NICHQ
National Institute for Children's Health Quality

# Improving Children's Vision: Systems, Stakeholders and Support Learning Collaborative

## 2018 Final Report

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# Executive Summary

## Overview

With support from Health Resources and Services Administration Maternal and Child Health Bureau (HRSA/MCHB), the National Institute for Children's Health Quality (NICHQ) and the National Center for Children's Vision and Eye Health (NCCVEH) at Prevent Blindness partnered to increase the number of children, ages 0-to-5 years, receiving vision screening and diagnosis through implementation of a learning collaborative. This report presents an overview of the methodology, accomplishments and challenges of the learning collaborative and recommendations for future work.

## Background

Millions of children in the United States have vision problems. If left untreated, vision problems can have an adverse impact on many areas of children's lives, such as their physical health, mental health, and ability to learn. Populations of focus included those known to be at risk for vision impairments due to lack of access to and utilization of vision care. Building on recommendations from a national panel of experts [1,2,3] and a pilot of five states, the "Improving Children's Vision: Systems, Stakeholders and Support Collaborative" aimed to increase the proportion of children ages 5 years and younger who receive vision screening and diagnosis in five states by the year 2018 by 20 percent compared to 2011-2012 levels [in the National Survey of Children's Health]. [4]

## Results

Three state-based teams (Arizona, Ohio and Wyoming) participated in a 21-month collaborative that used quality improvement methodology to drive system change and track progress towards improved vision screening along the continuum of care. The teams focused their improvement work in diverse settings: primary care practices in Arizona, preschools in Ohio and child development centers in Wyoming.

Led by NICHQ staff and the NCCVEH Director, the teams joined three virtual learning sessions and monthly calls where they heard from experts in the field and shared successes and challenges. They also leveraged NICHQ's online collaboration tool to track progress and share resources. For additional customized support, each team participated in two individual technical assistance calls and one site visit. Teams faced challenges obtaining baseline data and tracking improvement data in real time due to a lack of national, state or regional systems that collect national, state, or regional vision screening and follow-up data.

Key findings from the collaborative include:

- Engaging families who have navigated the vision care system is critical.
- At least one in-person meeting is important for building relationships and trust across teams and engaging keys partners and leaders. When developing the measurement strategy, consider the project scope and available resources. The measurement strategy should be adaptable enough to accommodate participating teams' capacity and resources.
- Data collection and reporting is limited by existing data collection processes and systems.
- Applying success from other teams is challenging when teams are working in diverse settings.

Recommendations for future work include:

- Recruit teams working in similar settings if possible. If heterogenous teams, customize the key documents at the start of the collaborative to ensure they support each teams' work.
- Include at least one (ideally two) family partners on the core improvement team
- Develop a simplified, feasible measurement strategy that informs improvement work. Conduct a pilot of the measures with the participating teams.
- Recruit teams with data systems in place or who have resources to develop data systems.
- Engage teams in-person if possible.

# Introduction

## The Problem

More than 12.1 million—or one in four—school-age children have some form of vision problem requiring treatment[5]. These problems can begin well before a child reaches school-age. Vision impairments caused by refractive error, amblyopia, strabismus, and/or astigmatism are common conditions among young children, affecting 5 to 10 percent of all children aged 3-5[6]. These terms are defined in Appendix A. Amblyopia is present in 1 to 4 percent of preschool-aged children and an estimated 4 percent of these children have myopia and 20% have hyperopia[6]. If not detected and treated early, vision impairment could affect all aspects of life, negatively impacting a child's ability to learn, athletic performance and self-esteem.

Vision in young children represents an important intersection of early development, learning success and physical health. Research shows that healthy sight helps children reach developmental milestones, improve school readiness, increase graduation rates, reduce poverty, and predict positive social relationships[7,8,9,10,11,12]. According to the 2016-2017 National Survey of Children's Health (NSCH), only 41 percent of children under age 5 received a vision screening. Of those receiving screenings, 26 percent received a screening at their pediatric provider, 13 percent at an eye doctor, and 7 percent at school. The remaining 54 percent were screened at a clinic, another setting or unknown setting[13].

A 2013 focus group of parents of children in a Head Start program found the most common barriers to eye care for families were cultural mistrust of formal healthcare systems, a lack of acceptance of vision problems by the parents, and misunderstanding of the vision screening referral information and/or prescribed next steps in vision care due to language and literacy level differences[14].

Disparities in access to and utilization of eye care or screening opportunities in these populations result in an unnecessarily higher incidence of vision problems without resolution. Public health initiatives must be planned with special attention to the needs of those populations at increased risk for vision problems.

Attention to vision and eye health in young children is critical to long-term vision outcomes. Unfortunately, many children do not receive timely vision screenings or eye care. Improvements in key public health activities—including education, surveillance, vision screening, access to eye care, and encouraging state and local efforts to establish policies that promote action—are critical steps for improving children's vision and eye health in the United States[15].

## History

The Health Resources and Services Administration Maternal and Child Health Bureau (HRSA/MCHB), recognizing the importance of early vision health as a component of a child's overall development, supported the establishment of the National Center for Children's Vision and Eye Health (NCCVEH) at Prevent Blindness through a cooperative agreement (United States Department of Health and Human Services Cooperative Agreement #H7MMC15141 and #H7MMC24738). A National Expert Panel (NEP) comprised of leading professionals in ophthalmology, optometry, pediatrics, public health, and additional related fields, along with family advocates, was formed to develop national recommendations outlining how best to improve the public health infrastructure supporting the early detection of children's vision problems. The NEP undertook a consensus process incorporating review of available published literature (articles published through February 2014) including peer-reviewed research, reviews and policy statements, and consultation with states developing vision health program infrastructure. NEP recommendations were focused on three key areas:

- Performance measures that could be implemented across states to track both provision and receipt of vision screening or eye care in children aged 3-to-5 years
- Uniform management and integration of patient level data collected during vision screening
- Best practice protocol in vision screening methodology for children aged 3-to-5

These recommendations were published as the three lead articles in the January 2015 issue of the Journal of Optometry and Vision Science. The articles have initiated the move towards standardization in vision screening methodology in children aged 3 to 5, and have provided guidance in systems for accountability and surveillance for children's vision and eye health in the US[1,2,3].

The NCCVEH utilizes the guidance from the NEP as it works in collaboration with state partners to provide the technical assistance, education, training, resources and leadership necessary to advance a systems level approach to children's vision. Five states (Georgia, Illinois, Massachusetts, North Carolina and Ohio) served as pilot sites for the NCCVEH from 2009 through 2015. The five pilot states were tasked with forming multi-disciplinary coalitions to study strategies for establishing state level systems for children's vision and eye health; serving as state leaders in development and improvement of comprehensive vision programs for children; expanding existing efforts in surveillance of children's vision, screening, outcomes and health disparities; developing and disseminating educational tools and resources; and developing a state action plan based on a situational analysis of their current vision and eye health system. The state level programs supported the mission of the NCCVEH by providing a preview of how the vision systems would work, engaging and educating key stakeholders (including primary care, public health, eye care professionals, educators, nurses, researchers, families and community programs), and developing best practice examples for future use. Key successes from this work included: integration of vision screening, eye exam and treatment outcomes data into the state immunization information system in Ohio; improved access to eye care in Georgia; establishment of a workgroup comprised of diverse professional community and family representatives to seek out an evidence-based approach to vision assessment in Massachusetts; and expansion of vision screening training and certification for school nurses in North Carolina through an online training.

## Improving Children's Vision: Systems, Stakeholders and Support Collaborative

With continued support from MCHB (grant #H7MMC24738), Prevent Blindness partnered with NICHQ to lead the "Improving Children's Vision (ICV): Systems, Stakeholders & Support Collaborative" a quality

improvement (QI) project to increase the detection and diagnosis of visual impairment in children ages 0 to 5. The ICV project was designed to build on the NEP recommendations and leverage the learnings from the pilot states. This three-year project aimed to support the development of comprehensive and coordinated approaches to children's vision and eye health in five states. The specific aim was to increase by 20 percent over 2011-2012 [National Survey of Children's Health] 4 levels the proportion of children aged 5 years and younger who receive vision screening and diagnosis in 5 states by the year 2018.

Specific goals included:

- Strengthening statewide partnerships and coordination among key stakeholders in children's vision and eye health
- Increasing access to and utilization of vision health services in hard-to-reach communities
- Increasing early detection and treatment of vision problems
- Establishing state-level surveillance
- Implementing vision health system measures of accountability

The project employed QI principles and practices to implement system-level changes. The population of focus represented the cultural and geographic diversity of the state, families with various sources of health care insurance coverage, and locations with high numbers of children considered at increased risk of vision problems or barriers to care. Populations of children at an increased risk of vision problems include low income, minority populations (specifically African American, Native American and Hispanic children), uninsured and underinsured families, and rural populations[16,17].

## Improving Children's Vision Learning Collaborative Overview of Activities

### Learning Collaborative

ICV used a modified version of the Institute for Healthcare Improvement's Breakthrough Series™ (BTS) learning collaborative model as a framework for the initiative[18]. A BTS learning collaborative is a vehicle for rapidly spreading changes that is demonstrated effective for improving care and outcomes for defined populations. In this model, teams from participating organizations come together in a highly-structured program that emphasizes shared learning, continuous data collection and iterative testing. A traditional BTS model includes three in-person learning sessions of teams working on QI over a 12 to 18-month period with monthly action period calls in between. Action periods are a time when teams focus on testing and implementing changes using small tests of change (i.e., Plan-Do-Study-Act (PDSA) cycles) and regularly collect and report measures to track improvement. Teams can adapt and spread changes quickly because evidence-based (including research and empirical evidence) changes are provided to the teams at the beginning of the BTS learning collaborative. The model used for ICV was modified from the standard BTS in that all learning

> "Our work to improve children's vision and eye health in the U.S. has always centered on big ideas and massive systems shifts, thus we found the process of continuous quality improvement to be an exciting new way to tackle the challenges we face in our work."
> - Kira Baldonado-Project Partner

sessions were virtual rather than in-person. The ICV Learning Collaborative began in July 2016 with a welcome webinar and ended in a celebration webinar in March 2018. Please see Appendix B for a detailed project timeline.

## Project Leadership Structure

This project was led by the NCCVEH Director with support from NICHQ, an independent, nonprofit organization that has worked for nearly two decades to improve the systems impacting children's health through collaboration with organizations and professionals with a shared mission. Working in close partnership with NCCVEH, NICHQ provided foundational support for a QI initiative with the aim of making substantive improvements to vision and eye health systems for young children. The NICHQ team consisted of a project director, improvement advisor, senior project manager and project manager. Appendix C illustrates the organizational structure of the project.

This project drew on the wealth of professional and family advocate expertise found in the volunteer NCCVEH Advisory Committee (AC). The AC included nationally recognized leaders in children's health, vision care, public health, early education and childcare, vision research, and family advocacy, many of whom had served on the independent NEP that published the national guidelines for children's vision in 2015. The AC brought content expertise in children's vision and eye health in the context of public health systems and program interventions and provided presentations at the learning sessions of the QI collaborative. They assisted in the development of the measurement strategy and change package (detailed below) and participated in the recruitment and selection process of state teams. Finally, members of the AC provided individual technical assistance, as requested, to the state teams. Please refer to Appendix D for a complete listing of AC members. The NCCVEH Director acted as the liaison between NICHQ and the AC.

