Final Report

THE INNOVATION & PROBLEM IT IS TRYING TO SOLVE

Before the age of 5, children develop and learn a wide range of physical, mental, and emotional skills which affect their lives. However, 1 in 6 children in the U.S. are diagnosed with developmental delays and disabilities, such as ADHD, autism, and anxiety disorders. Children in low-income families are twice as likely to experience developmental delays, potentially impacting their cognitive, physical, communicative, or emotional/social skills.

Early detection of these developmental delays can help families seek early intervention. Regularly engaging with the healthcare system (e.g., pediatricians) helps monitor how children are progressing, assessing and detecting developmental delays, if any. Moreover for low-income populations, access to community-based preventive health care services for children becomes essential.

Although there are developmental screening practices and tools, these are currently:

- **Fragmented** as parents, pediatricians, schools, and community organizations use different platforms, different screening tools, or different screening schedules.
- **Pen and paper-based** which: (a) can take a lot of time to fill out, asking all parents the same screening questions (which might not apply for their child and can become mentally & emotionally taxing to fill out repeatedly), (b) is not well-integrated into a centralized system and hence, a child's development screening information might not transfer well to different sectors which could benefit from having it (e.g., schools, special educators)

There is a strong need for a tool (a) that centralizes and digitizes these efforts and (b) uses a responsive-questionnaire approach so as to shorten time spent by parents on filling developmental screenings and make more appropriate suggestions for interventions for their children.

The innovation being researched by my PIs is **a new tool for development screening** that uses Computer-Adapted Testing (CAT) and draws on Item-Response Theory (IRT) to select items that function best in composition, domain coverage, and appropriateness of response options for different parents. The tool aims to use **a single assessment** to track the progress of the child and assess developmental delays in relation to other similar-aged children. The new tool and assessment aim to improve developmental screening by addressing inequities in the design of current tools while supporting efficient screening administration and effective response to positive screens. Further, this is an innovation that provides a systems level intervention and not just something for families to use for monitoring their child's progress.

Why is this innovation unique?

1. The new development screening tool uses IRT and CAT for a single assessment that:
    a. Tracks the progress of the child's development as often as deemed appropriate
    b. Assesses if a child's development is delayed in relation to other children their age
    c. Shortens time and gives families more appropriate suggestions for interventions for their children.
2. The development assessment aims to be more contextually and culturally appropriate across languages, specifically focusing on low-income, Black, and Latino children and families.
3. The research team collaborates across different clinics and is using their existing establishment of personal connections with providers and stakeholders in the developmental screening, early education, and technology design space.

Wider social impact

Given that 1 in 6 children who have developmental delays go undiagnosed until kindergarten, they miss opportunities for free services (e.g., speech therapy, occupational therapy) mandated for children under 3 years of age (Individuals with Disabilities Education Act). Service providers also miss this opportunity to provide care. Thus, early detection of developmental delays can help families access early interventions - which get reimbursed by public funds - and help increase clientele for service providers. Moreover, making developmental screenings more culturally and contextually appropriate can ensure appropriate care to children from underserved communities (e.g., low income, Black, Latino populations).

An integrated, coordinated, community-based developmental screening system can have further impacts, such as potentially reducing education and treatment costs associated with childhood disabilities and disorders.

Status of Development

The innovation is currently in the research phase. There are no prototypes of the tool or assessment as of yet.

MARKET ANALYSIS & CUSTOMER DISCOVERY

Existing research & market analysis by team

[This section contains text and a table directly picked up from previous grants and market research work done by my PIs/past research by their team. The content in this subsection is not my own. New insights I gathered from customer discovery during my fellowship are in the following subsections.]

The Centers for Disease Control and Prevention estimates that 1 in 6 children between the ages of 3 and 17 will be diagnosed with a developmental disability, and approximately half of these children will not be diagnosed until they enter kindergarten. Contributing to this issue is that half of all children in the United States under the age of 5 do not attend preschool or daycare, which means they are not seen by as many childcare experts, and despite improving access and affordability of primary health care, almost half of Washington State's neediest children are not making their Well-child visits in the first 5 years of life. This disparity increases as children reach adolescence [1]. In addition, only 30% of children receive a developmental screen.

