and experience lack of access to care to appropriate health services in the general community.

This project was funded under the Healthy Tomorrows Partnership for Children Program through Title V of the Social Security Act. The current project falls under the Healthy Tomorrows purpose of

increasing the number of innovative community initiated programs that promote access to health care for children, youth and their families. In alignment with Healthy Tomorrows priorities, this project employs preventive health strategies, improves access to high-quality health care and services, and promotes health for medically underserved and disadvantaged children. The project is also closely aligned with the Maternal and Child Health Bureau's (MCHB) identified components of adequate systems of care for children with special health care needs. These components include families as partners in care, early and continuous screening, access to coordinated care in a medical home, adequate insurance and transition planning.

Needs and Problems Addressed

Approximately one in six children ages 3-17 in the U.S. are thought to have an intellectual or developmental disability (I/DD) that can include autism, cerebral palsy, intellectual disability, Down syndrome and other similar conditions.¹ The prevalence of children with I/DD in the U.S. has increased significantly in recent years due to increased survival rates after premature births, improvements in parent education, improvements in screening and diagnosis, and environmental changes.² As with other Children with Special Health Care Needs (CSHCN), children with I/DD often experience numerous functional limitations, life challenges and co-occurring medical conditions at a higher rate than children without disabilities, including obesity, diabetes, respiratory conditions, gastrointestinal issues, neurologic disorders and mental health conditions.^{3,4} These chronic and complex conditions experienced by children with I/DD necessitate access to a multitude of health services such as medical, dental, mental health,

¹ Centers for Disease Control and Prevention. *Developmental Disabilities*. Available at <https://www.cdc.gov/ncbddd/developmentaldisabilities/about.html>

² Boyle CA, Boulet S, Schieve L, Cohen RA, Blumberg SJ, Yeargin-Allsopp M, Visser S and Kogan MD. Trends in the Prevalence of Developmental Disabilities in US Children, 1997-2008. *Pediatrics*. 127(6): 1034-42.

³ Schieve LA et al. Concurrent Medical Conditions and Health Care Use and Needs Among Children with Learning and Behavioral developmental disabilities, National Health Interview Survey, 2006-2010. *Research in Developmental Disabilities* (2012). 33(2): 467-476.

⁴ U.S. Department of Health and Human Services Health Resources and Services Administration. The National Survey of Children with Special Health Care Needs - Chartbook 2005-2006. Available at <http://mchb.hrsa.gov/cshcn05/>.

therapies, prescription medications, specialized equipment and social supports in order to maintain health, development and quality of life.

Despite the clear need for access to services, studies have shown that children with I/DD, especially those with multiple complex health conditions, face significant barriers to accessing needed health and support services. In fact, children with I/DD are even less likely to access health care services and to receive quality health care compared to other CSHCN and children without special health care needs.^{2,3,5} Families who have lower income levels have even greater unmet need.⁶ Possible reasons for lack of access to, and quality care for, children with I/DD is inadequate provider training or comfort with caring for these children, lack of care coordination between multiple providers, poor insurance coverage and poor referral processes.⁵ Too many children at risk for developmental delays and disabilities receive screening, evaluation and interventions too late or not at all. Others try to receive services but become lost in a convoluted, fragmented, uncoordinated system of care while trying to access services. Unfortunately, unmet needs in childhood can lead to poor health and functional outcomes through adulthood.

Several research studies have found that children with I/DD who belong to a family-centered and coordinated medical home are less likely to have unmet healthcare needs.^{7,8} Increasing access to care through medical homes for children has been identified as a priority for child health policy at local, state and national levels. There is a clear need for developing medical home models for children with I/DD that incorporates specialized providers, enhanced care coordination, culturally- and developmentally-competent care, family empowerment and education, and appropriate screenings and referrals.

⁵ Cheak-Zamora NC and Thullen M. Disparities in Quality and Access in Care for Children with Developmental Disabilities and Multiple Health Conditions. *Maternal and Child Health Journal* (2017). 21(1):36-44.

⁶ www.dds.c.gov

⁷ Cheak-Zamora NC and Farmer JE. The Impact of the Medical Home on Access to Care for Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders* (2015). 45(3):636-644.

⁸ Farmer JE, Clark MJ et al. The Relationship Between the Medical Home and Unmet Needs for Children with Autism Spectrum Disorders. *Maternal and Child Health Journal* (2014). 18(3):672-680.

GOALS AND OBJECTIVES

The goals and objectives of AIM HI are related to creating a medical home, improving access to care, improving quality of care and improving health status of participants. These encompass structure, process and outcome measures in relation to preventive care, access to care, quality of care and/or care coordination.

Goal 1: To create an innovative, developmentally- and family-centered medical home for children with, or at risk for, intellectual and developmental disabilities.

Objective 1a: In 2 years, 150 families will consider the AIM HI to be their medical home of choice and report satisfaction of with services. In 5 years, this number will rise to 350.

This objective tracks patients served over the course of the project period and demographic characteristics, as well as number of well-child visits and assigned primary care providers as a measure of medical home. Additionally, this objective looks at satisfaction as reported through a Patient Satisfaction Survey.

Objective 1b: AIM HI will align its operations to adhere to the basic tenets of the Patient Centered Medical Home (PCMH).

This objective measures structure and processes as related to the tenets of a medical home based on the National Committee for Quality Assurance (NCQA) definition.

Objective 1c: The AIM HI team will share best practices and lessons learned regarding operating a health center focusing on treating individuals with I/DD.

This is a qualitative measure focusing on dissemination of results and lessons learned, as well as potential model replication.

Goal 2: To improve the quality of care and access to primary and specialty health care services for children with or at risk for I/DD, and their families, through AIM HI.

Objective 2a: By the end of the project period, the percentage of patients ages 0-17 years with at least one visit during the measurement year who have their immunization record documented in searchable EHR fields will increase to 80% from a baseline of 25%.

Immunizations are proven to reduce morbidity and mortality, and are a core component of primary care practice. By documenting immunization records in a central medical record, AIM HI hopes to ensure immunizations are up-to-date, reduce unnecessary vaccinations, and promote timely immunization for children who switch healthcare providers. Documenting these vaccinations in a searchable EHR field can facilitate reminder prompts and coordination of immunizations with routine care.

Objective 2b: In 5 years, at least 75% of pediatric patients (ages 3-17) will have had their height, weight and Body Mass Index (BMI) percentile documented in the preceding year.

The rapidly increasing prevalence of obesity among children and adolescents is a significant public health issue, and children with I/DD are at a higher risk for developing overweight and obesity. Thus, obesity screening and prevention is a key component of a medical home for children, especially those with I/DD. This objective tracks the practice of obesity screening within AIM HI. This measure correlates to the NCQA Health Effectiveness Data and Information Set (HEDIS) Child Core Set measure.