The NCCVEH Director provided ongoing expertise and support for all aspects of the project including: co-development and approval of the materials and curriculum; presentation of vision care content at the action period calls; review of the project design, strategic approaches, progress and data analysis against the agreed-upon goals; and dissemination of the project outcomes.

## Setting Aims, Strategies, and Measures

With guidance from the Advisory Committee, the NICHQ team and NCCVEH Director created the key documents intended to guide the work of the collaborative. The key documents are listed below:

- The charter, which provides an overview of the project, goals, and guidance for developing a state level improvement team for this three-year initiative.
- The driver diagram, titled "The Public Health System Driver Diagram to Increase Detection and Diagnosis of Vision Impairment in Children Aged 5 Years and Younger", which included primary drivers directly tied to the five goals outlined above. The primary drivers included: broad access to preventive care and treatment, infrastructure and capacity to support optimal outcomes, and data monitoring and population-level surveillance.
- The measurement strategy, which included four outcome measures and eight process measures. Outcome measures included screening, referral, receipt of care and one optional measure on treatment adherence. Process measures included access to preventive care and treatment, infrastructure and capacity, information sharing with medical home, parent and family education and comprehension, and two optional measures on preferred language and

high-risk children. The measurement strategy was meant to track improvement over time to ensure tested and implemented changes would support the project aim.

- The change package, which lists a menu of changes under each secondary driver for teams to test. The change package represents changes used in the pilot project period, in similar public health intervention programs; those used by Prevent Blindness in other areas; and those culled from journal articles.

## State Team Recruitment & Selection

NCCVEH and NICHQ led a competitive application process to identify state teams for participation. NICHQ, in partnership with NCCVEH, developed a recruitment plan including criteria for state participation in the virtual learning collaborative. States were required to identify and engage a diverse group of stakeholders (e.g., primary care, public health, strong family representation from the populations of focus, vision care providers, and community-based organizations) to support the improvement work by providing input on the existing system of care and strategic planning around testable change ideas. The following additional criteria for participation was recommended but not required in its entirety:

- Broad sector engagement (e.g., private sector, schools, child care and Head Start programs).
- Clarity of aim.
- Leadership engagement.
- Identification of vision as a strategic priority.
- Service of communities at high-risk for vision problems or eye care access issues, and children from diverse cultural backgrounds, including tribal communities.
- Provision of financial and staff resources to support the project.
- Integration of project goals into existing programmatic efforts.
- Data systems and data analysis support.
- Health provider reimbursement systems support.
- Support networks for eye exams, glasses and treatments.

As previously noted, the goal was to recruit five state teams. The opportunity was shared through public health information networks, press releases, HRSA program networks, social media, and NICHQ and NCCVEH listservs. NICHQ and NCCVEH held a webinar to provide an overview of the project, as well as details and benefits of participation. The announcement of the project and associated invitation for state level participation coincided with a major national transition in state Title V programs, which resulted in a greatly reduced capacity for state departments of public health to leverage resources (staff, time and money) to engage in the QI collaborative. Three states (Ohio, Arizona, and Wyoming) completed applications. All were accepted for participation.

## Team Composition

States participating in the Collaborative were required to convene a core team of four to five members. The teams worked together over a period of 18 months to share, test and implement recommendations previously developed by the NEP. Though the recommended team structure was standardized, the membership of the core team differed from state to state based on unique state-level staffing and programming structures and the setting where the improvement was focused. The common ingredient

among teams was the potential and drive to improve children's vision outcomes and systems. Specifics of team membership on each state team is presented in the state sections.

Core team members were responsible for active participation in all learning sessions and action period calls. Some of the key individuals included representatives from public health, vision care providers, community-based organizations and most importantly strong family representation (defined as a minimum of two family representatives) from the population of focus. Roles in the core team included: a team lead, family partner and data lead. The team lead was tasked as the project's point person. The team lead facilitated team function, led a strategic stepwise approach to improvement that included assuring a continuous cycle of small tests of change leading to implementation and supporting the collection and submission of data for learning and improvement, engaged extended team participants and partners, served as point of contact between the state and extended teams, and recruited additional extended partners to spread changes. Later responsibilities of the team lead included assuring that there was a plan in place for implementing and sustaining changes that led to improvement. The family partner served as the point of contact with other parents and community groups to ensure real-life experiences and challenges were reflected in the planning for improvement. The family partner assured PDSAs chosen for quality improvement reflected a direct impact on families; helped with data development and collection, especially data coming from families; and assured that processes completed in the improvement work had a functional outcome for families. The data lead was responsible for gathering accurate and timely data, coordinating with partners for data collection, and compiling and submitting data reports.

## Learning Collaborative Components and Activities

The ICV Learning Collaborative included:

- One learning session pre-work webinar.
- Three virtual learning sessions.
- Three action periods.
- One celebration webinar.
- The Collaboratory ("CoLab").
- Individual technical assistance.
- Site visits.
- Interviews.

The Learning Session Pre-Work Webinar provided an orientation of the project and prepared teams for the first learning session by reviewing the learning session pre-work materials and activities.

NICHQ convened teams for three virtual learning sessions in September 2016, March 2017, and September 2017. These 8-hour sessions were facilitated in two four-hour days. The purpose was to provide time for the teams to jointly identify gaps in the system of care, challenges to improvement, interventions to be tested, PDSAs, and strategies to leverage evidence-based best practices. The learning sessions also provided a component of learning and sharing around the QI models and data for improvement. NICHQ used strategies to ensure the virtual learning sessions were engaging and interactive.

The first learning session set the stage for the improvement work by bringing a level of credibility to the project. It instilled a sense of urgency for change through compelling presentations by experts in the

field, the inclusion of family stories, and sharing experiences from clinical and community-based providers.

Each learning session was specifically designed to create and renew momentum and was customized to the teams' needs and improvement progress status. Learning sessions provided a forum for collaborative learning and the sense of being a part of vital work that has the potential for a sustained and collective impact. The three learning sessions provided time for the teams to come together around children's vision as they shared their wins and supported each other around challenges and lessons learned. The learning session agendas are included in Appendix E.

Action periods followed each of the learning sessions. During action periods, teams applied QI methodology, conducted small tests of change and participated in monthly group coaching calls. ICV teams' participation and level of collaboration that developed during the ICV action period calls was evident by an outstanding commitment to attend and enthusiastic participation in interactive sharing and learning. Building on learning session presentations, several action period calls included presentations by experts in children's vision and by family partners who shared compelling stories of the value of early childhood vision screening and of the challenges with navigating the system after their child's vision issues were identified.

> Participating in NICHQ's Improving Children's Vision project has facilitated a rich opportunity to pursue robust quality improvement strategies to enhance early childhood vision health in Wyoming. [We] appreciate the expertise provided by the leadership team and the opportunity to share ideas and feedback with other states in the Collaboratory."
> - Hannah Ginn-Project Participant

One celebration webinar completed the last action period. This uplifting call highlighted the accomplishments of the project, as well as individual wins and learnings. Teams discussed plans for continuing the improvement work by sharing tangible next steps.

ICV teams used the Collaboratory (CoLab), NICHQ's web-based platform, which offers a secure space for sharing resources, best practices and challenges. Teams used CoLab to communicate with each other, NICHQ, and NCCVEH; to post pre-work and PDSA worksheets; and to enter qualitative and quantitative data for review and analysis. Quantitative data was automatically summarized in run charts to show trends over time. NICHQ provided coaching and technical assistance to the teams through CoLab.

Individual technical assistance was provided to teams via scheduled telephone conference calls. These calls were informal and responsive to the needs of the teams. Specific agenda items were identified by the teams in collaboration with NICHQ's ICV Project Director and Improvement Advisor. Topics included strategizing around data collection challenges and building ongoing partnerships of stakeholders and families.

Each of the three states received a site visit from the NCCVEH Director, NICHQ Project Director, and NICHQ Improvement Advisor. A standardized agenda was developed and customized by each site to ensure both the project and the site gleaned value from this activity. Each site was provided a summative site visit report that included the highlights of the conversation and outlined next steps. Site visits were unique to the setting and the team. Each team shared their appreciation for this activity; they

all also suggested that the site visits might be more valuable in future work if they occurred earlier in the initiative. A sample agenda can be found in Appendix F.

Team Interviews: The NICHQ Improvement Advisor conducted interviews with team leads and family partners in the final year of the project after the celebration webinar was completed. The purpose of the interviews was to collect qualitative data that would build on and support the quantitative data. The Improvement Advisor created a summative report to identify themes to support the content of this report. However, due to the small sample size participants were assured that their individual interviews and responses would not be shared as they might be easily identified with the state and or the interviewee. The broad themes from the interviews are included below. The complete qualitative interview guide, including purpose, methodology and logistics, is included in Appendix G.

## Highlights from Interview Responses

The questions posed were focused on: 1) value of participation; 2) building partnerships with key stakeholders; 3) key successes; 4) recommendations for future collaboratives; and 5) additional learnings.

When interviewees were asked about the value of participating in the collaborative the following themes emerged:

- Clear objectives and structure to frame a formal review of vision screening systems
- Potential for peer learning across diverse participants
- Increased referral rates for participating providers
- Alignment with and strengthening of sites' on-going work to improve vision care for children
- Involvement of family partners with continued opportunities for shared learning
- Increased creditability due to national partner involvement

**Responses to the question, *"what is the value of participation?"* included:**

- *"…understanding of the needs and how to address them."*
- *"Helped me think through ideas and brainstorm."*
- *"Allowed states to pause and think about their systems."*
- *"It's easy to focus on your part of the work. The tension between how do we improve in a specific setting and how do we improve the systems. Both have to happen!"*
- *"…and it has been hard to get our data but I think that just the conversations, the fact that you get one person talking to another person, is valuable."*
- *"I [family partner] thought that, because the initial information I got was that they [participating team] were inviting folks who had a hard time obtaining vision services and that wasn't our story. It was while listening and learning during the project that I realized that my daughter was not receiving proper vision screenings the whole time. So I learned why I was on the project while I was on the project."*
- *"Families are impacted through their screening experience, but it is subtle."*
- *"Having the national voice to help inform the state voice is influential and meaningful."*

"I think that just the conversations, the fact that you get one person talking to another person, is valuable."

When interviewees were asked about their success and challenges in building partnerships with key stakeholders the following themes emerged:

- Variation in levels of support needed to build partnerships due to different levels of experience with key stakeholder engagement prior to collaborative participation.
- Changing the system takes time.
- Messaging should be consistent with what we know about spread: we will have a certain percentage who are early adopters (i.e., ready to change) and a larger percentage who are early or late majority adopters[19].
- Initiatives need to make time spent by stakeholders and partners valuable.
- Family partner themes:
    - Important to be sensitive to their unique stressors (e.g., navigating the system on behalf of their children with needs related to vision and frequently other areas) and to whether they are experienced in participating in this type of work.
    - Beneficial to engage family partners who had children with vision problems and were professionals in the system.
    - Important to develop more ways to engage family partners and make them feel part of the work.
    - Family partners with experience navigating the system are invaluable.

