Developmental Screening in Alaska
Status | Leadership | Data | Structure
Challenges and Opportunities

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**Prepared for Help Me Grow Alaska
by Prentice Consulting**

Project Overview

Help Me Grow Alaska (HMG-AK), a program operated by the All Alaska Pediatric Partnership (AAPP), engaged Prentice Consulting to research and analyze options for statewide data and reporting needs specific to developmental screenings. The project also included an assessment of the current systems of data sharing, examining and assessing existing limitations to this system, and recommendations for restructuring the Ages and Stages Questionnaire (ASQ) online system.

Prentice Consulting has had a contractual relationship with the State of Alaska to provide technical assistance for the ASQ online system since its inception in 2012 and, as such, brings significant background knowledge to this project.

This report is divided into two main parts. Part one provides background information on current activity related to developmental screening in Alaska, based on key informant interviews with organizations which have intersected with the statewide ASQ online system. Part one also includes information on the current status of the statewide ASQ online system.

Part two addresses the topics of governance, data, and structure of the statewide ASQ online system. The governance section references information from the December working session of key stakeholders, including broad topics of governance and ideas for a statewide plan for developmental screening efforts. The sections on data and the ASQ structure discuss the current status, opportunities, and challenges. Recommendations are offered for access to and use of developmental screening data as well as options for restructuring the current ASQ online system.

Methodology

To inform this report, Prentice Consulting researched the current status of developmental screening in Alaska. This was done primarily through a series of key informant interviews with 13 stakeholder groups. With the exception of Public Health Nursing, these interviews were conducted face-to-face in Anchorage and Juneau. These interviews provided important information on current screening efforts, screening tools being utilized, estimated cost of screening, and how screening data is currently utilized. Interviews were conducted with:

- Part C/Infant Learning Program (ILP), Department of Health and Social Services (DHSS)
- Part B, Department of Education and Early Development (DEED)
- Governor's Council on Disabilities and Special Education, DHSS
- Division of Behavioral Health, DHSS
- LaTouche Pediatrics
- Child Care Program Office, DHSS
- Learn & Grow, Alaska's Quality Recognition and Improvement System (QRIS)
- Alaska Center for Pediatrics
- RurAL CAP Parents as Teachers (PAT) and Head Start/Early Head Start (HS/EHS)

- Head Start Collaboration Office, DEED
- Public Health Nursing, DHSS
- State-funded pre-elementary, DEED
- Help Me Grow Alaska

Prentice Consulting compiled data on the current status of the statewide ASQ online system, housed at the State of Alaska Part C/ILP Office, under the Division of Senior and Disability Services. This data includes current and past usage of the statewide ASQ online system and the number of active and dormant programs within the current ASQ online system.

Following this initial research, a working group comprised of six stakeholders convened in Anchorage to review the information and engage in an open discussion about developmental screening in Alaska. The conversation was intentionally open-ended to provide room for new ideas to emerge on how Alaska can improve its developmental screening efforts and efficiencies. Prentice Consulting facilitated the four-hour session. The working group included representatives of:
- Alaska Center for Pediatrics, Administrator
- All Alaska Pediatric Partnership, Executive Director
- Division of Senior and Disabilities Services (DSDS), Deputy Director, DHSS
- Help Me Grow Alaska, Program Director
- Learn and Grow, Director
- Part C/ILP, Chief of Developmental Programs, DSDS, DHSS
- Women's, Children's, and Family Health, Health Program Manager III, DHSS

Three representatives of Brookes Publishing, which holds the rights to the ASQ and manages the ASQ online system nationally, were engaged to discuss options for restructuring Alaska's ASQ online system, to identify characteristics of a successful system, and to share their insights from a national perspective of working with states and regions across the country.

Prentice Consulting also reviewed online resources for a comprehensive online screening system called "Patient Tools, Inc." and met with its founder and CEO to discuss possible applications for Alaska.