Objective 2c: In 5 years, at least 75% of pediatric patients will have had an age-appropriate hearing and vision screening documented in the preceding year.

Poor vision and hearing can lead to poor education outcomes, delayed development, difficulty with daily activities and learning delays. Early identification and intervention can ensure that children obtain needed resources in order to achieve their full potential. Hearing and vision screenings for children ages 3 and older are recommended by the American Academy of Pediatrics (AAP) as a primary component of a well-child visits within a medical home. This objective tracks the incidence of hearing and vision screenings for AIM HI patients who have had visits in the measurement year.

Objective 2d: In 5 years, at least 75% of pediatric patients ages 0-5 years will have been appropriately screened for developmental, social and emotional delay using a standardized tool.

Early identification of developmental delays is critical to ensuring children receive intervention services and supports needed to reach their full potential. The AAP recommends standardized routine developmental screening for children. Screening using a standardized tool, in addition to physician surveillance, is more effective at detecting risk than surveillance alone. This objective tracks standardized screening as part of the medical home.

Objective 2e: By the end of the project period, the proportion of patients screening positive for developmental, social or emotional delay using a standardized assessment tool who are referred for further evaluation and/or treatment will increase to 80% from baseline.

The screening tool identifies and refines risk of developmental delays and areas in which a child's development differs from same-age norms. Once risk is identified, children are referred for further evaluation. This objective measures follow-through with referring patients whose screenings indicate possible delays.

Goal 3: To improve the health status of children with or at risk for I/DD who receive care through the AIM HI.

Objective 3a: In 5 years, at least 70% of participating families will report an improved health status and quality of life for their child(ren).

Research has shown that being part of a medical home provides health benefits to all children, especially those with I/DD and special needs. This objective measures the health benefits based on self-reported (or parent-reported) quality of life and health status changes in patients.

Objective 3 b: The percentage of patients ages 3-18 who have a documented BMI percentile, and receive nutrition and physical activity counseling, will increase from a baseline of 12% to 60% by the end of the project period.

As with height, weight and BMI documentation, the NCQA recommends that primary care physicians provide guidance for maintaining a healthy weight and lifestyle as part of a medical home. In accordance with the HEDIS measure, this objective tracks documentation of nutrition and physical activity counseling for pediatric patients with an assessed BMI percentile.

METHODOLOGY

Founded in 1996 by a group of parents, Achievable began to offer safety net supports to low-income families of individuals with I/DD when no other funding source was available. Our legacy programs provided basic necessities, equipment, and summer camp scholarships for individuals with I/DD and their families. In 2008, Achievable directed its focus to critical issues affecting individuals with I/DD: health disparities and access to healthcare. In September 2013, Achievable launched its own state-licensed community clinic, the Achievable Health Center, which was custom built to be accessible and welcoming for patients of all abilities. In November 2013 this health center was awarded Federally Qualified Health Center (FQHC) designation. To our knowledge, ours was the first FQHC in California, and possibly the nation, with services specifically tailored to meeting unmet healthcare needs of patients with I/DD. Achievable is co-located with the Westside Regional Center, a social services agency providing case management services to all individuals with I/DD in the local catchment area. This strategic location allows for familiar and comfortable accessibility for patients, integration with social supports and the leveraging of resources to educate patients and families about the benefits of the medical home. Further, Achievable was built and designed to be accessible and equipped with adaptive equipment such as accessible exam tables, listening devices, wheelchair scales and desensitization equipment. The health center design helps ease patient anxiety, improve comfort and cooperation, and increase quality of care, especially for patients with I/DD and mobility challenges.

As a key component of this new FQHC, Achievable developed the AIM HI project, funded through Healthy Tomorrows, to create a medical home for children with, and at risk for, I/DD and other medical complexities. In the beginning stages, methodology was largely focused on organizational and administrative activities around creating a model of care and building operations. Initial activities included recruiting, hiring and training key providers and staff; developing and implementing Policies and Procedures; contracting with insurance plans; creating an outreach plan and developing a patient base; acquiring an electronic health record system; implementing a continuous quality improvement plan; developing data collection tools and evaluation methodology; and creating partnerships with key specialists, community organizations and providers.

After groundwork was established, the AIM HI project used several key methods to develop and implement our medical home model:

- A range of primary care medical services is provided to AIM HI participants, in addition to in-house pediatric neurology services and in-house mental health services, two specialties which are difficult to access for children with I/DD in the general community.
- Care is structured such that patients are assigned to a primary care provider (i.e., Pediatrician) and encouraged to establish a strong, consistent relationship with that provider. The AIM HI project also utilizes the team-based service delivery model in which specialty providers and support staff work with the primary care provider in a collaborative manner to result in whole-person care.
- Family-centered primary care visits are structured using guidelines set forth by Bright Futures, and include solicitation of parent and child concerns, surveillance and screening, assessments of strength and discussion of visit priorities for improved child health and development, and improved family functioning. Standardized assessments and tools are used.
- Extended visit times of 30-60 minutes are offered to patients with complex needs to ensure that comprehensive care is provided.

- All staff and providers are trained in cultural competency and disability awareness, and the majority have prior experience working with individuals with I/DD and/or medical complexities. Also, the majority of staff is bilingual and/or comes from culturally diverse backgrounds.
- An Outreach and Enrollment (O/E) Specialist is a key part of the AIM HI team. This staff member helps families navigate the intricacies of the health insurance system. The O/E Specialist is a parent of a child with I/DD, giving them intimate knowledge of challenges and first-hand experience with the system. The O/E Specialist works with families to raise awareness of coverage options, help them understand changes in coverage, determine eligibility, provide application assistance, facilitate enrollment and utilization, and ensure continuous access to services.
- A Referral Coordinator is a key member of the AIM HI team. This individual is responsible for processing and coordinating specialty referrals by working closely with referring providers, specialists, patients and families. As with the O/E Specialist, this role is critical to helping patients, especially those with I/DD, who require care from multiple specialty care providers, navigate the health care system and ensure follow-through with care. A written referral procedure was developed and implemented for this project.
- Patient Care Coordination is provided to patients and families. A Patient Care Coordinator works closely with the pediatrician, specialty care providers, social workers, other providers, patients and families to coordinate appropriate and timely delivery of services. Care coordination is vital to the successful implementation of a medical home and is needed to provide high quality, comprehensive care for children with I/DD and medical complexities.
- An electronic health record (EHR) system is in place with an integrated population health data management system. Through the EHR, patient information is documented and tracked in a timely manner to improve information sharing and continuity of care. The EHR provides tasking tools to help track patient services and provide timely follow-up as well.