**Responses to the question, *"how did you build partnerships with key stakeholders?"* included:**

- *"Our department of health contact was a great advocate for the work."*
- *"I [parent partner] think that there was a perfect balance of valuing the family perspective and encouraging that engagement and, at the same time, allowing for flexibility in the event we couldn't attend a meeting or call. The only thing that could have been nice to have sometimes would have been more direction (here's what we are doing, here are our goals). I felt timid on the calls sometimes because I felt I was out of the loop. My education isn't as high as everyone on the team and I didn't always understand their work. That could have been nice but, then again, it may have been intimidating and made me feel like it was over my head."* (Note: This was in reference to the state team's work and not the collaborative.)

"I didn't feel like I was coddled or involved because I was some box that people had to check off...I felt like a valued member of the team and so appreciated being invited to the site visit."
- Parent Partner

- *"I remember talking to my child's pediatrician about the project and about how we were aiming for some measurable results in improving the vision screening and referral process and them saying that it's really nice to take part in that but that things won't change because it costs too much money. Seems either they [stakeholders] embrace the challenges or seeing where this goes before taking it on."*
- *"Give them [partners and stakeholders] a role and value their time—take advantage of what they know. Give them a purpose!"*
- *"I [parent partner] didn't feel like I was coddled or involved because I was some box that people had to check off just because they needed a parent involved. I felt like a valued member of the team and so appreciated being invited to the site visit."*
- *"I was excited that, when the project was ending, we really focused on public awareness for vision health and we still have the wheels in motion for that…I remember wondering 'what now' when I heard it was going to end so I am so grateful for that."*

- *About having various stakeholders at the table: "Super valuable to have them in the room because still hear it. They won't or can't always promise anything [this is regarding change in the system] immediately but boy do they hear it."*
- *"The people [parents] we engaged had personal experience with vision—they are parents and dedicated to the work which was advantageous."*

When interviewees were asked about their team's key successes the following themes emerged:

- Qualitative data showing the impact on children's lives
- More screeners trained
- Referrals increased
- Increased family knowledge
- Established relationships with the other participating states
- Successful collection and reporting of some measures and recognition of importance of measurement to inform improvement work
- Teams' increased knowledge of improvement science

**Responses to the question, "*what were your team's key successes*?" included:**

- *"A little boy came in and his eye was turned and had been told it was because of facial structure. Because they [teachers] had been trained to refer based on observation alone, they did recommend a second opinion. They [the family] followed through and when he came back to school, he had had surgery and was patching and when we did the vision screening and he passed on the weak eye, it was so nice to look at that and say, wow. The point is a year later it was a completely different situation for him. I think that when you can drill it down to an individual situation like that and you sit there and look at the formal structure you had in place because of this Collaborative, it makes it all worthwhile—one child at a time."*
- *"When my kids went through school, focusing on a vision problem was more of a reactive thing—like they noticed my son's eye crossing and so intervened but today I think you would see a more proactive approach just because of all of the education that is now happening both for getting permissions, at screening and at follow up and during treatment. Things are being done more formally than previously."*
- *"The collaborative helped me thinking it through better rather than working by myself to think it through. It was always more helpful to have more than just me asking, 'How can we improve'?"*
- *"Launching vision screening was our core success and having Kira to review training materials was very helpful. Referral knowledge and processes for screeners has increased and new forms, including forms translated to Spanish, have helped reach families more broadly."*

"Referral knowledge and processes for screeners has increased and new forms, including forms translated to Spanish, have helped reach families more broadly."

When interviewees were asked if they had recommendations for future collaboratives the following themes emerged:

- Build in site visits, as standard part of the work - the earlier in the process the better.
- Allow for customization of measures, the driver diagram and the aim statements by the participating teams.

- Reduce the burden of data collection (i.e., fewer measures) and reporting because it discourages participation.
- Encourage teams to scale down their aims—start small.
- Leadership support, adequate resources and a fully engaged teams are critical for success.
- Eighteen months was a good length of time for all except the school-based program.
    - School vacation fell during the collaborative, so the school-based program did not have the opportunity to test with children during that time

Build in more time for the teams to share and talk with one another during the virtual learning sessions and action period calls

**Responses to the question, "*what recommendations for future collaborative do you have*?" included:**

- *"Site visits were very advantageous. They were helpful in getting the team aligned and to provide direction."*
- *"State has an antiquated data system (still using Internet Explorer), which resulted in some difficulties with data entry and team leader had to do it retrospectively. And, there were months when we didn't have data because of our environment. Our project didn't fit with the data entry that had been set up."*
- *"Our first year, the project was just too big. Once we downsized it, the data entry was easier—everything was easier."*
- *"As I recall, the driver diagram wasn't quite right for us and one of the things we talked about was customizing it. I think that it helps people working in complex systems see the big picture. What's interesting is unless you deliberately go back and show it all the time, it is out of sight, out of mind. It serves an important purpose and something that I think will need to be customize if it is going to be useful for each group…"*
- *"The thing that made me most crazy was time for the collaborative learning (not enough time)."*

When interviewees were asked if they had additional learnings from their participation that they would like to share the following themes emerged:

- Consider recruiting families of children with vision impairment who are interested in vision health instead of only including those who have or had problems navigating the system
- Following up on referrals is a remaining area for improvement work
- Eighteen months is a good length for a collaborative, but teams need much longer if expecting to impact the system
- Sites were interested in receiving assistance to spread improved vision screening throughout the system
- Results Based Accountability is a complimentary model to that of the Breakthrough Series Model and may help with thinking more about how to build capacity amongst collaborative participants[20]
- Technical assistance support for data and improvement was helpful

# Journey to Improvement: The Stories of the State Teams

## Arizona

### Background/Overview

Arizona focused on engaging primary care providers to improve vision screening and care. Arizona's state-specific ICV aim was:

> B*y January 2018, 80 percent of children aged 3 to 5 years receiving well-child care in targeted primary care sites will have had at least one valid vision screening. If screening is failed* [not passed*], 100 percent have had an eye exam by an eye care provider. If appropriate, 95 percent of children receive treatment as prescribed.*

The aim aligned with Arizona Eyes on Learning, a coalition of a diverse group of organizations committed to vision health and learning success for all children in Arizona. Team membership included: a team lead who was also the Director of Eyes on Learning; leadership from Virginia G. Piper Trust, which funds Eyes on Learning; two family representatives; three data team members from Frameshift Group, an organization that specializes in QI methods; an optometrist; and the Chief of the Office of Children with Special Health Care Needs at the Arizona Department of Health Services. The Arizona team identified their strengths as having a high rate of instrument-based screening, a community network of pediatric eye care providers, and good community resources for visually impaired and blind children and families. They also had a strong foundation in QI. The Arizona team planned to recruit federally qualified health centers (FQHCs) and primary care practices serving vulnerable populations. To start, they invited four FQHCs to participate. The FQHCs reported that they were performing vision screening for children ages aged 3 to 5 but had no system to track referrals to follow-up care. None of the centers had established data systems that would allow them to easily gather vision screening and referral data to identify gaps and areas ripe for improvement.

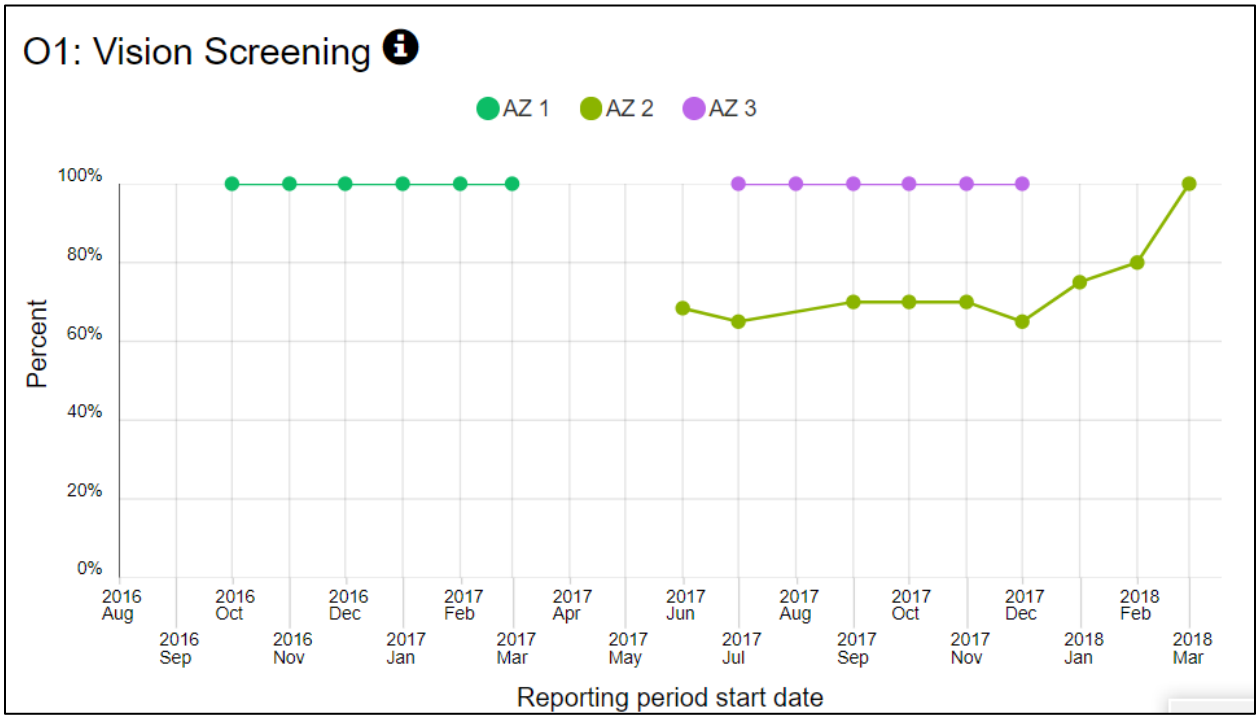
The Arizona state team engaged three pediatric primary care practices that were interested in improving their systems and outcomes for children's vision. These office-based settings focused on improving their overall rates of vision screening on children ages 3 to 5 and on improving children's vision care education for office staff, pediatric providers, parents and children. The pediatric practices recognized a gap in their system for tracking child vision assessments along the continuum of care: office-based screenings through referrals and treatment. The establishment of parent partnerships was a critical element of this improvement effort. The Arizona team fostered a strong working relationship with parents of children with vision challenges to better understand the gaps in the current system of care and to vet the feasibility of change ideas prior to testing and implementation.