Part I: Status of Developmental Screening in Alaska

Through key informant interviews conducted in September and October of 2019, information was compiled related to current screening efforts, screening tools utilized, the use of developmental screening data, and the direct cost of the statewide ASQ online system. This information is not inclusive of the entirety of developmental screening efforts in Alaska. Rather, it includes agencies that have intersected with the statewide ASQ online system.

Who is screening?

- In calendar year 2019, 5,680 ASQ-3 screens were entered into State of Alaska ASQ online system
- All Head Start (HS), Early Head Start (EHS), and Parents as Teachers (PAT) programs are required to conduct developmental screening annually on all children enrolled
- Infant Learning Programs (ILP) conduct developmental screening in their communities as part of Child Find activities and engage partner organizations in screening
- Public Health Nursing serves "as a safety net, trying to fill gaps and not duplicate services"
- State-funded pre-elementary programs have no requirement for developmental screening, although some programs do developmental screening voluntarily
- There are currently 20 private medical practices participating in the Developmental Screening Stipend Initiative
- HMG-AK will help families complete developmental screening if the family does not have a medical home or is not enrolled in an early childhood program that does screening
- The State of Alaska's Child Care Program Office is required by the federal government to adhere to certain guidelines related to developmental screening, such as providing parents with information on how to access no-cost screening
- Learn & Grow, Alaska's Quality Recognition and Improvement System, is implementing guidelines and requirements for child care programs related to developmental screening

What tools are being used?

- DHSS selected ASQ-3 as the preferred screening tool in approximately 2010
- PAT programs are required to use ASQ-3
- HMG-AK utilizes ASQ-3
- HS/EHS can select from tools approved by federal Office of Head Start
- Most EHS programs use ASQ-3 while HS programs use a variety of tools
- Most ILPs use ASQ-3 but each ILP can select the tool deemed appropriate for their region
- Public Health Nursing uses ASQ-3, PEDS, and PEDS DM
- Medical practices engaged in the stipend initiative utilize the ASQ-3

How is developmental screening data being used?

- Part C/ILP has data reporting requirements related to developmental screening and Child Find efforts
- Early Childhood Comprehensive Systems Impact Project (ECCS) has requirements for developmental screening data reporting

4

- The Developmental Screening Stipend Initiative requires participants to report on screening data
- Potential uses of developmental screening data include:
  - Regional or community analysis of screening rates (percentage of children screening by age group)
  - Analysis of screening results by region or community to identify possible patterns of low or high scores in certain domains
- The potential use of developmental screening data is largely unexplored, however examples of possible uses are described in Part Two of this report

What is the direct cost of the statewide ASQ online system?

- Each Enterprise costs $500 per year (annual subscription) -- 17 Enterprise accounts x $500 = $8,500

- Each Family Access account (one per Enterprise) cost $350 per year-- 17 x $350 = $5,950

- Hub linking fee cost = $1,000 per year

- .50 for each screen entered into ASQ online – 2019 screening cost = $2,840

- Cost of starter kits for new programs currently $240 per kit (price shown on Brookes website but there is often a discount for bulk orders)