- To ensure comprehensive care, each provider receives a morning report generated through the EHR of all patients scheduled for the day. This pre-visit summary identifies needed care such as immunizations or routine screenings, as well as issues that should be addressed during the visit.
- The AIM HI Project is located in the same building as Westside Regional Center, the local state-contracted agency which provides early intervention and social services for all children and adults with I/DD in the local catchment area. Co-location with a regional center is an ideal location for AIM HI, allowing for familiar accessibility for patients and families, as well as integration of social services, behavioral supports, case management and other resources.
- Our 6-member Advisory Council consists of patients, parents of patients, or professionals working with children with I/DD and vulnerable populations. The Council reflects the diversity of our constituencies and its members provide intimate perspective into the needs of patients. This Council meets quarterly to provide valuable feedback and guidance on services, as well as patient engagement strategies and efforts to improve the patient experience. The use of an Advisory Council to help guide practice aids in ensuring that our services remain patient-centered and that our efforts reliably serve patient needs.
- Throughout the project, the AIM HI team formed partnerships with those most closely linked to the community of children with I/DD, including specialty providers.

EVALUATION

The focus of the AIM HI evaluation is to determine if AIM HI was effective in accomplishing its goals and objectives. The AIM HI evaluation was formed using Donabedian's structure-process-outcome evaluation framework which assesses health care quality based on the structure or environment in which care is provided, methods of provision and consequences of provided care. The AIM HI evaluation was guided by the logic model found in Figure 1. This logic model has been revised from the originally submitted logic model in order to enhance clarity and better align with revised goals and objectives.

Figure 1. Achievable Innovative Medical Home Initiative - Logic Model (revised)

Target Population	Inputs	Activities	Outputs	Outcomes
<p>Children ages 0-18 who live in the proposed service area within Los Angeles County and are:</p> <ul style="list-style-type: none"> -Living with or at risk for a range of developmental delays or disabilities; and/or - Have complex medical conditions. <p>*Target population mostly has low-income, and low access to appropriate health care services.</p>	<ul style="list-style-type: none"> -Board of Directors -Health center management -Health center providers and support staff - Health center facility and equipment - Information technology system -Evidence-based guidelines for care -Funding - Advisory Council members - Children - Families 	<ul style="list-style-type: none"> - Equip facility - Create P&Ps - Implement electronic health record and data management system - Recruit, hire and train staff - Develop QI program - Convene Advisory Council to meet regularly - Develop collaborations with specialty providers and community organizations - Outreach to target population and community - Develop patient base 	<ul style="list-style-type: none"> - Number and types of providers and staff hired and trained - P&Ps and practice guidelines in place - Implementation of health information technology - Accessible location and equipment - Patient portal in place - Communication system in place - Funding system in place - Number of patients over time - Number of patients assigned to PCP - Number of Advisory Council members 	<p>Creation of a medical home specifically tailored to children with I/DD and medical complexities.</p>
		<ul style="list-style-type: none"> - Comprehensive range of primary and preventive services offered regularly to all patients - Provide care in accordance with evidence-based anticipatory guidelines - PDSA cycles to improve services as needed 	<ul style="list-style-type: none"> - Frequency and types of early intervention screenings (PEDS, PEDS:DM) - Number of preventive health services (hearing vision screening, BMI checks, nutrition/exercise counseling) - Percentage of patients receiving well-child visits - Documentation of immunizations - Complete range of primary and preventive services offered 	<ul style="list-style-type: none"> -Improved quality of primary and preventive care (including screenings, preventive care, well-child visits, immunizations, etc.) -Children will experience improved health status.
		<ul style="list-style-type: none"> - Referral coordination processes in place - Appropriate referrals to specialists as indicated - Extended care coordination offered to patients - Families connected to community resources - PDSA cycles to improve workflow and processes as needed 	<ul style="list-style-type: none"> - Number of processed referrals to specialists and other community resources - Number of completed referrals - Care coordination and referral coordination contacts and activity logs 	<p>Children will have greater access to primary and specialty care.</p>
		<ul style="list-style-type: none"> - Open communication between family, providers, supports and specialists - Solicit feedback from patients and Advisory Council members - Train staff on cultural competency, disability and customer service - Conduct PDSA cycles around patient feedback and satisfaction results 	<ul style="list-style-type: none"> - Patient satisfaction survey results - Patient feedback via opportunity reports - Patient and family interview data 	<p>AIM HI patients and families will report an improved experience with, and satisfaction with, care.</p>
<ul style="list-style-type: none"> - Community providers - Community leaders - Other health centers 	<ul style="list-style-type: none"> - Board of Directors -Health center staff - Advisory Council members 	<ul style="list-style-type: none"> - Document processes for replication and information sharing - Build collaborations with community agencies, legislators and health centers statewide - Attend conferences and make presentations to a wide audience 	<ul style="list-style-type: none"> - Number of community presentations and publications - Contacts with community stakeholders - Number of community events 	<p>The AIM HI team will share best practices to create a replication model for high quality care for all children with I/DD and medical complexities.</p>

Our evaluation methods evaluated both basic service utilization (number of visits, patients, screenings, etc.) as well as quality and access to care (types of screenings, patient satisfaction, what is done at the visit, etc.). The majority of data is continuously collected through an EHR system which was implemented upon health center launch in 2013. During the grant period, Achievable also integrated a population health data management system (i2i) with our EHR to allow. This system has allowed our team members to create streamlined data documentation, collection and reporting, as well as identify opportunities for targeted health interventions. As part of operations, the health center continually conducts staff trainings and workflow analysis around collection and documentation of essential data in order to ensure necessary information is available in a usable format to facilitate evaluation. In addition to the EHR, other data sources for the AIM HI evaluation include policy and procedure documents, intake forms, staff notes and activity logs, standardized assessment tools, evidence-based anticipatory guidelines, surveys and interviews.

Over the course of the grant period, portions of the AIM HI evaluation were integrated into Achievable's traditional quality improvement (QI) methods in order to better understand processes of care and how to improve upon these processes over time. The AIM HI team conducted Plan-Do-Study-Act (PDSA) cycles as part of the QI program to plan and implement activities, review data and conduct action periods to implement changes to care processes aimed at improving quality.