### Data

Arizona was able to work with its three participating sites to collect and report data for the three outcome measures but was unable to collect the process measures due to lack of capacity at the primary care practice sites. Figures 1-3 present a summary of the data. The patterns that emerge in the figures support their story of how difficult it was for their practices to collect and report the data in a

way that was not burdensome. As with many data collection exercises, it took some time to set up their systems of data collection and reporting such that they were reporting the correct numbers; this is evidenced by the substantial decrease in their "N" after month one of the project. AZ 1 was able to collect and report up until the time they changed their electronic health record and, at that point, was no longer able to collect and report. This is unfortunate because they had very reliable processes in place for vision screening and referral and were showing some opportunities to improve upon the percent of children receiving the follow-up care. Due to the lack of data, it is unknown whether their continued work resulted in improvement. Based on the submitted data, AZ 3 had very reliable systems in place at the start and maintained them throughout the time they reported data. AZ 2 showed improvement from December 2017 through March 2018. One more point increase would have been a favorable trend. Similarly, they were beginning to show a favorable shift in receipt of eye care beginning in December. Since, when using statistical process control rules, their data is close to showing a trend and shift, further investigation into what may have changed in November or December of 2017, and shifted that data, may prove revealing.

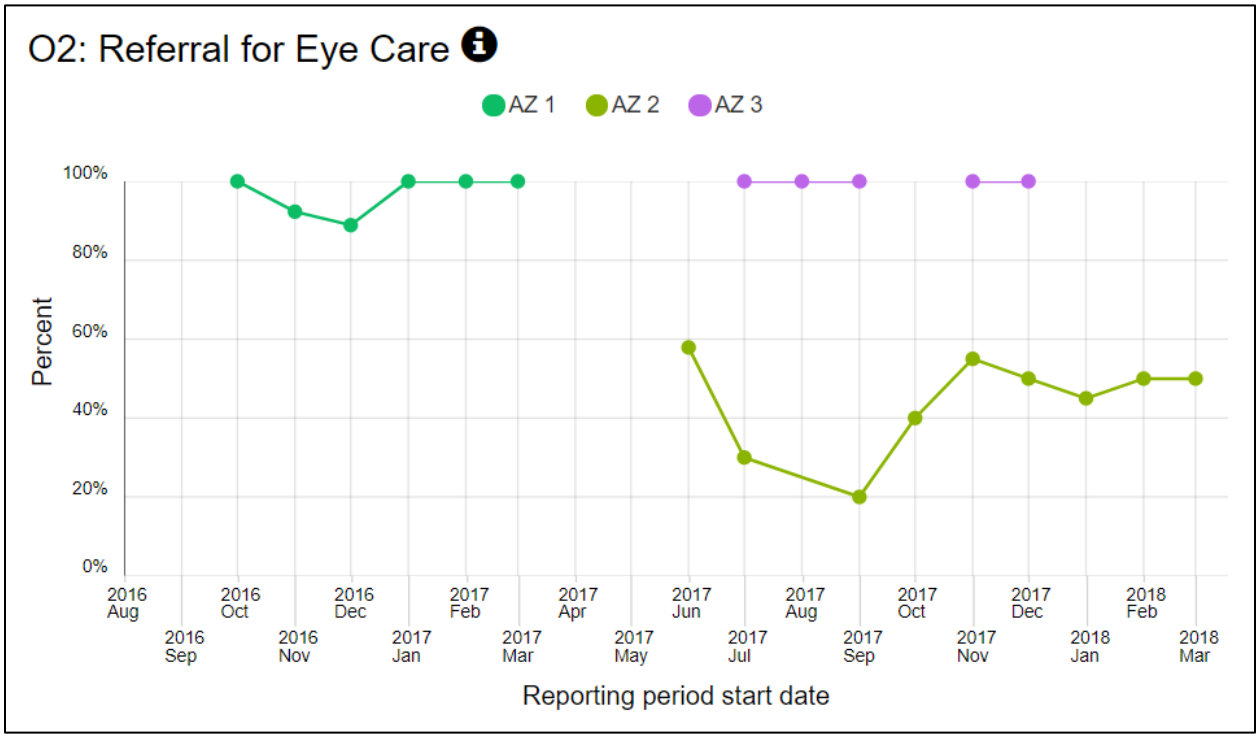
**Figure 1**




| Vision Screening Ns | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| "N" | Oct 16 | Nov 16 | Dec 16 | Jan 17 | Feb 17 | Mar 17 | Apr 17 | May 17 | Jun 17 | Jul 17 | Aug 17 | Sep 17 | Oct 17 | Nov 17 | Dec 17 | Jan 18 | Feb 18 | Mar 19 |
| AZ 1 | 578 | 13 | 9 | 9 | 12 | 30 | | | | | | | | | | | | |
| AZ 2 | | | | | | | | | 19 | 20 | | 40 | 40 | 40 | 40 | 40 | 40 | 40 |

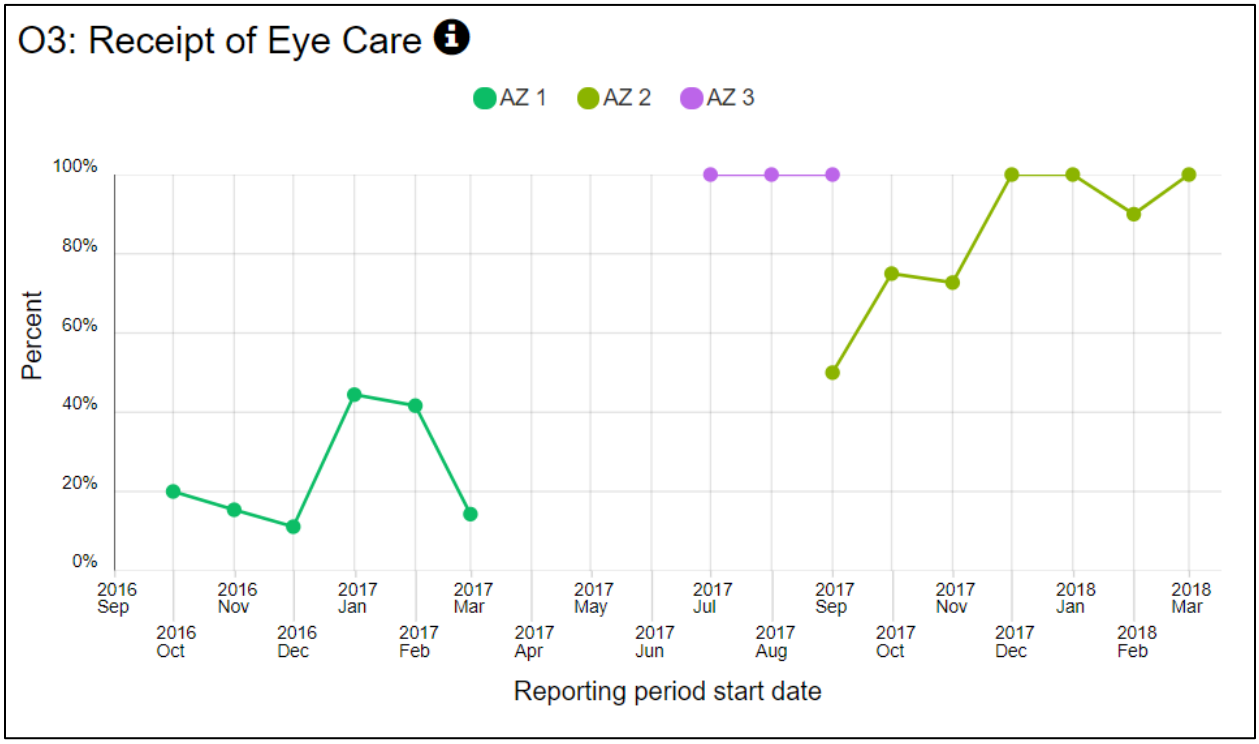
| | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| AZ 3 | | | | | | | | | | 41 | 41 | 45 | 39 | 45 | 29 | | | |

**Figure 2**




| **Referral for Eye Care Ns** | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| "N" | Oct 16 | Nov 16 | Dec 16 | Jan 17 | Feb 17 | Mar 17 | Apr 17 | May 17 | Jun 17 | Jul 17 | Aug 17 | Sep 17 | Oct 17 | Nov 17 | Dec 17 | Jan 18 | Feb 18 | Mar 19 |
| AZ 1 | 240 | 13 | 9 | 9 | 12 | 7 | | | | | | | | | | | | |
| AZ 2 | | | | | | | | | 19 | 20 | | 40 | 40 | 40 | 40 | 40 | 40 | 40 |
| AZ 3 | | | | | | | | | | 1 | 6 | 4 | | 3 | 1 | | | |

**Figure 3**




| **Receipt of Eye Care Ns** | | | | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| "N" | Oct 16 | Nov 16 | Dec 16 | Jan 17 | Feb 17 | Mar 17 | Apr 17 | May 17 | Jun 17 | Jul 17 | Aug 17 | Sep 17 | Oct 17 | Nov 17 | Dec 17 | Jan 18 | Feb 18 | Mar 19 |
| AZ 1 | 240 | 13 | 9 | 9 | 12 | 7 | | | | | | | | | | | | |
| AZ 2 | | | | | | | | | 19 | 20 | | 8 | 16 | 22 | 20 | 18 | 20 | 20 |
| AZ 3 | | | | | | | | | | 1 | 6 | 4 | 39 | 45 | 29 | | | |

## Accomplishments

Arizona's main accomplishments included the establishment of strong partnerships with family leaders and primary care providers known to have previously engaged in quality improvement initiatives, testing of and learning when to abandon changes, development of a public awareness campaign, and simplification of the measurement strategy to engage additional practices.

Arizona developed strong partnerships with two family leaders and included them as part of the QI team. These families had relevant experiences within the system that provided an honest and realistic frontline view of what was successful in the current system, the gaps in children's eye health awareness, the challenges with navigating the care system and the impact of the day-to-day struggle of prioritizing the needs for busy families regardless of their socioeconomic and educational status.

They also built partnerships with primary care practices. Each of the three primary care sites engaged in testing changes to improve vision screening for children under 5 years of age and to improve their systems for referral and follow-up. The primary care sites tested different ideas to encourage families to take their children for an eye exam following a vision screening referral. For example, one site tested having caregivers wear astigmatism glasses, showing them blurred images using impaired vision simulators to demonstrate their child's current vision status. Although this strategy was eventually abandoned because the sites didn't have the necessary skills to administer the test, it represents a great opportunity for future application as a change strategy. If a future site had the capacity (e.g., staff with the correct skills and competencies) the intervention might be successfully tested and implemented. Having a team demonstrate that abandoning a tested idea is an option along with adapting and adopting, was also a very important milestone in the life of the collaborative.

To build awareness within families, Arizona partnered with a marketing firm to implement a public awareness campaign. The public awareness campaign aimed to make children's eye health irresistible to families. The campaign had recently launched at the close of the collaborative and the team was unable to report its impact. However, they did report that it further strengthened their relationship within their vision screening state-wide system.

With their strong foundation in QI, Arizona understood the importance of measures to inform improvement and that measures for improvement should be useful and not burdensome. With NICHQ's support, they worked diligently to create a measurement system that was least burdensome to the participating practices and were able to recruit an additional practice mid-way through the collaborative because of their efforts.