In 2015, King County (the largest county in Washington State, which consists of approximately 2 million of the state's 9 million people) passed a $325 million, 5 year levy called Best Starts for Kids. Best Starts for Kids has earmarked half of the funds for public health projects for children aged 0-5 and specifically includes developmental screening as one of its key pillars. The team could consider submitting a proposal to this program.

Moreover, a number of tools exist for conducting screening for developmental delay (e.g., the Ages and Stages Questionnaire (ASQ), M-CHAT, DENVER II, SWYC, etc.). These tools usually are paper-based screeners completed by parents in a single sitting or websites using a survey-like interface of questions completed in a single sitting. The strength of these tools is their research validation, but current formats have several key weaknesses: 1) the delivery of the content is very static; 2) it is difficult to compile and assess the results of; 3) it is difficult to scale well to a large variety of underserved populations, 4) they do not engage parents over the long-term, and 5) they may scare off potential parent users by framing the questions as looking for problems or delay, rather than by celebrating accomplishments, which research shows can have a negative impact on self-efficacy and uptake.

Many government agencies have also spent decades looking for ways to reach low-resource families, primarily through static websites and traditional public health campaigns that may only reach parents at a single snapshot of their child's life. However, developmental screening and effective interventions require engagement over many years. Numerous commercial tools seek to reach families, but they lack research-backing, connection to government and nonprofit agencies, and providers of interventions. These linkages are required to have population-level impact.

Previously, my PIs also worked on creating a set of tools - called Baby Steps - to engage parents in completing development screenings of their children by combining it with sentimental record-keeping. During their commercialization efforts, they came up with a potential public-private partnership (PPP) model between the UW Baby Steps research team, a technology partner - Cayzen Technologies, and the Washington State Department of Health. The table below describes their PPP model proposed by the team in a previous grant document. The three parties had also collaborated on the business analysis of a universal data system for WA, and envisioned a more sustainable collaboration evolving with funding from the WA State decision package.

	Gives	Gets	Dependencies
WA Dept. of Health	Creates a universal screening and referral data system to enable early intervention. Pays for "PaaS" from participating IT vendor once it is created.	1) Public health benefits as more parents and providers are engaged in timely interventions for children. 2) Ability to report to federal entities and other agencies, improving compliance and ease of operations.	1) Reliable inputs from parents based on a Baby Steps. 2) Budget to build an integrated UI and database that is useful to multiple state agencies and providers.
Baby Steps	Reliable inputs from engaged parents. Enriches database and ensures its relevance.	Data system support to compliment the front end (Baby Steps as end user app).	Budget and bandwidth to design the integrated data system and UI.
Cayzen Tech.	Investment to support the integration of the data system and the Baby Steps UI.	Commitment from the state to pay for software as the platform that runs this integrated system.	Commitment that if they invest in partnership, they will earn business of WA state and can showcase approach to other states.

Who did I speak with?

Spoke to a total of 15 stakeholders.

- 3 primary care providers / pediatricians (who are also clinical partners on the broader developmental screening work being done by my PIs)
- 1 mental and behavioral health specialist
- 2 early intervention services specialists
- 2 public health practitioners
    - 1 is the universal screening lead at Best Starts for Kids
    - 1 was involved in creating and standardizing the SYWC
- 1 family resource coordinator
    - Work primarily with immigrant populations and Black populations
- 3 developmental navigators
    - Work with Swahili-speaking, French, Arabic, Chinese, and Hispanic populations, among others
- 1 parent with 2 children with developmental disabilities
- 2 public health and design researchers who have experience in the developmental screening space as PhD students and were directly involved in research, design, and development of BabySteps (the parent-facing developmental screening system designed by Julie Kientz and her team).