RESULTS/OUTCOMES

Over the course of the grant period, Achievable worked to create our medical home for undeserved children, youth and young adults through the AIM HI project. One of the main accomplishments is recruiting and hiring a solid, dedicated team of professionals to care for AIM HI patients. The core team currently includes a Pediatrician, a Family Physician, a Psychiatrist, a Pediatric Neurologist, 2 Referral Coordinators, a Patient Care Coordinator, and an Outreach and Enrollment Specialist. Other health center staff that support this project include senior management, family physicians, nurse practitioners, therapists, IT and Programs manager and medical assistants. All staff have

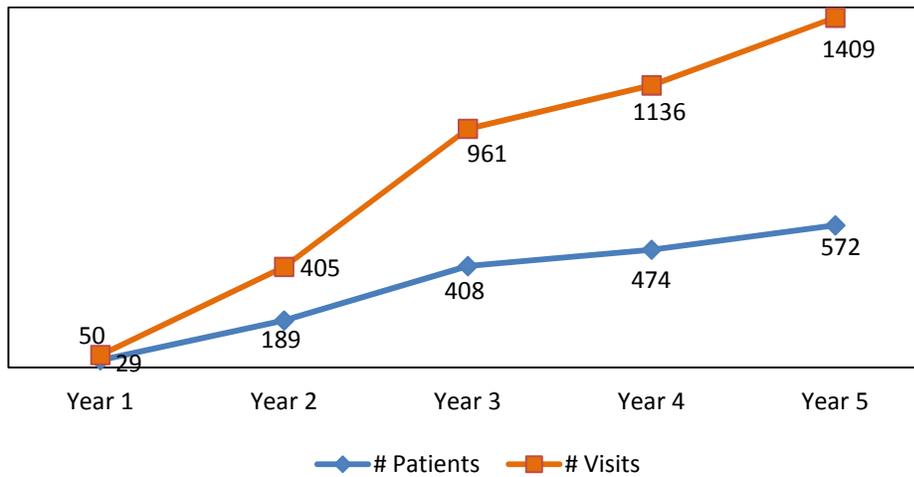
expertise and experience in assessing and caring for children with I/DD, and all have been trained in disability competence, cultural competency and family-centered, sensitive services.

Health services provided by the AIM HI project include a full range of developmentally-appropriate primary care services such as well-child services, developmental evaluations, preventive screenings, immunizations, hearing/vision screenings, health education, disease management and in-house neurology. Further, our health center has introduced integrated on-site mental health services into our primary medical home model in order to address the mental and physical conditions experienced by underserved children, especially those with I/DD. All patients and families receive enhanced care coordination services by a patient care coordinator who works with team members to coordinate access to care, and appropriate and timely delivery of services. We also go beyond basic medical care and provide insurance eligibility and enrollment assistance, outreach, transportation and other enabling services to our patients. Patients receive extended visit times up to one hour to ensure that patients are adequately cared for and all family questions and concerns are addressed. AIM HI prides itself in providing a family- and child-friendly environment that promotes comfort and wellness for individuals of all ages. In fact, one of the key aspects of our health center is that we serve individuals throughout the lifespan so that a pediatric patient who reaches adulthood will be able to transition from AIM HI yet maintain continuous care in the same location. This is critical for transition-age youth who often experience significant gaps in health care services when moving from multi-layered child health programs to fragmented adults services.

Individuals Served

AIM HI began providing health services to patients ages 0-18 years beginning September 30, 2013 when our health center first opened its doors. Over the grant period, as the health center grew, so did the number of individuals served by the AIM HI project. Figure 2 shows the number of unduplicated patients served by project year (3/1 - 2/28) for the entire project period (6/1/13 - 2/28/18). The project experienced significant growth over the grant period, going from only 189 patients and 405 visits in the first full project year to 572 patients and 1409 visits in the last project year.

Figure 2. Number of Unduplicated Patients Served and Number of Patient Visits, by Project Year



*"Year 1" is does not represent a full year of services. The period for Year 1 is 6/01/13 - 2/28/14.

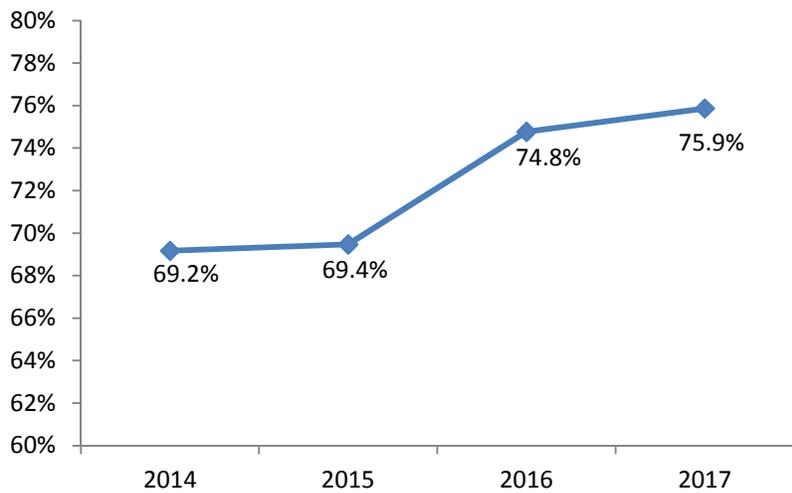
Over the entire grant period, AIM HI served a total of 922 unduplicated pediatric patients with 3,691 visits. Approximately 15% of these patients were ages 0-3 years, 42% were 4-11 years and 43% were ages 12 - 18 years old. Of these 922 patients, 756 (82%) had Medi-Cal coverage, California's version of Medicaid. Approximately 47% were female and 53% were male. Approximately 44% of the total patients served reported Hispanic ethnicity. The patients also represent a racially diverse group of individuals with 23% African American, 42% White, 6.6% Asian/Pacific Islander, 0.5% American Indian, and 4.4% from multiple races. Additionally, AIM HI has become the medical home for over 230 children with I/DD throughout the grant period. Overall, the percentage of total patients served in a given year who had an I/DD ranged from 27% to 34%.

Medical Home Measures

Regular well-child visits provide a critical opportunity for prevention, tracking growth and development, addressing parent concerns, influencing health and creating a strong relationship with a child's medical home. The AIM HI project utilizes the AAP's Bright Futures guidelines for age-appropriate well-child care, as this is an important component of a medical home. As shown in Figure 3, the percentage of pediatric patients with a well-child visit improved over time, indicating that AIM HI increasingly provided appropriate medical home services for patients. The numerator is pediatric patients

ages 0-18 with at least one well-child visit during the measurement year and the denominator is pediatric patients ages 0-18 with any medical visit during the measurement year. In 2017, almost 76% of pediatric patients had a well-visit during the calendar year.

Figure 3. Percentage of All Pediatric Patients (0-18 years) with a Well-Child Visit, by Measurement Year



As a medical home serving individuals with I/DD, the AIM HI team aimed to increase awareness among all families of the importance of well-care, especially for children with I/DD. In the last year of the project, 85.6% of pediatric patients with an I/DD diagnosis who had a visit during that measurement year had a well-child visit during that year, compared to 83.6% of patients who did not have an I/DD.