### Barriers and Solutions

The main challenge for Arizona was the inability to successfully engage more primary care practices. Although primary care practices were passionate about the work, they cited the administrative burden to pull vision data from electronic health records (EHR) as the barrier to participation. Arizona found that practices were dealing with many competing priorities and, if a query was not in place to pull the data from EHRs, most did not have the capacity to do document review and thus did not participate. For example, Practice 1 had EHR data at the beginning of the project but they stopped reporting data when they started their transition to a new EHR system. As noted previously Arizona streamlined the measurement strategy to require only data that was available for query in the EHR, which led to successful recruitment of one additional practice.

## Ohio

### Background/Overview

Ohio focused on engaging childcare providers. Ohio's state-specific aim was:

> *By August 2018, increase by 20 percent preschool age children that report a comprehensive eye examination within 6 months of a failed (not passed) vision screening according to Knox County Educational Service Center data from 2015-2016 school year.*

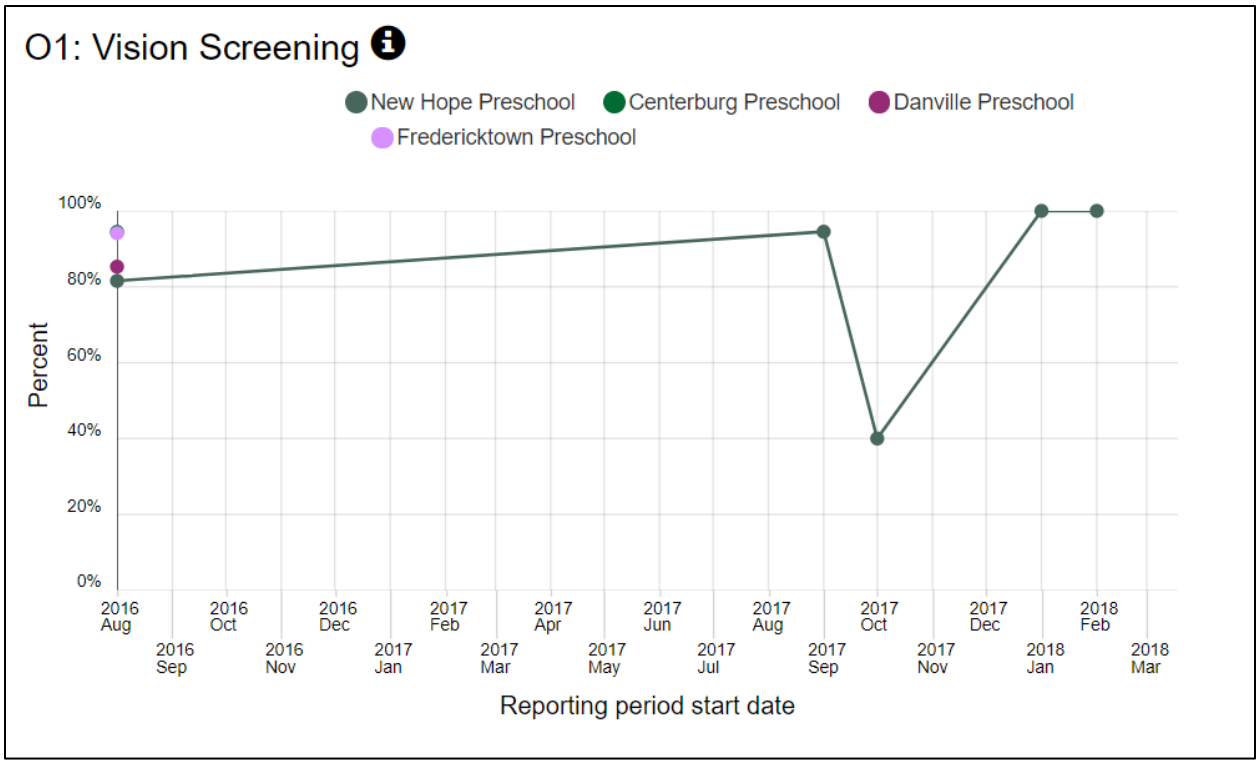
The improvement team consisted of a team lead based at the Ohio Department of Health, a data lead, three family representatives (also two teachers at one of the pre-schools), an optometrist, an optician,

and the Prevent Blindness president and CEO. The team identified their strengths as: having a nationally certified children's vision screening program in the state, collaboration between the Ohio Department of Health and Prevent Blindness, financial support to provide vision screening tools to those who completed the training, and strong state-level data collection. The team partnered with four childcare centers to screen children and increase the rate of parent follow-through of referrals. When the team members went to the schools to screen the children, they also trained the childcare providers to conduct the screenings the following school year. During the first few months of the Collaborative, the Ohio team realized that starting with four centers was a large undertaking; therefore, in the interest of the QI strategy of starting small, they narrowed their focus to first work with and learn from one of the centers with a plan to later scale up and spread to the other three centers and beyond.

### Data

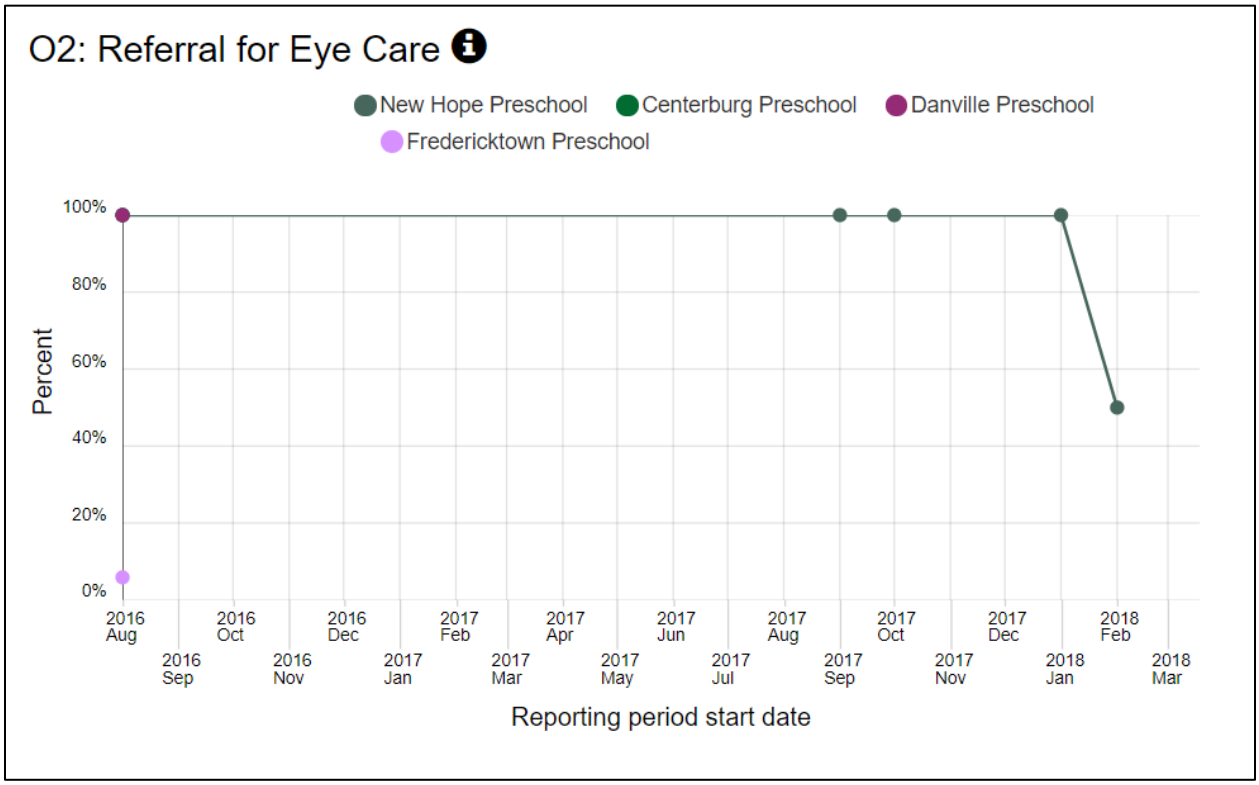
Figures 5-8 present Ohio's data. Ohio reported the outcome data but, similar to Arizona, were not able to report the process data due to lack of data systems that provide an opportunity for them to track screening and intervention through to treatment. The resources that were needed to be brought to bear were not available. As evidenced in the data and noted above, Ohio realized the need to narrow their scope of work to New Hope Preschool, beginning around March of 2017. Within the New Hope Preschool, they further narrowed the scope from several classrooms to one. The gap in the data reporting reflects the time it took for them to develop their data collection and reporting systems, and the months that school was not in session (June-August 2017). Ohio's revised plan was to continue to test and implement changes at the New Hope site and have a plan to reach additional sites. Completing the vision screenings and referrals for those who had not passed a screening test were reliable processes. The Ohio team focused much of their testing for improvement on the follow-up to the referral, which was their biggest challenge. By the end of the collaborative, the team had qualitative data—in the form of stories about individual children who sought follow-up—indicating that the system had improved. They surmised that future data points might indicate a favorable shift although no favorable shift or trend occurred during the collaborative. The short duration of the collaborative coupled with the months that school was not in session made it challenging for the preschool to gather enough data points to see any patterns emerge. However, Ohio has plans to continue to review the data moving forward.

**Figure 5**



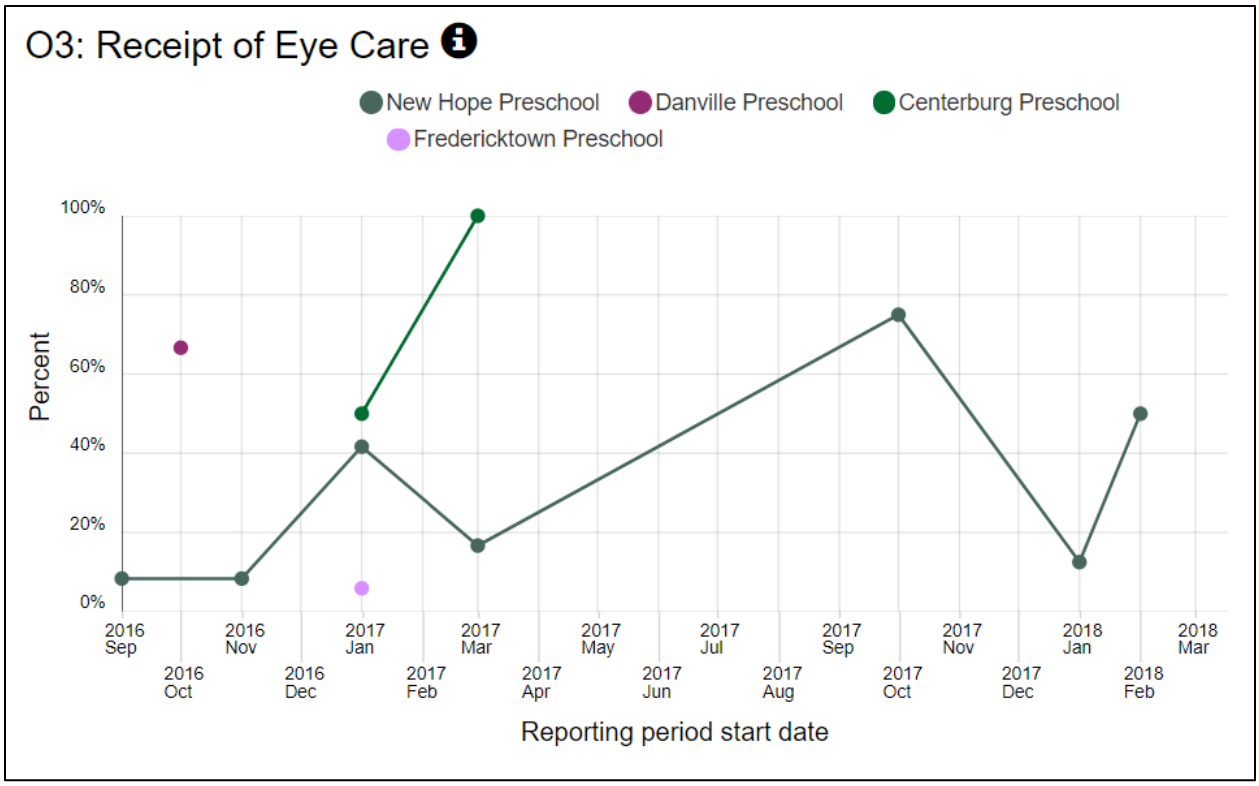

| **Vision Screening Ns** | | | | | |
|---|---|---|---|---|---|
| "N" | Aug-16 | Sep-17 | Oct-17 | Jan-18 | Feb-18 |
| New Hope Preschool | 130 | 91 | 5 | 15 | 2 |
| Centerburg Preschool | 72 | | | | |
| Danville Preschool | 68 | | | | |
| Fredericktown Preschool | 34 | | | | |