- Direct costs are currently paid by State of AK, DHSS

- **System fixed cost = $15,450 per year plus variable cost of screenings ($2,840 in 2019) and starter kits**
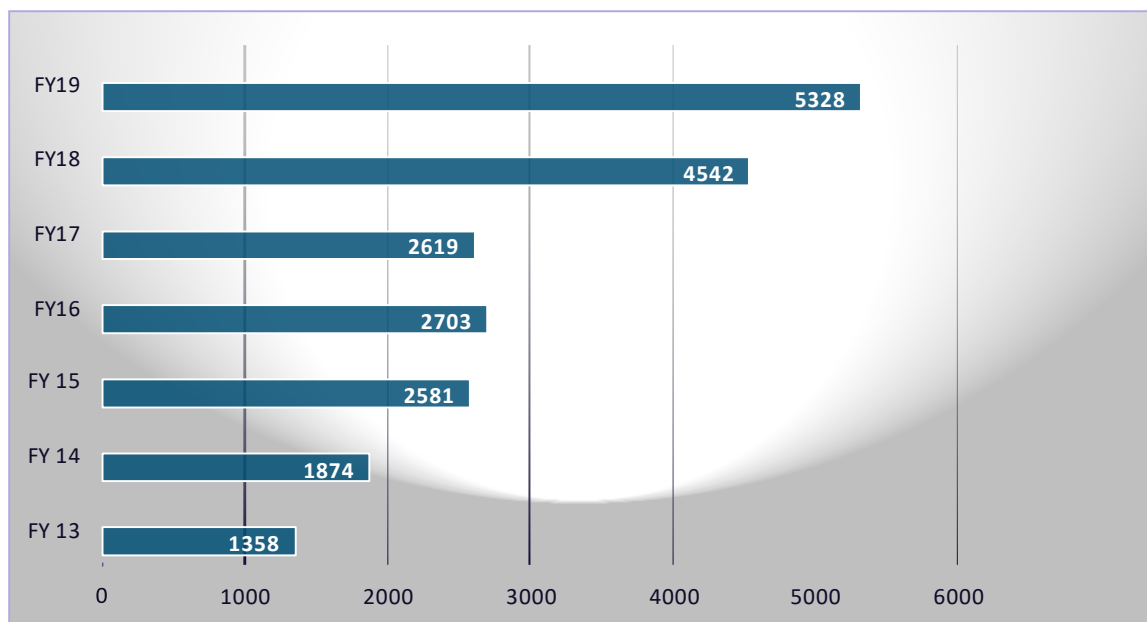
Status of Statewide ASQ Online System

Alaska currently has a Hub and Enterprise ASQ online system. The State of Alaska Part C/ILP Office (Division of Senior and Disability Services, DHSS) acts as the Hub with the 16 Infant Learning Programs (ILPs) acting as Enterprises. In 2017, HMG-AK was added as the 17th Enterprise. A centralized Hub system such as this has the advantage of running system-wide aggregate reports, having a centralized organizing structure, and potential for coordinated management for the system. The option exists for the child data to be identified or de-identified at the Hub level, based on the policies and preferences of the entity. Alaska elected to have data de-identified at the Hub level, meaning information that could identify a particular child, such as name and date of birth, is not visible or reportable. Community and gender are additional useful fields for data analysis but are also hidden variables at the Hub level.

Like the Hub, the Enterprise is an organizational structure. It is at the Enterprise level that individual organizations such as medical practices and early care and learning centers, are established as "programs" and given access to the ASQ online system and can enter child profile and screening

data. Enterprise account administrators can play a critical role in the smooth operation of an ASQ online system. Examples of responsibilities of Enterprise account administrators are adding programs by entering a unique key code, running data reports for individual or aggregate programs within the Enterprise, and providing training and technical assistance.

At-a-Glance Summary of ASQ-3 Screenings entered into Online System

The graph below displays the number of ASQ-3 screenings entered into the ASQ online system beginning in fiscal year 2013. Alaska's fiscal year begins July 1 and concludes June 30 of each year.

Fiscal Year	Screenings
FY19	5328
FY18	4542
FY17	2619
FY16	2703
FY 15	2581
FY 14	1874
FY 13	1358

As of October 2019, there were a total of 88 programs in the statewide ASQ online system. Of those 88 programs, 46 are considered active and 42 are considered inactive. "Active" is defined as having entered a screening since January 1, 2018. "Inactive" is defined as not having entered a screening since January 1, 2018.

Part 2: Leadership, Data, and ASQ Structure

Part two includes information on:
- Developmental screening leadership
- Access to and reporting of developmental screening data
- Statewide ASQ online structure

Part two also discusses opportunities to optimizing the ASQ online system, and options and opportunities for restructure, proactive management, and data utilization.

Developmental Screening Leadership: Needs and Opportunities

The section on leadership is informed by discussions from the December working group, identified earlier in this report, as well as discussions with Brookes Publishing, which holds the rights to the ASQ and ASQ online system.