Another important aspect of a medical home is having an assigned primary care physician, preferably a Pediatrician. In the last year of the project, 345 (63.2%) pediatric patients had our Pediatrician listed as their primary care physician. Of these patients, 77% had a well-visit with this pediatrician, indicating a high level of continuity of care through the medical home.

Finally, we included a medical home measure with our Patient Satisfaction Survey. For this measure, patients were asked if AIM HI is their usual source of care. In January 2018, 100% of Patient Satisfaction Survey respondents for patients ages 0-18 years confirmed that AIM HI is their usual source of care.

Immunization Documentation

Because our health center was a start-up during the grant period, a high proportion of patients each year were new patients, and many received their immunizations at another health center prior to joining AIM HI. Thus, instead of measuring administration of immunizations, we measured documentation of the immunization record in our EHR. Over the project period we participated in the California Immunization Registry (CAIR), which is California's statewide network for maintaining immunization information for patients. We also began a streamlined process of requesting and receiving records from prior physician offices, improved our own electronic health record data capture, trained staff on documentation, outreached to families regarding the importance of immunizations and incorporated pre-visit planning summaries to ensure required immunizations are conducted at visits. The results of our efforts are presented in Table 1. Due to the high percentage of new patients, the percentage with 10 or more immunizations documented is not as high as we would like, but we reached our goal of 80% of patients with a documented immunization record. We will continue to work on this measure.

Table 1. Percentage of patients (0-17) Who Have Immunization Record Documented in the EHR

Measurement Year	% of patients with immunization record documented	% of patients with 10+ immunizations documented
2015	80.5%	26.6%
2016	81%	23.6%
2017	80%	23.2%

BMI Documentation, Nutrition and Physical Activity Counseling

In accordance with the NCQA HEDIS measure, we assessed the percentage of children and adolescents ages 3-17 years old who had a primary care visit during the measurement year with a documented height, weight and BMI. Further, we assessed the percentage of the patients with a BMI documented who received nutrition and physical activity counseling from the physician as measure of obesity prevention and healthy lifestyle guidance. As shown in Table 2, AIM HI surpassed our goal of

ensuring that at least 75% of patients age 3-17 would have a height, weight and BMI documented. We also surpassed our goal of ensuring that at least 60% of patients with a documented BMI would receive nutrition and physical activity counseling.

Table 2. Body Mass Index Documentation and Nutrition/Physical Activity Counseling

Project Year	% of Patients (3-17 years) with Height, Weight, BMI Documented	% of Patients (3-17 years) with BMI documented who received nutrition and physical activity counseling.
2015/2016	83%	48%
2016/2017	93%	69%
2017/2018	99%	70%

Hearing and Vision Screenings

In the last full year of the project, 70.9% of patients ages 3-18 years had an age-appropriate hearing and vision screening compared to only 58% of patients in 2016 and 53% of patients in 2015. Although we did not reach our goal of 75% for this measure, we were successful in improving these rates over time and will continue to work on operational processes and data capture processes to continue improving. Hearing and vision screenings are often challenging to perform on children with I/DD who may have behavior challenges or sensitivities. AIM HI has developed desensitization strategies and has been able to overcome challenges to hearing and vision screenings for our patients, especially those with I/DD.

Developmental Screenings

AIM HI physicians followed the AAP and Bright Futures periodicity schedule of screenings and assessments recommended at each well-child visit from infancy through adolescence. AIM HI uses the Parents' Evaluation of Developmental Status (PEDS) and the PEDS-Developmental Milestones (PEDS:DM) for conducting developmental screenings. We chose these tools because they have strong test-retest reliability and inter-method reliability. Further, items capture unique dimensions of child

development, including communication deficits, psychosocial risk factors, social-emotional deficits and academic status. During the project, we implemented workflow changes and quality improvement cycles around this measure, and began implementing an online version of the tool. Due to these efforts, we were able to surpass our goal for this measure. In the last full year of the project, 76.7% of AIM HI patients between the ages of 0-5 years were appropriately screened using these standardized tools.

Referrals

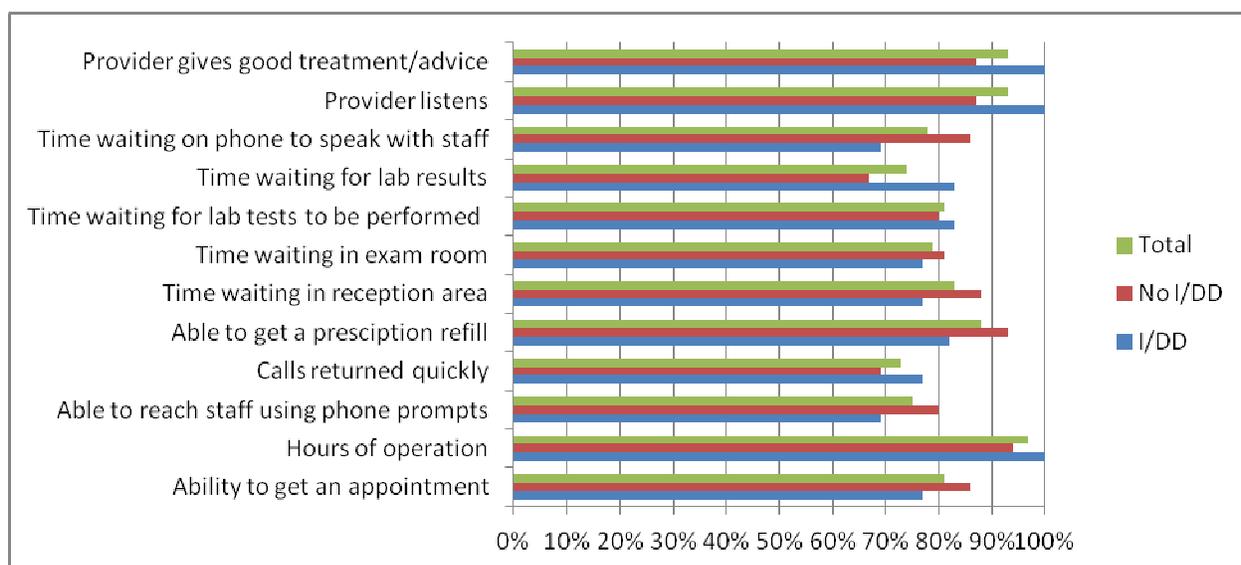
Developmental screens are meant to be used as a tool alongside physician assessments, parent and child interviews and other visits to aid providers in identifying concerns that require more detailed screenings and/or referrals to specialty care to address developmental concerns. For AIM HI's last full project year, 18.3% of patients 0-5 years with positive screens utilizing the standardized tool were already receiving appropriate services at the time of the screening; 50% were further assessed by the pediatrician, showed low risk of delay, and were provided education and follow-up; and 31.7% were referred for additional services. For those referred for additional services, 31.6% had the referral completed within 90 days, 15.8% refused services, and the remaining are pending appointment scheduling. Our Referral Coordinator will work to ensure follow up for pending visits.