The stakeholders belong to the following clinics/organizations:

- Harborview
- Sea Mar

- Odessa Brown
- Child Haven
- Mother Africa
- CISC
- Hope Central
- King County
- Washington State Medical Homes
- Metro United Way (not WA based)

The stakeholders work with different cultures and populations including Arabic, Swahili-speaking, French, Hispanic, Chinese, Black, immigrant, and low-income populations.

I also attended the Child and Youth with Special Health Care Needs (CYSHCN) meeting facilitated by the Washington State Department of Health.

Outside of project stakeholders, I spoke with David Cooper, who has a lot of experience in digital health tools, to explore strategies for launching developmental screening tools nationally.

What I learned

STAKEHOLDERS ROLES & KEY BENEFICIARIES

Parents play a pivotal role in developmental screening. Parents are often the ones filling out the screening questionnaires. They are the primary caregivers and most likely the first ones to notice/witness their kid's milestones and development. Although educated, higher/middle class parents do not have a problem with monitoring their child's developmental milestones (including regularly visiting pediatricians and clinicians), low income and immigrant parents may not check progress as regularly (e.g., have insurance issues), are behind on schedule, with their children more likely to get diagnosed with developmental delays later than others. Also, lots of parents who do not fill out developmental screenings questionnaires because they are reluctant to think about their child's delays. If it is a good result, they might be okay with it. But if there is an issue, they might not acknowledge or believe it.

Moreover, due current lack of interoperability across different programs and sectors that use developmental screening results (e.g., early support toddlers program, pediatricians, early education systems), the overload of relaying developmental screening results also falls on parents. These are some major reasons why the BabySteps team focused on parents and understanding their needs/practices of conducting developmental screenings.

Pediatricians play a more background role in child developmental screening than expected, to the extent a lot of pediatricians do not even know about different types of developmental screening tests (e.g., TS-GOLD). It is the childcare, daycare workers, social workers, schools, parents, etc who actually identify a child's developmental needs as the best way to identify indicators of delays is by observing children in the day to day (which the pediatrician doesn't really do). Pediatricians might notice signs which are “very obvious” to them but not to, say, first time parents. However, pediatricians play an important role of referring to specialists and determining eligibility for specific services; they are the intermediary to direct parents to early intervention services. Once the service starts, the school system takes over.

Daycare teachers might notice developmental milestones or delays before parents do (e.g., child walking or speaking). For busy parents, their child might spend a lot of time in daycare putting daycare teachers also in a suitable position to conduct developmental screenings. However, there are many questions here from both the parent side (e.g., how will the parents feel about this? Will they feel like one less thing for them to do or will they be angry that they wanted to be the ones involved? Will parents trust their results?) and the daycare side (e.g., Will the daycare running people even want to fill these questionnaires? Will they even have time? Also think about ethics?). There is a case study of China, where caregivers, including daycare teachers were being trained on doing developmental screenings, i.e., they were being made aware of what “signs” to look for. While this might not be feasible for very small children (e.g., < 6 months old), training of other caregivers and daycare providers might be an opportunity.

Developmental navigators can play a key role in conducting developmental screenings and need to be a part of the picture if we really want to focus on equity and access to child development services. The Early Support for Infants & Toddlers (ESIT) program is really interested in reaching different populations, including BIPOC, and they send developmental navigators to do house visits, observe the child in their natural environment, and conduct developmental evaluations, recommending relevant services to parents, if needed. Although developmental navigators may not spend as much time with the child as their parents, they observe the child more frequently and for longer durations as compared to pediatricians and can help parents narrow down on services they should be looking at/asking pediatricians for referrals. However, given the current practice and communication norms around developmental screening, another challenge could be understanding in the clinical ecosystem developmental navigators fit and how that impacts trust pediatricians & other clinicians might have on their practices, screenings, results, or service recommendations.