The workgroup discussed the need for a comprehensive and cohesive statewide approach to developmental screening. This effort was initially spearheaded through a "Universal Developmental Screening Task Force" established under the Governor's Council on Disabilities and Special Education. In January 2020, the Program Coordinator for the Council's Early Intervention Committee conducted a survey of task force members seeking input on the work of the task force and decisions about moving forward. The results of the survey were summarized in this way and sent, via email, to task force members:

> We have received feedback from 18 participants with the general consensus being support for continuing this work; however, with a different umbrella/leadership entity at this time. **If your agency, division, or program would be interested in facilitating these activities, please feel free to contact me**. It is important to note that the Council would still continue to be part of, and support the Task Force, but following your feedback we would assume a different role within this group. As many of you know, for years universal screening has been, and continues to be on the Council's radar via a myriad of different work areas, including within the scope of the Early Intervention Committee, Autism Ad Hoc, and the FASD Workgroup. We are committed to collaboration on early identification with statewide partners to advance universal developmental screening by using a standardized tool. We look forward to hearing from you regarding your activities and if this work, in a leadership capacity, fits within your efforts.

The State of Alaska is at an important crossroad regarding the leadership for developmental screening efforts. The invitation from the Governor's Council on Disabilities and Special Education opens the door for a new "agency, division, or program" to work in a "leadership capacity" on universal developmental screening.

While this opportunity had not yet become available at the time of the December workgroup session, the participants devoted time to a discussion of the several key components required for a comprehensive statewide approach to universal developmental screening. The following outline is not a comprehensive list of these components; rather, it provides a sense of what the workgroup identified as important elements of a comprehensive plan.

1. Identification of the goals of a universal developmental screening plan, including:
   a. Achieve best practices related to developmental screening, based on guidelines from credible sources like the American Academy of Pediatrics (AAP) and the Center for Disease Control and Prevention (CDC)

      b. Meet federal Child Find requirements

      c. Identify children at risk for disability and delay

      d. Increase parent engagement and education

      e. Help families connect to medical homes

2. Development of a marketing strategy and plan, including:

      a. Develop branding for developmental screening

      b. Identify target audience

      c. Develop a marketing plan including social media, public education and outreach

      d. Implement plan

      e. Measure outcomes and results

3. Identification of training needs and development of a plan to meet them, such as:

      a. Identify training needs around developmental screening

      b. Set standards for training requirements

      c. Develop training to meet those needs

          i. In person using certified and/or experienced trainers

          ii. On line using approved modules

      d. Develop and implement training plan

4. Clarification of authority for decisions and actions related to developmental screening

      a. Clarify current and future role of Universal Developmental Screening Task Force (currently under the auspices of the Governor's Council on Disabilities and Special Education)

      b. Decision making regarding the best entity(ies) to oversee developmental screening work

      c. Establish authority and responsibilities

      d. Determine viable funding structure for developmental screening, including ASQ online system

Again, there is a clear opportunity and need for leadership to guide developmental screening efforts in Alaska. The Women's, Children's, and Family Health section within the Division of Public Health has a strong history of involvement with developmental screening efforts as does the Part C/ILP Office of the Division of Senior and Disability Services. Representatives of Part C/ILP and Senior and Disability Services, which currently has oversight of the statewide ASQ online system, expressed uncertainty about their capacity to maintain their current role with ASQ online or to take on additional responsibility for oversight of developmental screening efforts. There are also private nonprofit agencies who are highly engaged in developmental screening efforts, which may be poised to apply their skills and resources to this effort.

Alaska's Early Childhood Coordinating Council (AECCC), or other early childhood governance structure, could play an active role as the statewide council for early childhood. The following statement of purpose appears on the AECCC State of Alaska website:

> The purpose of the Alaska Early Childhood Coordinating Council (AECCC) is to promote positive development, improved health outcomes, and school readiness for children prenatal through age eight by creating a culturally responsive, comprehensive, and accessible service delivery system that links service providers, empowers families, and engages communities. The AECCC shall support the creation of a unified, sustainable system of early care, health, education, and family support for young children and their families.
>
> The AECCC will facilitate the integration and alignment of services, planning efforts, resources, policy development, and funding as well as establish connections between health, mental health, education and family support systems and public and private partners.