**Figure 6**



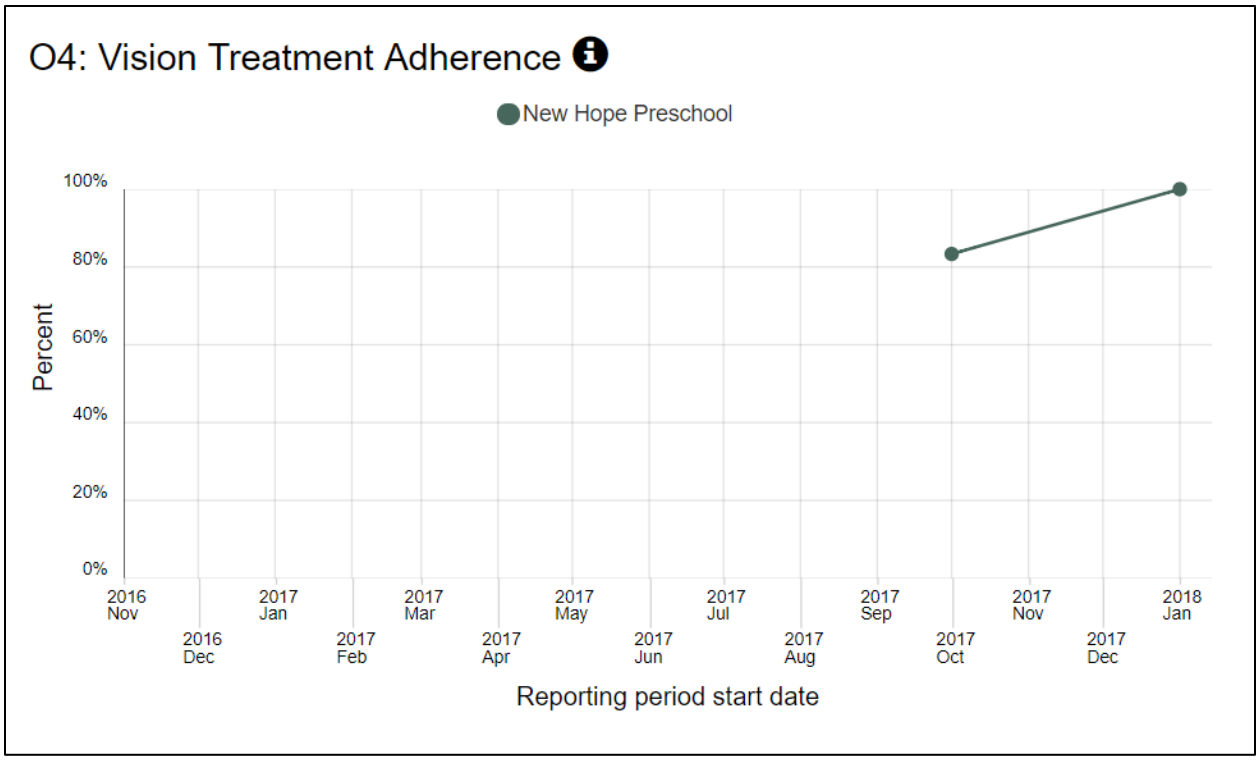

| **Referral for Eye Care Ns** | | | | | |
|---|---|---|---|---|---|
| "N" | Aug-16 | Sep-17 | Oct-17 | Jan-18 | Feb-18 |
| New Hope Preschool | 24 | 7 | 1 | 8 | 2 |
| Centerburg Preschool | 2 | | | | |
| Danville Preschool | 6 | | | | |
| Fredericktown Preschool | 17 | | | | |

**Figure 7**




| **Receipt of Eye Care Ns** | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| "N" | Sep-16 | Oct-16 | Nov-16 | Jan-17 | Mar-17 | Oct-17 | Jan-18 | Feb-18 |
| New Hope Preschool | 24 | | 24 | 24 | 24 | 2 | 8 | 6 |
| Centerburg Preschool | | | | 4 | 2 | | | |
| Danville Preschool | | 3 | | | | | | |
| Fredericktown Preschool | | | | 17 | | | | |

**Figure 8**




| Vision Treatment Adherence Ns | | |
|---|---|---|
| "N" | Oct-17 | Jan-18 |
| New Hope Preschool | 6 | 1 |

## Accomplishments

Ohio's key accomplishments included: developing a more reliable screening process for children at one childcare center; training teachers to vision screen in the future; following up with families whose child did not pass the screening; and partnering with family leaders to promote the importance of healthy vision for learning, to follow up on screening referrals and to conduct a telephone survey of families.

The Ohio team provided vision screenings to most children enrolled at one childcare center and trained teachers to screen children in subsequent years using a nationally certified training. They screened all children who were in school on that day and created a contingency plan for screening children who were absent.

The school tested ways that teachers could communicate with parents and caregivers differently to see if it would favorably impact getting children to follow-up visits. Their strategies included using brightly colored notices sent home in the child's backpack, teachers calling the families directly to discuss results, simplifying the forms, engaging bus drivers to alert parents of the important messages in the backpack and revising the admissions packet to include more information about vision screenings. Ohio focused on improving their processes and finding ways for the families to overcome common barriers to follow up on referrals.

Two family representatives were engaged in the process. The family representatives were staff from within the system but they all had experience navigating the system of vision screening on behalf of their children, so offered invaluable insight from both sides of the equation.

To better understand the challenges around follow-up and to gather ideas for improvement, the team created and administered a telephone survey (see Appendix H). Team members contacted families of children who did not passed the school-based vision screening to gather information through a supportive conversation. This data was a catalyst for the team because it created a list of opportunities for improvement including the need to increase caregiver's knowledge and provide information on available support and resources.

### Barriers and Solutions

Ohio faced three challenges: getting systems of data collection and reporting in place; school being out during a portion of the collaborative; and inability to reach families of children who did not pass their vision screening.

Although Ohio noted as a strength their state data system, the team found it extremely challenging to access the data they needed to report the measures. Based on early learning in this project, they started small and manually collected data from one school with plans to spread further. In addition, they began building partnerships with key stakeholders who could support access to the state level data in the future.

As noted in the data section, working with the schools posed a challenge because they were not in session for the summer when they needed to collect data and test changes. The Ohio team decided to focus the summer to make plans for data collection and PDSA cycles in the fall.

Ohio had a difficult time reaching families of children who did not pass their vision screening. Families often had changed phone numbers, disconnected phones or no voicemail.

## Wyoming

### Background/Overview

Wyoming focused its work on training staff from Child Development Centers throughout the state to screen for vision problems. Wyoming's state-specific aim was originally:

> *By August 2018, the Wyoming Vision Collaborative will train 60 percent of screeners at Child Development Centers and have a determined location for all vision screening data.*

Part of the way through the Collaborative, they narrowed the aim to help them focus their work. Their revised aim was:

> *By August 2018, the Wyoming Vision Collaborative will finalize its evidence-based practice vision screening program and train one professional from each Child Development Center in the state.*

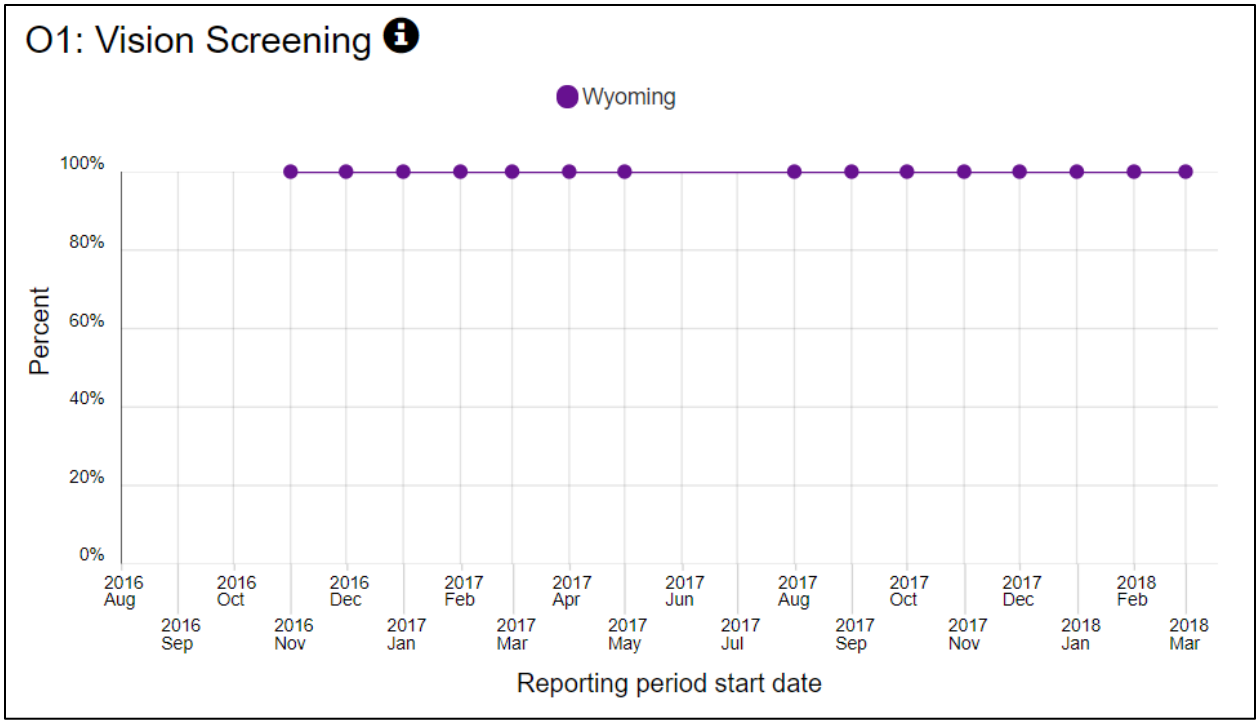
The improvement team included: a team lead (Project Coordinator at Wyoming Institute for Disabilities), the Coordinator of Community Education at Wyoming Institute of Disabilities, a parent partner who was also a vision service provider, two optometrists and the Wyoming Department of Health Early Intervention Education Unit Manager. The Wyoming team noted the following strengths going into the ICV initiative: strong network of child development centers, Head Starts and state offices; vision

screening in all 14 regions around the state (but not all using the evidence-based programs); and feasibility of follow-up for referred children and community education due to smaller communities and personal connections throughout the state.