Also, the role of developmental navigators is not a universal role across different states, as compared to say, a pediatrician. It is usually a subset of or specific role played by Community Health Workers (CHWs). Currently within Washington, from the child developmental assessment perspective, community health roles with 2 different focuses are taking off: (i) birth to 5 years, (ii) mental and behavioral health. Family navigators also are a part of this broader CHW role as they work with children with disabilities and developmental delays. Outside of Washington and the Harborview/Odessa Brown/Child Haven collaboration, these roles could also be played by “patient advocates” or “family resource coordinators” for whom conducting developmental screenings would be a part of their many other roles (e.g., checking if families have access to basic needs like food or housing, etc). For example, Metro United Way, an affiliate of Help Me Grow Kentucky, hires individuals from specific neighborhoods and cultures to conduct the developmental screenings with populations of that neighborhood/culture as they are able to instill trust by “speaking their language” and understanding their cultural ways.

State and federal public health organizations who work in the area of children’s health and education could be key beneficiaries. The tool can help reduce costs and time spent by these organizations in providing developmental screening to children in hard-to-reach and low-income populations. The tool can also help reduce the burden of special education needed by children whose developmental disabilities are not identified early on. Examples of such organizations are:

- **Nonprofits** that provide developmental screening to low-income populations (e.g., WithinReach, Thrive)
- **Government organizations** who have a vested interest in ensuring the health of its citizens (e.g., the Department of Health, Department of Early Learning)

For Baby Steps, key beneficiaries were public health organizations, who recoup the upfront cost of early intervention services through the eventual savings in special education and the increased capacity for productive lives of these children when they become adults. Washington State estimates that successful early intervention can save the state $30 million annually in special education costs in the long term [35].

Schools, special education centers, and early childhood educators could also benefit from an integrated tool that shares a child’s developmental progress with them directly. This would help these organizations and educators identify the best route/options for educating and working with the child early on, reducing potential special education costs.

Other paying customers for the tool could be **service providers (e.g., pediatricians, public health clinics, behavioral therapists, PCPs,** etc). The tool can help increase their clientele by referring appropriate parents to their services and guarantee income (paid by public funds if children with developmental disabilities are identified early enough).

ISSUES WITH CURRENT DEVELOPMENT SCREENING TOOLS & QUESTIONNAIRES

Some concerns in current developmental screening questionnaires and tools, especially in terms of being inclusive to different populations, are:

- Questions are culturally embedded in practices of specific populations which makes them hard to understand for cultures they are not designed for. For example, activities or practices described are not familiar to people coming from low-income or BIPOC communities.
- Language of questions can be complex and does not translate well into other languages. For example, ASQ has some questions which are hard to translate into other languages.

- The examples and images shown in developmental screening questionnaires are not representative or relevant for different cultures or segments of the population, i.e., they might depict activities or practices only a subset of the population does.
- Due to the pen-paper format of screening questionnaires and different types of questionnaires, it is hard for those conducting developmental screenings to always be equipped with all versions depending on the population they are working with. Plus, the questions are limited to what fits reasonably within a sheet (cannot pick from different questionnaires which questions are more relevant to specific populations) and the process of answering irrelevant questions can seem time consuming and even daunting (e.g., a child isn't showing any developmental delays) for parents.

CHALLENGES IN INTEROPERABILITY BETWEEN CLINICAL, PUBLIC HEALTH, & EARLY EDUCATION ECOSYSTEMS

Although it would be ideal for there to be interoperability between clinical and early education systems, allowing for developmental screening results to be relayed between the two to provide a better care and educational experience, the communication system becomes complicated because of privacy and protection laws. For example, with HIPAA on the clinical/health side and FERPA on the education side, the legality of things find parents to be in the best position to take on the communication between the two.

One potential way to centralize this communication and remove some burden from parents would be for having some sort of state involvement. **The goal has always been to be bigger than the clinical setting**, extending to other sectors like early education and public health, and this is where a state level database or system can be useful.