A lead agency should be identified to take the leadership role for oversight of developmental screening efforts in Alaska. It is most appropriate for this leadership to be based within state government, which has the authority to establish policy and regulations. A group of key stakeholders, acting in an oversight capacity, could guide the work, develop and approve a statewide plan, act as liaisons with interested organizations, and champion developmental screening in Alaska. Implementation activity could be contracted out to independent contractors or organizations that have the capacity and skill sets for identified activities.

Data Access and Reporting: Opportunities and Challenges

This section will focus on data possibilities that exist with the current ASQ online data, the current limitations with the ASQ data, and recommendations on how to increase utilization of developmental screening data. As mentioned earlier in this report, while certain user groups are utilizing ASQ online data to meet specific reporting requirement, the area of data utilization is largely unexplored.

An example of possible uses of developmental screening data is provided on the Association of Maternal and Child Health Programs (AMCHP) website. A particularly relevant tool within their Child Development Toolkit is a "use case" on developmental screening data. Below are links to both the toolkit and the referenced use case:

http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/ChildhoodDevelopmentToolkit/Pages/Use-Cases-.aspx

http://www.amchp.org/programsandtopics/CYSHCN/projects/spharc/ChildhoodDevelopmentToolkit/Documents/Developmental%20screening.pdf

As noted in this use case, there are two fundamental questions that data, such as that provided by Alaska's ASQ online system, can answer:

1. How many children birth through age 5 are receiving a developmental screening using a parent-completed screening tool?

2. How many children birth through age 5 are achieving 5-domain developmental health as demonstrated by a parent-completed developmental screening results?

These are two of the measures being reported for the Early Childhood Comprehensive Systems (ECCS) Impact Project. Alaska's ECCS team, which includes HMG-AK and Prentice Consulting, is currently reporting on these measures for the three Alaska communities. Alaska's three designated "Place-Based Communities" are Kodiak, Mat-Su, and Norton Sound. While this is a start, there are additional possibilities for this data that would inform Alaska's developmental screening efforts.

1. How many children birth through age 5 are receiving a developmental screening using a parent-completed screening tool?

A regional analysis which included the number of children 0-5 compared with the number of children screened would provide the percentage of children receiving developmental screening. A breakdown by age (0-11 mo., 12-23 mo., etc.) is also possible. This information could inform decisions about resource allocation and outreach efforts for geographic areas with low screening rates. In more densely populated areas, data can be analyzed by zip code to create a more precise picture. Analyses can be conducted using other data points collected in the ASQ child profile such as gender, age, ethnicity.

Of course, the ASQ online only captures screenings entered into the statewide system. Many other entities are conducting developmental screening using tools other than ASQ or using the ASQ but not participating in the statewide online system. The data would be more accurate if the analysis included data from these community partners, through data sharing agreements. As one example, in Nome the Norton Sound Health Corporation (NSHC) Primary Care Center conducts screens and enters the data into the ASQ online system. Kawarek Head Start conducts developmental screening utilizing the ASQ but does not participate in the ASQ online system. If, through a data sharing agreement, the screening data from Head Start could be provided to NSHC, the screening data for the community of Nome would be fairly comprehensive. This would also provide information about frequency of duplicate screenings.

2. How many children birth through age 5 are achieving 5-domain developmental health as demonstrated by a parent-completed developmental screening results?

This question is also being reported for the three ECCS Place-Based Communities and could be analyzed using community, regional, and/or statewide ASQ data. Developmental screening identifies individual children at risk for delays or disabilities; however, use of aggregated data can measure overall progress toward achieving five-domain health as well as patterns among certain communities, programs, or other designated groups. This could potentially inform interventions in particular communities and/or programs.