Patient and Family Satisfaction

AIM HI implemented a Patient Satisfaction Survey throughout the project period. This survey was adapted from a standardized survey utilized by many FQHCs and developed by the Bureau of Primary Health Care. The survey is stratified by age, primary care physician and I/DD status. Throughout the project period, AIM HI staff used survey results to conduct quality improvement cycles. Our most recent survey was conducted in both print and electronic form in January 2018. Results of this survey show an overall high level of satisfaction with care, with "very good" or "good" responses ranging from 67% - 100% on all domains. All respondents reported "very good" or "good" with regards to friendly and helpful staff; staff answering questions when asked; neat/clean building; convenient location; comfort/safety; patient privacy; provider takes enough time with patients; provider explains everything well; and AIM HI is the usual source of care. Figure 4 reports on the percentages of respondents rating

"very good" and "good" on a variety of other domains and compares responses of patient with I/DD to patients who do not have an I/DD. Patients with I/DD report greater satisfaction with hours, returned calls, labs and provider communication and advice. Patients without an I/DD report higher satisfaction with getting an appointment, using the phone system, ability to get a prescription refill, and time waiting (exam room, reception area and phone).

Figure 4. Percentage of Survey Respondents Reporting "Good" or "Very Good" on a Variety of Domains, by I/DD Status



Self-Reported Health Status

As part of our Patient Satisfaction Survey, families and patients were asked to report quality of life and health status changes. In January 2018, when rating child health at the time of the survey compared to one year prior, 82% of survey respondents with an I/DD reported "much better" or "somewhat better" child health than the prior year compared to 53% without an I/DD. Further, when rating child's quality of life at the time of the survey, 82% of survey respondents with an I/DD reported "much better" or "somewhat better" quality life than the prior year compared to 60% without an I/DD. These results show that AIM HI is helping to improve health status and quality of life in children with I/DD. Although the percentages of improved health for those without an I/DD is not as high, we suspect that this may be because the baseline level of health status for children without an I/DD is already higher than children with an I/DD, so changes may not be as necessary or pronounced as for children with I/DD.

Qualitative Data

Our specialized providers and care team have truly made a difference in the quality of care received by patients with I/DD. For example, providers have cared for many patients who have come to us from other health centers not having received quality care. Many of these patients were experiencing emotional meltdowns and impulsive behaviors because they were having severe earaches, toothaches, belly aches and other common pains as a result of undetected infections. Due to their cognitive disabilities, many patients were not able to adequately describe their symptoms to parents or providers prior to coming to AIM HI. Our providers were able to see past the disabilities and get to the core of an individual's health issues. Once their medical conditions were adequately identified and treated, the frightening outbursts these patients were exhibiting abated.

Following are patient or parent quotes on how AIM HI, and our specialized providers, have had a positive impact on the health of and life of children with I/DD:

- "Feeling that I have a team that is on our side and really advocating with us to whatever capacity they can. Just giving me information...It feels like I'm not doing this alone."
- "They recognize [my daughter] as an individual, not limited by any limitations that society perceives for her."
- "Here everyone listens to your symptoms and concerns - from the doctors on down."
- "I know quality care when I see it. The doctors and staff treat people compassionately - whatever place in life they're in."
- "I get to come here with people that actually get my daughter, get her diagnosis. I know her needs will be met."
- "We like the idea that we can come to a place where all of our needs will be met. We have a child with special needs and a child that's developing typically. We can come here as a family and they'll take care of our needs. This is the perfect place."

Through our quantitative results, and our patient stories, we believe that the AIM HI project is successful in creating a novel, integrated model of providing a medical home for children with I/DD and their families that will positively impact overall health and well-being.

PUBLICATIONS/PRODUCTS

Following is a list of main products and publications which were developed and utilized during the AIM HI project period:

- Quarterly newsletters were published in electronic and print form and distributed to over 500 stakeholders, including patients and families. Each newsletter contains information on the healthcare landscape, provider or staff spotlights, patient stories, information about services and other important medical home topics.
- During the project period, Achievable as a whole released two annual reports. The annual reports provide an overview of financials and operations, while featuring several personal patient stories.
- The health center website (www.achievable.org) was redesigned to improve accessibility, usability and clarity. The website contains visit information, intake forms, patient stories, resources, newsletters, a patient portal and other useful information for patients and community stakeholders in a clear, user-friendly design.
- The Achievable team created a video describing what to expect at a visit through the perspective of a pediatric patient with I/DD. The video is featured on the Achievable website and available at https://www.youtube.com/watch?time_continue=5&v=BdCFCEmtsP8. This video can be utilized to reduce patient fears and anxiety, assist with desensitization and help prepare a patient for their visit.
- A Referral Passport form which depicts the referral process in pictures and text, and which can be used for patients to track where they are in the referral process, was created for patients.
- A Patient Satisfaction Survey was created and revised.

- Our Pediatricians and Referral Coordinator created a resource list of providers who are experienced in working with children with I/DD and who accept Medi-Cal . This list is useful for referring patients to appropriate providers and for families seeking resources.
- AIM HI's Project Director, Dr. Michelle Catanzarite, was featured on 89.3 KPCC radio show segment on May 2, 2018 to speak about the difficulties young adults with I/DD face in finding a physician when they transition out of the pediatric care system. The recording and article titled "Kids with disabilities face a tough transition to adult care" can be accessed at:
<https://www.scpr.org/news/2018/05/02/82536/kids-with-disabilities-face-a-tough-transition-to/>
- The following presentations were made during the project period and included information on our pediatric medical home model:
 - Dr. Alicia Bazzano presented "The Achievable Health Center: Journey to a Developmental Health Home" at the University of California, San Francisco's 14th Annual Developmental Disability Conference in March 2015. The conference topic was "Developmental Disabilities: An Update for Health Professionals". Conference participants included Family Physicians, social workers, health care providers, and mental health providers.
 - Dr. Michelle Catanzarite, Dr. Alicia Bazzano and Dr. Ari Zeldin presented "A Model for a Developmental Health Home: The Achievable Clinic" at the American Academy of Developmental Medicine and Dentistry's 2015 international annual conference on health and healthcare for people with I/DD. Conference participants included practitioners, researchers and providers from around the world.
 - Dr. Alicia Bazzano presented "Intellectual Disabilities in Children to residents at Pediatric Grand Rounds at the UCLA David Geffen School of Medicine in April 2016. Objectives were to inform about the diagnostic process, discuss guidelines and management, provide resources, and inform of future care, research and policies for children with I/DD.
 - Dr. Meredith Rimmer and Dr. Alicia Bazzano presented "The Achievable Clinic Integrated Care Model" at the research symposium of the NADD's 33rd annual conference in

November 2016. The topic of the conference was "Weaving Solutions: Research/Policy/Practice in IDD/MI - Intellectual Disability/Mental Illness". Conference participants included for practitioners, professionals, care providers and families. Objectives were to discuss Achievable's novel, integrated model of providing a developmental health home for those with I/DD and mental health issues.