EXISTING CLINIC STRUCTURES, FUNCTIONING, & FUNDING

There is great diversity in the functioning of individual clinics and organizations that administer developmental screening. This includes differences in:

- **Where and how developmental screening is being conducted**, i.e., at the pediatrician's clinic vs in-home visits, do navigators guide parents on how to fill developmental questionnaires or do parents fill out questionnaires themselves?
- **What questionnaires and methods are used**. Different clinics used SWYC or ASQ or M-CHAT for autism screening, and they each had their own reasons (e.g., what they felt worked best/were more understandable for the populations they were working).
- **Available funding for developmental navigators or community-health workers (CHWs)**. There were also differences in the size of the clinic and the amount of funding they had for hiring people to conduct developmental screenings or do in-home visits/observations. For example, larger clinics could get funding for CHWs or dedicated developmental navigators whereas hiring CHWs was a luxury for smaller clinics given budget constraints.

- **Service referral process.** Although most services required referrals from providers or pediatricians, some accepted self-referrals or referrals from community groups/ developmental navigators. These referrals could be made directly to the service providers or in some cases, parents had to present printed versions of pediatrician referrals to their service providers.

Moreover, all clinics were supported by some sort of grant funding (mostly grants by the county or state) for making developmental screening more relationship-based, family and community-centered.

An existing clinical collaboration in WA focused on family-centered developmental screening is the **Early Childhood Developmental Navigator Program**. This is a collaboration between:

- Child Haven: the organization that runs the ESIT program. It trains and sends developmental navigators – who are Child Haven employees – to partnering clinics for administering family-centered developmental screening.
- Harborview, Sea Mar, Odessa Brown Seattle Childrens: the clinic partners.

The goal of this program is to build relationships and trust within communities and work closely with families to provide more culturally-appropriate developmental screenings, adapting to their language and cultural contexts. Although the program started with developmental navigators being employees of Child Haven, one of the clinics – Odessa Brown – has evolved to include developmental navigators as a part of their clinic budget, i.e., Odessa Brown now hires developmental navigators directly as salaried employees of its clinic.

OTHER COUNTY & STATE-LEVEL FUNDING EFFORTS

The Washington State Department of Health is very much interested in developmental screening and family centered care, and has been pushing funds in the space. Recently, they soft launched a state-level developmental screening registry which contains early childhood information, including immunization records. However creating this registry has been very slow and complicated work because:

- Lack of interoperability between different providers and hospitals, especially because parents may change or shift between different providers. This causes missing information (e.g., the child got immunization elsewhere but was not documented by their pediatrician).
- Immunization recording has been complex, especially given controversies around the child COVID immunization.
- Concerns about developmental screening results in a state database & how they will be used (e.g., privacy and protection? How will this information be used? Who has access to this information? How do parents get to decide who has access?)

The state has been also thinking about various incentive structures around training for and conducting developmental screenings.

- ➢ Recently got Medicaid funding to cover 5-6 types of developmental screenings. It is not much but it is something. Primary care providers (PCPs) were not doing any developmental screenings for the longest time but now, because of Medicaid or other insurance coverages, they are doing some screenings (3 development centric, 2 autism centric). However, to get these screenings covered under Medicaid or other insurances, providers need to use a standardized tool (e.g., ASQ, SWYC) and protocol. There needs to be a system in place to do these screenings but once it is set up and the standards are set, screenings can be done. However, the above mentioned reasons contribute to the wider set of complexities around developmental screenings that need to be addressed.
- ➢ State also gave around $100,000 to each physician to cover services such as training CHWs as well as parents to do developmental screenings.
- ➢ There was also a push for childcare providers to developmental screenings. For example, the CHEAT program where in Childcare providers would get points, which counted towards higher reimbursements, for doing developmental screenings.

There are a lot of other national, state, and local programs working on developmental screening. For example, Help Me Grow is a national program out of Connecticut. Within Reach is a maternal health sciences program that adapted Help Me Grow and is a non-profit operating in multiple areas, including King County. Some places these programs are more active and help provide more developmental screening support (e.g., Help Me Grow Pierce County).