## Data

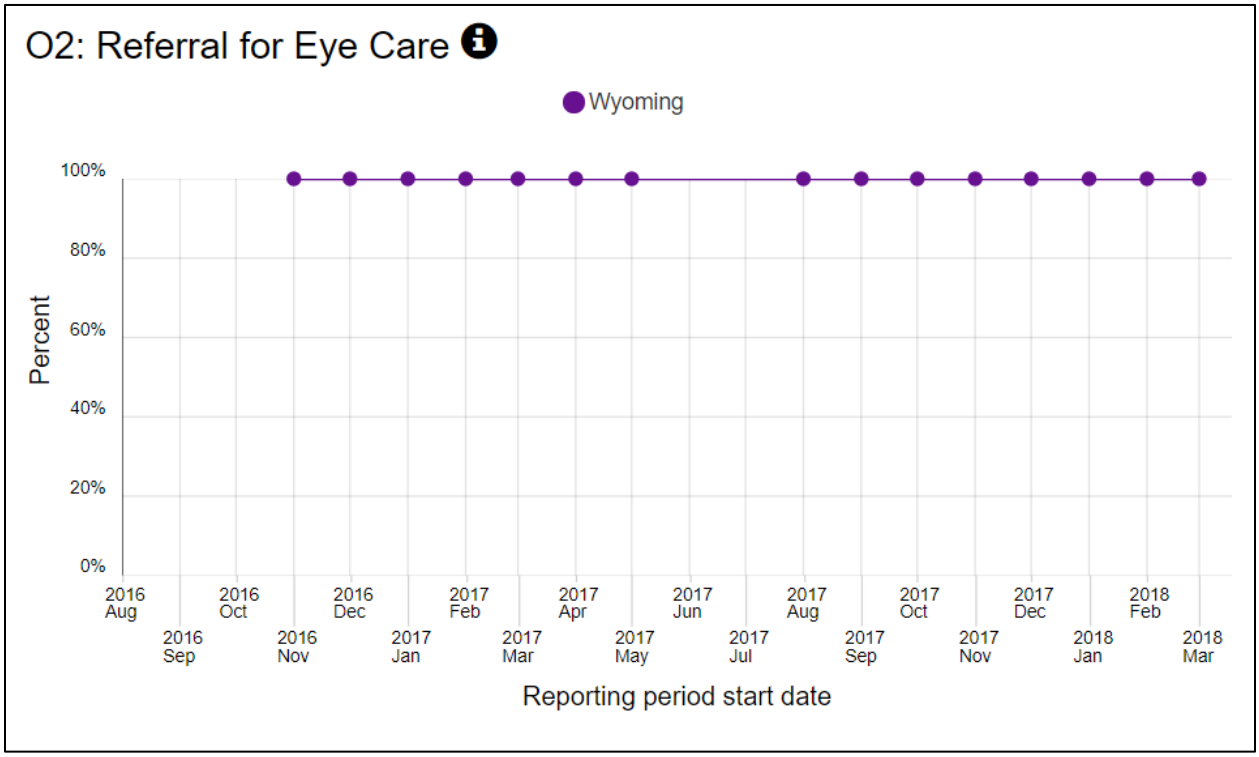
Figures 9-11 present the Wyoming data. Similar to Ohio and Arizona, Wyoming wrestled with collecting and reporting the data as it was requested for the ICV collaborative. The NICHQ team worked closely with them to develop a system of data collection and reporting that would be useful for them. Due to barriers around obtaining data from the statewide child development centers, the Wyoming team collected what they could by partnering with the Lions Club to access data from the vision screenings they had completed. Families were accessing this community resource to have their children's vision screened, which explains why the vision screening and referral rates are high (see figures 9 and 10). The team discovered that the referral process was also being tracked and was easy to capture for those children. Again, as with the other states, the hardest data to collect and report was related to whether those referred received follow-up eye examinations as shown in figure 11. While Wyoming tested various ways to follow up on referrals, this remained their biggest opportunity for improvement and the biggest opportunity to develop more reliable systems for data collection. They tested several variations of follow-up forms to collect the information, but the data stayed stable throughout the project.

**Figure 9**



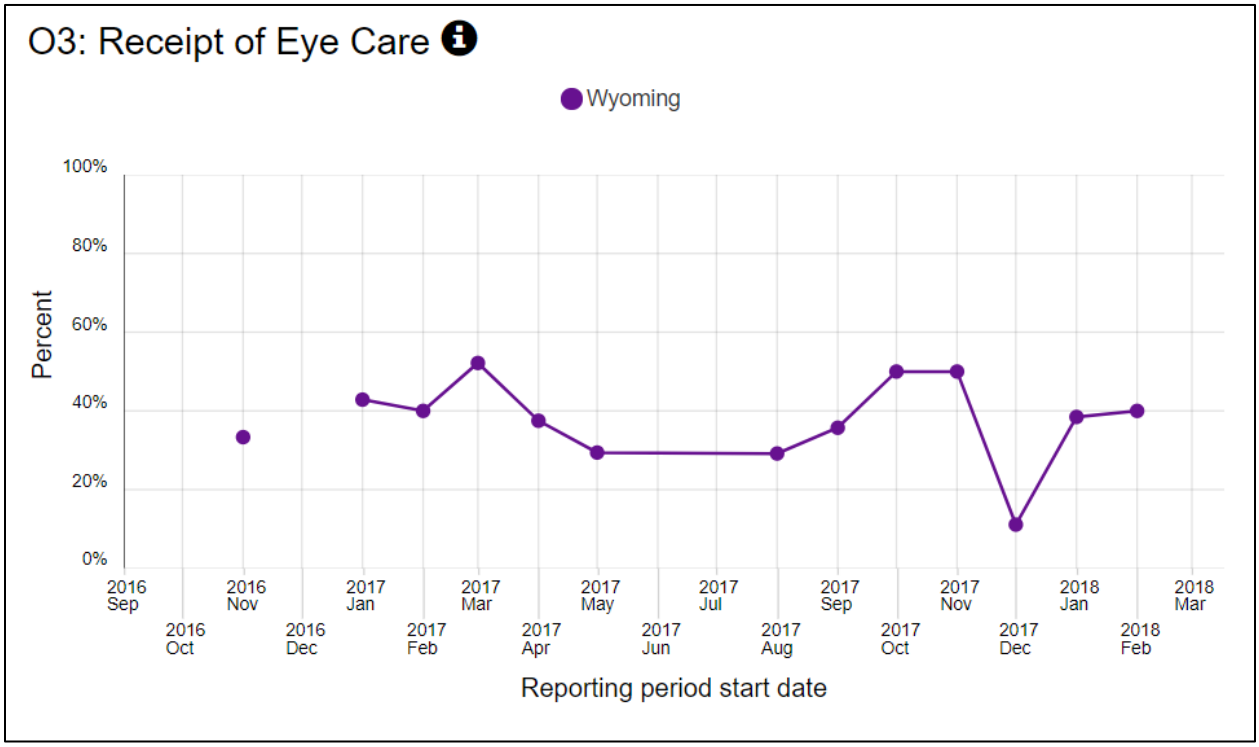

| **Vision Screening Ns** | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| "N" | Nov 16 | Dec 16 | Jan 17 | Feb 17 | Mar 17 | Apr 17 | May 17 | Aug 17 | Sep 17 | Oct 17 | Nov 17 | Dec 17 | Jan 18 | Feb 18 | Mar 18 |
| Wyoming | 174 | 17 | 71 | 183 | 229 | 116 | 168 | 116 | 276 | 333 | 98 | 53 | 129 | 129 | 104 |

**Figure 10**




| **Referral for Eye Care Ns** | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| "N" | Nov-16 | Dec -16 | Jan -17 | Feb -17 | Mar -17 | Apr-17 | May - 17 | Aug -17 | Sep -17 | Oct - 17 | Nov -17 | Dec -17 | Jan -18 | Feb - 18 | Mar - 18 |
| Wyoming | 21 | 2 | 14 | 20 | 23 | 8 | 17 | 24 | 28 | 36 | 9 | 9 | 26 | 20 | 5 |

**Figure 11**




| **Receipt of Eye Care Ns** | | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| "N" | Nov 16 | Dec 16 | Jan 17 | Feb 17 | Mar 17 | Apr 17 | May 17 | Aug 17 | Sep 17 | Oct 17 | Nov 17 | Dec 17 | Jan 18 | Feb 18 | Mar 18 |
| Wyoming | 21 | | 28 | 20 | 23 | 8 | 17 | 24 | 28 | 72 | 18 | 9 | 26 | 20 | |

## Accomplishments

Wyoming's accomplishments included raising awareness around children's vision health and the need for data infrastructure amongst key stakeholders, involving a family leader on the improvement team, starting small, linking families to needed vision care and developing online training materials. According to Wyoming, one of their biggest accomplishments was how they "grew" the conversation around children's vision in their state. This was partially facilitated through efforts to build a strong, working relationship with the state department of public health to leverage resources that could promote and activate a focus on improving the system of care around child vision screening, referral and treatment. During the collaborative, conversations with the Wyoming Department of Health Early Intervention Education Unit Manager indicated the potential of requiring standardized training for vision screeners at child development centers. As a result of the project, stakeholder awareness increased regarding the challenges of decentralized, non-standardized practices of vision screening procedures, data collection, and follow-up processes. ICV was a catalyst for growing stakeholder momentum around the need for centralized and standardized data collection, conversations about transitioning to using Total Health

Record—a web-based record of patient's healthcare information, and for standard vision screening across the state. [21]

Wyoming engaged one active family partner whose child was visually impaired; she also worked with the department of education in seven child development centers, providing support for children and their families across the state who faced child vision challenges. Her perspective on the challenges of rural Wyoming provided a critical lens in this effort. She supported the improvement work in a variety of ways including providing input into the development of follow-up processes, questions and forms. She actively participated in the project's site visit and provided a family voice about the barriers families faced in regards to vision care for their children, such as access to care, given the remote and rural nature of the geography, and access to resources for daily living priorities. In summary, the family partner kept the issues of social determinants of health front and center during the work. She constantly reminded the team of the stressors that families are under and kept the team focused on their aim to improve systems, not lay blame on families.

The Wyoming team learned to break down a large system into smaller more manageable parts, a skill that will be important to them as they move forward with this work. For example, they realized that it was easier to start with training at one child development center, and then spread to other centers, rather than have a training in every center from the beginning. Between August 2017 and the end of the collaborative, they had trained screeners in the evidence-based training program in 10 of the 14 child development centers. As a result of this improvement learning community, Wyoming also produced professional training materials that are currently being tested for use in a statewide capacity.