- Dr. Alicia Bazzano and Dr. Ari Zeldin presented to The American Academy of Pediatrics, California Chapter 2 (AAP-CA2) Town Hall on Best Practices in Developmental Screening in November 2017. Topics included best practices in developmental screening and early detection of I/DD, and the services provided by the Achievable Health Center.

Other products developed as part of the health center as a whole include patient intake packets (includes consent forms, release of information, patient information form, medical history, etc.), health center fact sheets, customer service training materials, newspaper articles and disability training materials for providers.

DISSEMINATION/UTILIZATION OF RESULTS

Achievable continually collects data on all projects to demonstrate the impact our projects and model of care can have on patients and their families. In addition to being reviewed and shared internally, key results are shared with our community partners and stakeholders, including healthcare associations, health centers, community leaders, policymakers, patients and families. As indicated from the previously mentioned publications, the AIM HI team has presented at state and national conferences that have, and will continue to, contribute to dissemination of our model and findings. Further, members of our team have been actively involved in maintaining partnerships, building local and statewide collaborations, increasing awareness and conducting outreach activities to policymakers, providers and leaders. The goal of such outreach is to generate state-level interest in improving the health care for individuals with I/DD throughout California by creating similar health centers throughout. Achievable is leading this movement by delivering a program that can serve as a blueprint and role model for other organizations, and continuously offers guidance and shares lessons learned. We are pleased with the positive response we are

receiving at the local, state and federal level, and are confident that the current project will increase awareness of the health disparities of our vulnerable community members.

Our staff also has implemented various strategies for communications with our patients and families about the availability of our medical home and the benefits for families: 1) Front line staff discuss this with families; 2) Creation of fact sheets, flyers and posters to help educate current and potential patients; 3) Publication of quarterly newsletters which highlight the key aspects of our health center, including the medical home model of care; 4) Revision of our website to better reflect our mission and services; 5) Presence and updates on social media to increase awareness and educate the community; 6) Continued partnership with the regional center and case managers who can relay awareness to clients; and 7) Convening of an Advisory Board to further our mission.

FUTURE PLANS/SUSTAINABILITY

Future Plans

Our organization as a whole has reached a critical juncture where we have grown from a start-up health center and are now an emerging leader in healthcare delivery for individuals with I/DD. As part of our strategic plan, which extends into the next five years, we will continue to develop and perfect our medical home model of care and continue to improve the quality of care provided to our patients. We expect to continue conducting outreach to the community and grow our patient base, especially children with I/DD and their families. We will periodically conduct community health needs assessments and engage our Advisory Council to ensure that our services are relevant and meet our community needs. Further, AIM HI will continue collaborations that have been forged during the project period, including those with Help Me Grow, Community Clinic Association of Los Angeles County, West LA College, The Chicago School of Professional Psychology, The Children's Dental Center of Greater Los Angeles, Venice Family Clinic, Westside Family Health Center and Westside Regional Center. We will also form new partnerships that will result in improved access and quality care for our community. Finally, within the next five years, our organization hopes to launch a new health center site in collaboration with another

local regional center. This new site will also incorporate the AIM HI project into operations to ensure a medical home for children with I/DD and medical complexities.

The Achievable team also recognizes that in order change the face of health care for children with I/DD, we must first start by changing the face of education for the healthcare workforce. Over the next few years, Achievable intends to partner with universities, colleges and other educational institutions to increase the knowledge and ability of those entering the healthcare field to care for individuals with I/DD. We are already impacting the mental health care workforce through our partnership with The Chicago School of Professional Psychology. In this project, clinical psychology doctoral students complete an advanced practicum at our health center in which they provide therapy services to patients and acquire the skills necessary to serve those with I/DD in the future. We are also creating a program with a local community college to provide a training externship for students studying to be medical assistants. Through this program, MAs will enter the workforce with the skills and comfort level to work with individuals with I/DD. As the first and most consistent point of contact that a patient has with a providers office, MAs can contribute to a deep and comprehensive understanding of patina needs, and training MAs to interact with and care for people with I/DD can have a profound impact on a patient's overall healthcare experience. Finally, Achievable is forming two additional partnerships with local medical schools; one to help train nurse practitioners and one to become a training site for physicians. The hope with all of these programs is to educate and train a medical workforce to offer more culturally appropriate, compassionate care to patients with I/DD and medical complexities, thereby improving the healthcare system for all children with I/DD.

Sustainability

Achievable's Board of Directors, leadership, staff and advisors fully support AIM HI, and are committed to its sustainability within the health center. The AIM HI project is streamlined with Achievable's overall operations and incorporated into our overall system of program and services. AIM HI's outcome measures are incorporated into our quality improvement plan. To ensure financial sustainability, Achievable's Board, leadership and development team will an active role in securing

funding to ensure sustainability of all aspects of the program. Achievable's financial sustainability plan for AIM HI includes revenue from grants, individual & corporate donors, events, campaigns, in-kind supports and clinical services. Our development team and Board of Directors continually work hand in hand to diversify our funding portfolio to ensure financial sustainability and our ability to continue providing the utmost in quality care and services. Our development activities allow us to balance a broad base of fundraising and community support with our federal grants and patient service revenues.

ANNOTATION: This report outlines the Healthy Tomorrows grant project awarded to The Achievable Foundation, called Achievable Innovative Medical Home Initiative (AIM HI). The major purpose of AIM HI was to create a medical home that provides developmentally-centered, continuous, coordinated and comprehensive care specifically tailored to serving children with intellectual and developmental disabilities (I/DD) and medical complexities, and their families. Children with I/DD often experience life challenges, poor health and complex, co-occurring medical conditions that necessitate access to a multitude of health services. Unfortunately, these children are also less likely to access appropriate health services. The goals of this project were to develop a medical home that improves quality of care, access to primary and specialty health care services, and health status of children (ages 0 to 18 years) with or at risk for I/DD. Key innovations of the model include specialized providers, team-based care, coordination of care, co-location with social supports and extended visits. The AIM HI Project served as a medical home to 922 children over the project period, providing key preventive services, well-child care, developmental screenings, early intervention, referrals and continuous, coordinated care as part of its medical home model. The project team has documented key aspects of its model in order to encourage replication of the model throughout the state to improve quality of, and access to, health care for all children with I/DD.