EXISTING PRACTICES OF DEVELOPMENTAL NAVIGATORS

Developmental or family navigators, i.e., those who help conduct the developmental screenings, described their role and day-to-day practices. Navigators work closely with families to build relationships and gain their trust so that families feel comfortable sharing personal details, including challenges they may face with access to basic needs (e.g., housing, food insecurity, language-related barriers, etc). Navigators guide families in filling out the developmental screening questionnaires, explaining to them the meaning of different questions. Some questions in the ASQ and SWYC are confusing/weirdly worded and families benefit from explanations about what skills (e.g., motor skills, communication or social skills, cognitive abilities, etc) are being tested by specific questions so that they do not interpret those questions literally.

Moreover, **navigators, in some ways, are already doing on-the-fly adaptive testing using the existing questionnaires**. They described:

- ➢ Reframing questions, changing the language or examples used to make questions more understandable and culturally appropriate for different populations. For example, a question testing for fine motor skills asks if the child is able to use a spoon correctly. If a spoon is not the common way of eating in a culture, navigators choose to change spoon to fork or chopsticks, or even completely change the question to give a more appropriate example for testing a child's fine motor skills.

- Change question ordering
- Skip irrelevant questions

Thus, conversations with navigators reinforced the need for the tool being designed by the team and its potential to better support their existing adaptive screening practices, while also ensuring some sort of standardization to the adaptations being made within the scope of different cultures.

PATH TO "STANDARDIZATION": LEARNINGS FROM CONVERSATIONS WITH CHRIS SHELDRICK & THE CREATION OF SWYC

While it is important to think about perspectives of various stakeholders in the developmental screening space, it is also important to think about who cares about "screening"? From a researcher perspective, a good screener provides "scores" which helps streamline and add "accuracy" to the process of identifying developmental delays and disabilities. However, apart from researchers, clinical practitioners may not see any value to screeners beyond the scores they generate. But the process of developmental screening is way beyond that. There is the screening component which is done by the questionnaires but also the communication component of working with parents in making them more aware of the importance of monitoring child development. This is similar to what some developmental navigators pointed out, i.e., while a screening tool can support cultural adaptation of developmental screening questionnaires, the human conversation and relationship-building component is the key to providing more inclusive and community-centric care, which cannot be replaced by technology.

This puts into question – what does "standardization" even mean for a developmental screening tool? Chris discussed how only very recently clinicians started moving away from the perspective that negative scores means referrals required while positive scores means the child doesn't need any intervention. There are possibilities of missed diagnosis and early intervention due to high scores. Moreover, research "validation" is something that cannot be done in a single snapshot of time. In fact, there is always a way to improve existing questionnaires and tools (e.g., questions which were a part of developmental screeners some years back might not be relevant to today's generations and need to be changed). An ideal scenario would be a community-based approach wherein the questionnaire is "re-validated" every few years to ensure it remains clinically-updated and culturally-relevant over the years. So without such scoring and concrete claims of "validation", the process of standardization can be challenging.

Chris explained that this disparity in expectations of researchers vs clinicians vs parents might be because of different interpretations of the goal of the developmental screening process. Looking at the example of SWYC:

- The SWYC was designed as a “questionnaire” and not a “screening tool”, i.e., it is a questionnaire which contains a screener for developmental delays and disabilities but there is also the communication component which includes, learning about the child, communicating about the value of monitoring child development milestones and what it means if there is a delay in terms of things their child should be able to do by a certain age. Reducing the questionnaire to a single screening score does not do the process justice. Moreover, while one can argue that such questionnaires might run the risk of making parents feel there is something wrong with their child, that doesn’t mean that questions need to be redesigned in a way that they miss out on the essential health information required by clinicians for identifying/diagnosing delays and disabilities. Reiterating, while community perspectives here are important, clinical value of the information collected by the questionnaire was also prioritized while creating the SWYC.