An important benefit of an online system is the ability to analyze data collected through the online screening process. However, access to the data and training in defining, generating, and analyzing reports are essential elements for getting the most from the online data system.

Because Alaska has elected to have data de-identified at the Hub level, only individuals assigned the role of Enterprise account administrator can run identified program and aggregate reports within each Enterprise account. Data at the Enterprise level is identified data, allowing for the elimination of duplicate records within a program and the Enterprise. Identified data also indicates children having screenings at multiple intervals. The ability to account for multiple screenings per child is critical for accuracy of reporting. For instance, a de-identified report run at the Hub level for the NSHC Primary Care Clinic shows that 536 ASQ-3 screenings were entered into the system for 2019 for children 0-47 months. A report run at the Enterprise level with identified data shows that 364 unique children ages 0-47 months received a developmental screening in 2019.

The reporting requirements for the ECCS Impact Project serve as a concrete example of the importance of access to data. As discussed earlier in this report, two reportable measurements of the ECCS Impact Project are 1) number of children 0-47 months who were screened in a given year, by age (birth year) and gender; 2) percentage of those screened who achieved 5-domain developmental health by age (birth year) and gender.

The ASQ online data enables Alaska to meet these reporting requirements. However, it has required working with the Enterprise account administrators, typically the ILP Coordinator, in each of the three place-based communities (PBCs) to teach them how to run the reports, check for duplicate children, etc.

An additional example is a recent request from a school district for ASQ-3 data within the district's catchment area. The district is interested in any patterns within the ASQ-3 screening results that might inform particular interventions and/or curriculum decisions. Without access to identified data, a report cannot drill down to include only data from a specific geographic location. As an example, if the Juneau School District requested ASQ-3 data on pre-elementary children in Juneau, there would not be a way to provide this. REACH, the ILP serving Juneau, also serves the communities of Haines, Gustavus, Skagway, Klukwan, Yakutat, Tenakee Springs, Pelican, and Hoonah. A de-identified report, the only option possible from the Hub level, would include all screenings entered through the REACH ILP program. The REACH Enterprise account administrator would need to be engaged and taught to run the report and eliminate data from non-Juneau communities. The level of skills and the allocation of time are not realistic expectations for highly trained early intervention staff working at ILPs.

Due to confidentiality concerns, no one outside the organization hosting the Enterprise has access to the data. It is worth exploring opportunities such as a data sharing agreement or

confidentiality statement that would allow a designated position access to the data. This could also improve quality control since the same trained individual would be reviewing the data and running the reports.

Maximizing data utilization could be achieved in at least three ways:

1. *Each Enterprise account administrator could be trained and tasked with providing ASQ data when requests were made, as currently happens with the ECCS reporting. The drawback with this approach is that the workload of the ILP coordinators who act as the Enterprise account administrators, have limited time to devote to this work. Their skill sets and training don't necessarily lend themselves to data retrieval activities.*

2. *A trained, skilled individual or small group of individuals could be allowed access to Enterprise level data through data sharing agreements. Once added as an Enterprise account administrator and provided a login and password, this designee could run reports on any individual program's data or Enterprise level aggregate data.*

3. *ASQ data could be identified at the Hub level, allowing the Hub administrator or administrators access to identified data at the Enterprise and program level.*

Option 2 seems both most realistic and most efficient. With the current system of 17 Enterprises, managing the reporting and maintenance for all 17 may be too much work for an individual. However, a small group of trained individuals who work for the State of Alaska, either as employees or under contract, could be provided access to this data through data sharing agreements or some other acceptable measure.

Statewide ASQ Online Structure

Alaska's ASQ online system was implemented by Part C/ILP in 2012 in an effort to increase Child Find efforts. Because it was the initiative of Part C/ILP, the system was organized around the 16 ILPs throughout the state. This assured that every family had access to online screening through the Family Access feature of ASQ Online. Due to a variety of factors, including changes in the oversight of Alaska's Part C/ILP program, staff turnover, increased demands, and shifting priorities, it is not clear that the Part C/ILP office has the capacity or desire to continue in its role as "home" to the ASQ online system.