The Wyoming team lead received calls from several parents whose children were identified as having vision problems through this screening program. Qualitative data from these parents indicated that they were grateful for the screening and for catching problems early so that their children could be linked to the necessary interventions and treatments.

The Wyoming team was involved in the development of standardized online training materials for screeners. Having the training available online was especially beneficial to the screeners due to the many rural areas of the state.

## Barriers and Solutions

Wyoming's barriers included: resistance to change at the state level and some child development centers, and the lack of a centralized data collection process.

Wyoming Optometric Association (WOA) stepped back from a partnership with this work due to some concerns that vision screenings could give families a false sense of security that would prevent them from taking their child into an eye exam before kindergarten. This concern was addressed by advocating for the use of "pass" forms that specify the need for eye exams, regardless of screening outcomes, and clarifying the purpose of a screening and an eye examination in the spectrum of children's eye health. Also, Wyoming talked with the Director of the WOA, who helped them disseminate the vision screening training opportunity with a workgroup on early childhood vision.

Wyoming also found it challenging to implement the training at some child development centers due to resistance to change. As noted above, they addressed this barrier by starting with a small number of

centers rather than trying to train everyone at once. They also were working on integrating the vision screening training as a requirement in child development center contracts.

Wyoming has a decentralized process for data collection making it challenging for them to achieve their aim of having a centralized location for all vision screening. Despite attempts to get data for the initiative, there never seemed to be an understanding of why the data was being collected. There remained a mistrust that the data would be not be used for purposes of informing improvement. As mentioned above, one strategy towards a solution was the start of a conversation about aligning data collection and reporting requirements between various state entities. Tracking data along the continuum of care is critical to improve follow-up and treatment outcomes and providing data on the gaps in access to care. The Wyoming team's efforts toward building partnership is critical to eventually achieving the aim of a centralized data collection process.

## Overall Progress

The table below presents the overall project goals originally outlined and progress made through the ICV initiative towards these goals. Given time and resource constraints, not all states were able to address or reach all project goals.

| **Project Goals** | **Progress** |
|---|---|
| Strengthening statewide partnerships and coordination among key stakeholders in children's vision and eye health | All state teams built new and/or strengthened existing partnerships with the goal of raising awareness and prioritizing children's vision and eye health.<br><br>Example: The Wyoming team developed a new partnership between the Wyoming Institute of disabilities and the Wyoming Department of Health Early Intervention Education Unit Manager. Plans were made to include, within child development center contracts, the necessity for standardized trainings for vision screeners at Child Development Centers.<br><br>Example: Arizona partnered with a professional marketing firm on an awareness campaign spurred by the desire to "Make Eye Health Irresistible to Families."<br><br>Example: Ohio strengthened their partnership with the Department of Health facilitating an alignment with state-wide efforts and the improvement work in the pre-school setting. |

| | |
|---|---|
| Increasing access to and utilization of vision health services in hard to reach communities | One state, Wyoming, demonstrated movement toward accomplishing goal by development of an online training tool as a resource for screeners. This has resulted in screeners not feeling so isolated in a very rural state and having a place to go for resources and information |
| Increasing early detection and treatment of vision problems | Although there is not quantitative data reflecting an increase in detection and treatment of vision problems, Arizona stated that, as a result of participation in the collaborative, the referral rate to eye care providers by primary health care offices increased. |
| Establishing state-level surveillance | Establishment of state surveillance was not accomplished in this initiative due to the short duration of the project. However, much was learned about the complexity of the work including resource limitations and the need to get buy-in from state-level systems around using the data to inform improvement. The ICV project provided evidence of the need for data coordination and started the conversation among key stakeholders. More work remains in identifying and addressing challenges to collecting statewide data. |
| Implementing vision health system measures of accountability | The ICV team developed a measurement strategy, described above, to help teams and the collaborative leadership gauge if the changes made resulted in process and systems improvement. By the end of the collaborative, all teams were able to collect and report a measure related to the percent of children screened and the percent being referred. Ohio was the most consistent in being able to measure and report on "Vision Treatment Adherence" at one preschool while Arizona reported only three months of data for this measure and Wyoming one month. Because of the variation in the sites participating (primary care providers, child development centers, preschools), each site customized the measures so that they were useful in informing their work. Additionally, state teams worked with the improvement advisor to create measures that were not burdensome to |

| | |
|---|---|
| | collect yet would inform their improvement work. |

# Recommendations:

Many lessons for future work to convene partners and improve systems of children's vision care can be harvested from the conclusion of the ICV initiative. The following represent NICHQ's top recommendations for enhancing three critical categories: Aim, Measures and Data, Frameworks for Executing Work.

## Aim

### Background and Lessons Learned

An aim, more specifically an aim statement, provides a clear compelling message that guides the work and creates a shared vision for all involved in an improvement collaborative. Measurable targets within that aim statement establish the foundation for a comprehensive alignment and deployment of the work to make and spread improvements. In a learning collaborative, the collaborative leadership establishes the overarching aim and the participating organizations develop aims that are specific to their environment but align with the overarching aim. Reflective of the project aim outlined in the Maternal and Child Health Bureau – Division of Children with Special Health Needs Funding Opportunity Announcement (HRSA-15-084), the ICV collaborative adopted the following aim: "to increase by 20 percent over [National Survey of Children's Health] 2011-2012 levels [4] the proportion of children aged 5 years and younger who receive vision screening and diagnosis in five states by the year 2018. Each team established an aim that was unique to their organization and to their state. It took several months into the project, as well as one-on-one coaching, to help the teams understand the importance of having a clear aim, their roles in increasing the rates over the 2011-2012 levels and develop aims that were appropriate in scope for the length of the collaborative.

### Recommendations

- Make an even stronger case for improvement by being very clear about the existing gap in the vision screening rates. Collaborative leadership should state the improvement goal in the aim in more specific terms. In this case, it would have been to specify what a 20 percent over the 2011-2012 levels would look like. Teams would then know many more children would need to be screened and diagnosed per year. Helping teams understand the baseline for their state would also help with specificity. For example, was the 20 percent increase goal from a baseline of 40 percent, 25 percent or 80 percent? Subsequently, help participating teams calculate their specific goals to help them better plan for how they could influence them.
- Provide additional support to teams and time prior to the first learning session to develop customized aims for their work that align with the overarching aim. This support is particularly important in collaboratives where the teams are as heterogeneous as in the ICV collaborative. Consider whether the aim is achievable over the time frame of the collaborative. In the case of the ICV collaborative, it took teams months to navigate their complex data systems before they could even begin to collect and report data. As a result, it was not feasible, within the timeframe

of the collaborative, to get data to know if they had made improvements over baseline. (See Measures and Data Section).

## Measures and Data

### Background and Lessons Learned

As with an aim statement, every collaborative has a measurement system so that leaders and teams know if the changes they are making are resulting in improvement. A family of outcome and process measures was designed for the ICV Collaborative. Some measures were required while others, because of the potential burden to collect, were optional. Teams used NICHQ's web-based CoLab portal to report measures. Collaborative leadership underestimated the work that it would take teams to create systems to collect and report measures beyond the basic outcome measures of vision screening rates, referral rates and follow-up to referral rates. It was slightly easier for the Arizona team to collect and report the measures because the primary care model had existing systems in place to report data [i.e., Electronic Health Records (EHR)] but even they ran into barriers when one practice transitioned from one EHR to another. Arizona also reported that the burden to collect and report data was a key obstacle that kept practices from taking part in the initiative and that, when they simplified the measurement system, they were able to recruit two additional practices. Ohio and Wyoming were dealing with very different systems and needed to design ways to collect and report the data. Both did what they could to report data—what was within their control and scope of work—and both learned about the complexities of mining for the data at the state level.

### Recommendations

- Intentionally recruit teams with a strong existing data infrastructure in place and who have access to data, or teams who demonstrate relationships with partners who are engaged in this topic and could support QI initiatives through data system development/enhancement or access to existing data.
- Be even more flexible about revising the measurement system based on the make-up of the participating teams. Provide a two-month period for teams to pilot the data collection and reporting and make modifications to the overall strategy based on the pilot results.
- Provide one-on-one technical assistance to teams earlier in the collaborative to support them in designing, which would better inform their improvement work.
- Simplify the measurement strategy. Consider two outcome measures, two-three process measures and balancing or structural measures if they are useful. This will acknowledge the limited capacity of teams as they balance many competing demands and, in doing so, will support an intention to limit the reporting requirements to essential core elements

## Framework for Executing the Work

### Background and Lessons Learned

As mentioned previously in the report, the BTS collaborative model is an approach to improvement in which organizations and teams test and measure practice innovations and then share their experiences in an effort to accelerate learning and widespread implementation of best practices.[17] Key to the success of a BTS is leadership commitment; a topic where there is evidence of a gap and a clear and compelling

need to close the gap; a change package of best practices designed to help teams close the gaps; a measurement strategy that helps teams know that the changes they are making are resulting in improvement; participating teams passionate about the work who have the capacity to do the improvement work, including testing and implementing changes using Plan-Do-Study-Act cycles; and multiple opportunities for teams to share with and learn from each other via learning sessions and action period calls. The ICV collaborative was a modified collaborative with the biggest modification being that all team networking opportunities were virtual. Other modifications along the way included added technical assistance calls for teams and site visits by collaborative leadership to each state.

## Recommendations

- Convene an expert meeting at the start of the initiative to refine the key documents: charter, driver diagram, measurement strategy and change package. [17]
- Recruit more than three teams to enrich the opportunities for the learning and sharing that takes place in a collaborative.
- Aim to recruit more homogeneous teams to support shared successes and learnings.
- Host at least one in-person two-day learning session, preferably at the beginning of the work, to allow teams to connect and form more trusting relationships.
- Assist teams at the early stages of the collaborative in identifying improvement partners they need to involve in order to lead to systems changes that will improve vision care for children. Consider a separate arm of the collaborative that supports teams in developing their relationships with these partners. Consider that the Collective Impact model [22] promotes having a common agenda, shared measurement, mutually reinforcing activities, continuous communication and backbone support.
- If future teams are as heterogeneous as the ICV teams (primary care, child development centers and pre-schools), customize the driver diagram, change package and measurement strategy to their unique systems and partnerships.
- In addition to a change package of ideas, design 10-12 PDSA cycles that teams can take and test immediately to help them get a jump start and better understand the concept of learning the way to implementation using PDSA cycles.
- In the event that some learning sessions are virtual, replace the loss of in-person time with teams by extending the length of the monthly action period calls by 15 minutes to allow for covering the necessary content and time for additional team sharing.
- If in-person sessions are not an option and there are a small number of participating teams, incorporate site visits as a key intervention. If held early in the collaborative, site visits can serve as a way to build relationships, help sites build their guiding teams, identify needed resources, gauge the leadership support for the work, and help foster partnerships essential to take on the complexity of the improvement work.
- Budget to include a closeout meeting including top performers to harvest learnings and to refine a change package to include successful changes for future improvement work.

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