- The SWYC was designed as a questionnaire to be filled by parents. While current efforts looking into cultural adaptation and more inclusive, community-centered developmental screenings often involve an intermediary, like a developmental navigator or CHW, administering the questionnaire to families (so that they better understand and engage with it), the SWYC was not designed to be used in such a manner. However, the IP model of SWYC is such that the questionnaire is free and it can be translated into different languages and cultural practices (e.g., replacing the use of a spoon for eating with chopsticks or eating with a hand, depending on the culture) as long as the translated version is shared back with the creators of SWYC so that other people can use the translated version as well. Thus, the creators are open to exploring ways to maximize the abilities of the questionnaire so that it is used for the purpose it was designed.

Moreover, with the SWYC, Chris explained how they *“rode the wave of screening mandates”*, with state and national programs providing various incentive structures for conducting developmental screenings. A lot of clinicians who wanted a new questionnaire had already made a decision to conduct developmental screenings. Their decision to use SWYC was often motivated by:

- SWYC was free, so they could easily incorporate it into EMRs

- Only a few practices had found ASQ to be useful (was very lengthy) and others, who used PEDs, did not feel that the questionnaire was providing them any new information/insights about the child. SWYC filled that gap of being a more reasonable length questionnaire and providing more valuable insights to clinicians

For thinking about standardization without a set scoring or validation process, Chris also bounced around the idea of having certain “norms” around how to conduct developmental screenings and build an understanding of child development in different communities. Again, the questionnaires are intended to serve a dual purpose of being a screener and a communication device for talking about child development. So if there were certain “norms” in place for different stakeholders to follow (e.g., How to flag developmental delays without scoring the screener? How to communicate to parents if their child has a delay or needs early intervention? How to engage clinics, CHWs, and parents in the bigger communication around child development?), that could help create a sort of "standardization" around the child development screening process.

However, the bigger question remains what it would take to get state insurance (e.g., Medicaid) to cover developmental screenings (and community engagement) using a new adaptive testing tool and is there a way to pitch a "standardization" process without scoring metrics.

COMPETITION & INSPIRATIONS

Our biggest competitors in the space are existing tools/questionnaires which are widely used for development screening across the country. These include:

- **Ages & Stages Questionnaire (ASQ):** This would be our biggest competitor as it is (i) the most commonly used screening questionnaire across the country for developmental screening, (ii) is currently working on revising their questionnaire (and we do not know what parts or how they are planning on revising it yet).
- **Survey of Well-being of Young Children (SWYC):** Another commonly used screening questionnaire. They tried to simplify the language of their questions and be more culturally sensitive but the pen-paper format limits the number of questions on the sheet.

To address concerns in existing questionnaires and tools, the new tool being researched by my team aims to:

- Have a wider range of questions that represent a wider range of populations. Here, Item Response Theory (IRT) and Computer Adaptive Testing (CAT) comes into play, creating a digitally-facilitated questionnaire that (i) can adapt to an individual's responses to ask more relevant follow up questions (from a wider range of questions which need not fit onto a single sheet) and (ii) provide recommendations for more appropriate services (not a laundry list of recommendations which can confuse parents/guardians).
- Make the questions asked and examples provided in the developmental screening questionnaire itself more culturally appropriate. This could include: simplifying the language & seeing how questions translate to other languages while remaining culturally relevant, using images & examples that show culturally relevant practices & activities, etc.

Further, the research team's inspiration for an adaptive behavior assessment tool for child developmental screening partially comes from PEDI-CAT, a Pediatric Evaluation of Disability Inventory Computer Adaptive Test. While PEDI-CAT uses CAT for mainly disability screening, my team is investigating its potential in broader child development assessment settings, i.e., not just focused on children identified to have developmental disabilities.