Options for restructuring the ASQ online system do exist. The system could, for example, be organized by user groups. In this structure, all ILPs could be under one Enterprise with 16 individual programs, one for each ILP. Similarly, medical practices could comprise one Enterprise, with each as an individual program. Early care and learning programs could be in a single Enterprise. Or, perhaps better, Head Start/Early Head Starts could be its own Enterprise with individual programs for each HS/EHS program. Parents as Teachers could be one Enterprise with multiple individual programs, etc. Structuring Enterprises by service types offers

advantages such as data analysis by service type and the use of customized fields pertaining to specific service types.

The technology to restructure existing ASQ online system exists and Brookes Publishing is willing and able to assist with this process. There would be a cost associated with this type of restructure, which is dependent on Brookes technical assistance. It is a fairly complex process and not one to be rushed into but it is worth considering as a possibility moving forward.

It is also worth considering a hybrid model in which the ILPs who have the desire and capacity to actively manage their Enterprise account are provided the training and support to do so. Those ILPs who lack the desire and/or capacity to actively manage their Enterprise account could pass this responsibility on to another identified party, and have their programs moved to the corresponding Enterprise of medical provider, early care and learning, etc. These programs could also be moved into the HMG-AK Enterprise where they could be actively managed.

Another product to note is called Patient Tools. Patient Tools is a product, available for purchase, that allows subscribers to access a wide range of screenings, including developmental screening. Essentially, an agency (medical practice, child care facility, etc.) purchases a subscription at a cost of $150. Scores or perhaps hundreds of screening tools are available through Patient Tools that cover the lifespan. Each tool has a specific cost per screen. For instance, ASQ-3 costs $0.75 per screen, with half allocated to Patient Tools and half to Brookes Publishing which holds the license for ASQ-3.

A primary advantage of Patient Tools is the ability to have multiple screenings for an individual within one portal. A much more thorough exploration of Patient Tools would need to be conducted before implementing Patient Tools, even on a pilot level. It is mentioned here to acknowledge that more inclusive screening data systems do exist and are available.

Benefits of Patient Tools include:
- Access to multiple screening tools beyond ASQ-3 and ASQ:SE2 within one portal
- Ability to report on developmental screening tools used in Alaska, beyond ASQ-3
- Individuals have their own login so all screenings are within one individual account
- Individual accounts are linked with each program or agency or practice
- Linking to EMR is reportedly very successful and smooth
- Patient Tools has primarily been used in medical practices but is expanding to include early care and learning programs
- Has fields to track screening, referral, and services received
- Meets HIPAA requirements

Optimal functionality of an ASQ online system requires trained and engaged Hub and Enterprise account administrators. In numerous conversations with staff from Brookes Publishing, Prentice Consulting was told that the key factor to achieving success with ASQ online is proactive account administrators. These individuals can support the programs within the Enterprise, run reports with identified child data, and communicate regularly with the Hub administrator.

Alaska's statewide online structure, organized through the Infant Learning Programs made sense at the time of inception. At present, the system is not able to be proactively managed due to factors that may include limited resources and lack of training. The system could continue in its current structure with active management of the system provided outside of Part C/ILP. Alternatively, the structure could be actively changed over time to reflect the current environment for developmental screening in Alaska.

Summary

There are specific actions that would enable Alaska to get the most out of the statewide ASQ online system. There is rich data to be mined in the thousands of child profiles and screening results. However, individuals with the knowledge and skills to analyze and utilize this data do not have access to it. Granting access to Enterprise-level data to a limited number of individuals through data sharing agreements would greatly increase the value of the information currently available in the ASQ online system.

Alaska's ASQ online system would benefit from consistent pro-active Enterprise account administrators who receive training, remain actively engaged with the programs within their Enterprise, and maintain regular communication with other Enterprise and Hub administrators.

There is an open door for an organization or agency to step in and define a leadership role for developmental screening efforts in Alaska, including oversight, proactive management, and strengthening the ASQ online system.