KEY WORDS:

Medical Home

Primary Care Services

Pediatricians

Children and Youth

Intellectual Disabilities

Developmental Disabilities

Developmental Issues in Children and Youth

Children with Special Health Care Needs

Family-Centered Medical Home

Integrated Care

ABSTRACT

Project Title: Healthy Tomorrows Partnership for Children Program - Achievable Innovative Medical Home Initiative

Project Number: H17MC25738

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Project Period: July 1, 2013 - February 28, 2018

Total Amount of Grant Awarded: \$235,191

PURPOSE OF PROJECT: As with other children with special health care needs, children with intellectual and developmental disabilities (I/DD) often experience numerous functional limitations, life challenges and co-occurring medical conditions at a higher rate than children without disabilities. These chronic and complex conditions experienced by children with I/DD necessitate access to a multitude of health services in order to maintain healthy, development and quality of life. Despite the clear need for access to services, children with I/DD face enormous obstacles in seeking basic care and supports due to lack of access to early intervention services, a shortage of providers trained in working with this population, low reimbursement rates to providers, lack of adequate insurance coverage, poverty, insufficient coordination services and fragmented systems of care. When they do access care, it is usually inadequate, discontinuous and uncoordinated.

The Achievable Innovative Medical Home Initiative (AIM HI) is a Healthy Tomorrows project which aims to improve access to care and quality of care for children ages 0 to 18 years who have, or are at risk for, I/DD. The major purpose of this project was to create a medical home that provides

developmentally-centered, continuous, coordinated and comprehensive care specifically tailored to serving children with intellectual and developmental disabilities (I/DD) and medical complexities, and their families. The AIM HI project is integrated into a Federally Qualified Health Center in Culver City, California and serves children throughout 30 adjacent zip codes.

GOALS AND OBJECTIVES: The AIM HI project expects to remove barriers to quality health care, improve access to care, enhance preventive services and improve health outcomes for children with and at risk for I/DD living in Los Angeles County. The three priority goals of the project were to: 1) Create an innovative, developmentally- and family-centered medical home for children with, or at risk for, intellectual and developmental disabilities; 2) Improve the quality of care and access to primary and specialty health care services for children with or at risk for I/DD, and their families, through AIM HI; and 3) Improve the health status of children with or at risk for I/DD who receive care through the AIM HI.

METHODOLOGY: The AIM HI project used several key methods to develop and implement an innovative medical home model specifically tailored to children with I/DD and medical complexities. A range of primary care services were provided throughout the project, as well as neurology and mental health services. The project ensured that staff and providers are experienced in, and trained in, working with children with I/DD and medical complexities. Team-based care was utilized throughout the project, and an emphasis was placed on forming a continuous relationship with the pediatrician as the primary care provider. Family-centered visits were structured using evidence-based guidelines, and utilized standardized assessments and tools were used for preventive services and developmental screenings. Participants with complex needs received extended visit times up to 60 minutes to ensure all needs are met. The AIM HI project also utilized several support staff members who were integral to improving quality of care and access to services. These team members included an Outreach and Enrollment Specialist who helped participants navigate the health insurance system, and a Referral Coordinator whose role was critical in ensuring patients receive needed care from specialists. Patients also received comprehensive care coordination. An electronic health record system and population health data

management system were used to document information, prompt reminders and implement pre-visit planning summaries to ensure comprehensive care. Finally, the AIM HI team established partnerships and collaborations throughout the community with those most closely linked to healthcare and services for children with I/DD. An Advisory Council was key in providing feedback and guidance on all services to ensure that our efforts reliably served patient needs.

EVALUATION: AIM HI utilized a combination of quantitative and qualitative methods within a structure-process-outcome model for evaluating the proposed project. Data sources for the evaluation included policy and procedure documents, intake forms, staff notes and activity logs, standardized assessment tools, evidence-based anticipatory guidelines, surveys and interviews. Over the course of the grant period, portions of the AIM HI evaluation were integrated into Achievable's traditional quality improvement (QI) methods in order to better understand processes of care and how to improve upon these processes over time. The AIM HI team conducted Plan-Do-Study-Act (PDSA) cycles as part of the QI program to plan and implement activities, review data and conduct action periods to implement changes to care processes aimed at improving quality.

RESULTS/OUTCOMES: The AIM HI project served as a medical home for 922 unduplicated patients ages 0 to 18 years throughout the 5-year grant period (06/01/13 - 02/28/18). By the end of the project period, almost 76% of pediatric patients had a well-child visit during the measurement year. In the last year of project, 85.6% of children with I/DD who used AIM HI as their medical home also had a well-child visit in that year, as did 83.6% of children without an I/DD. All AIM HI participants completing a Patient Satisfaction Survey identified AIM HI as their usual source of care. The AIM HI project demonstrated positive trends in recording immunizations and, by the end of the project period, 80% of participants had an immunization record documented in the electronic health record system. As part of a medical home, 99% of participants ages 3 to 17 years had height, weight and Body Mass Index (BMI) documented during a visit in the last year of the program, and 70% of these patients received nutrition and physical activity counseling. Also in the last year of the project, 70.9% of participants ages 3 to 18 years had age-appropriate hearing and vision screenings, and 76.7% of participants ages 0 to 5 years were

appropriately screened for developmental, social and emotional delay. In the most recent patient survey, 82% of patients with I/DD reported improved health status and quality of life in the last year of the project. Further, based on the most recent Patient Satisfaction Survey, both patients with I/DD and patients without an I/DD show an overall high level of satisfaction with all aspects of the project.

PUBLICATIONS/PRODUCTS: The AIM HI project developed and utilized several products and publications including newsletters, annual reports, a website, a video to prepare children with I/DD for a office visit, a referral passport form, a patient satisfaction survey, resource lists of providers experienced in caring for children with I/DD, contribution to a special radio segment on transition care for youth with disabilities, and multiple presentations to local, state and national audiences.

DISSEMINATION/UTILIZATION OF RESULTS: The project results are utilized to continually improve the project and positively impact participants. Results are also disseminated to community partners and stakeholders, including healthcare associations, health centers, community leaders and policymakers. Project components are disseminated to patients and families through frontline staff, brochures and flyers, newsletters, website and social media, partnership with a local regional center and through an Advisory Council.

FUTURE PLANS/SUSTAINABILITY: Over the next several years, the project team will continue to develop and perfect the medical home model of care and continue to improve quality of care. Future plans include several community collaborations and partnerships with educational institutions to educate and train the future healthcare workforce on the unique and special needs of children with I/DD. Future plans also include replication of our model at other health centers throughout the state to serve all children with I/DD. The project will be sustained through a variety of operational and philanthropic revenue sources.