MEASURING IMPACT

When thinking about the impact they aim to make with the new tool/innovation, the team should also consider certain measurable objectives and costs. Based on these measurements, the team can identify impact investors, who share similar objectives in their work, and have a list of costs they wish to be covered by funding/support provided by impact investors,

Measurable Objectives

- **Number of parents and children reached.** This includes those who were not coming into pediatrician clinics, did not follow-up after an initial visit, or fell through after a few irregular screenings. More specific measures within this would include:
    - **Number of screens completed per child** - since developmental screenings must be done regularly/ require long-term engagement with the child.
    - **Timeliness of completing screens in the time window** - while this measure might be less important than #screens completed per child, timely developmental screenings between the age of 0-5 year would be beneficial for close monitoring of delays and seeking early intervention (which is free till the child turns 3)
- **Number of pediatrician clinics doing screenings.** Although screenings are not done only at the pediatricians office (i.e., done by CHWs during in-house visits or by developmental navigators over phone before a child's wellness visit), this measure is still valuable because if a developmental delay/disability is flagged or a service referral is required, screening results often find their way to pediatricians/providers for diagnosis and intervention referrals.
- **Experience or satisfaction rating by parents & developmental navigators.** It would be beneficial for the team to know if/how the tool improves the experience, from a cultural competence perspective, for both parents and developmental navigators who conduct the screenings. That is, measuring the tool's impact in improving cultural relevance of screening questions and cultural adaption of the developmental screening process.
- **Referral conversion rate for early childhood services and interventions.** What happens to a referral that is made by a pediatrician/provider? A lot of times developmental navigators work with families after the referral, contacting and following up with service providers, helping address any barriers families may be facing in using the service (e.g., language or cost-related barriers, not knowing what the service is for or how to monitor their child's progress using the service). Thus, this is an important measure for understanding how many families are able to access, understand, and actually use the early childhood services or interventions they are referred for.

Impact Investors

- **Washington State and Counties (e.g., King, Pierce)**. The Washington State Department of Health is very interested in developmental screening and family-centered care, and has been pushing funds in the space. Recently, they soft-launched a state-level developmental screening registry, called Strong Start Screening Registry, which contains early childhood information, including immunization records. Moreover, the universal developmental screening lead in King county indicated interest in piloting the new tool with their developmental navigators, once it is ready. They also discussed the potential and value of integrating screening data collected using the tool directly into the state-wide registry. This could to some extent also help address issues related to interoperability between clinical, public health, and early education ecosystems.
- **Best Start for Kids.** The team can explore a potential partnership wherein Best Start can help connect parents with services they are recommended by the tool/ after developmental screening.
- **Other community partners (e.g., Within Reach, Help Me Grow).** These organizations have ASQ available on their websites for families to use to conduct developmental screenings. The team could explore a collaboration with Within Reach or Help Me Grow and get help with piloting, initial funding, and testing of the new tool.
- **Nation or International Organizations (e.g., United Way, Help Me Grow National).** To scale outside of Washington, the team could also explore partnering with or applying for funding from more national and international initiatives/organizations which support nonprofits.

MEASURING COST

Costs for completing research & development

To support research and development costs associated with creating the tool, the team has already applied for grant funding (K01 award that is available to individuals with health professional or research degrees). The team can continue to support the research and development phase using grant funding. Other options for grant funding include:

- NSF
- Population Health Initiative grants
- ITHS – interested in community partnership projects
- Research royalty fund at UW – not necessarily focused on community partnerships and is competitive but is always an option

- Diversity supplements for grants – some of these supplements can be for existing projects which are now looking to expand on doing research with other cultures.
- Smaller funding options within NIH (e.g., R34) which can support pilots
- Autism science foundation (ASF)

Operation costs: for piloting and further dissemination

For this innovation, it does not make sense to estimate cost per person as the users of the screening tool/people benefiting from its use (developmental navigators, CHWs, or families) might not be the ones paying for it. Instead, it is important to account for operation costs for running the use of the tool. This includes:

- **“Who” will be providing the developmental screening** services using the tool (e.g., developmental navigators, trained employees of specific clinics) and costs required to support them (e.g., if they do home-visits vs conduct screenings outside of pediatrician offices). The estimated salary of a full-time, bilingual, early childhood developmental navigator at Child Haven is $52,500 – $67,100 annually. Depending on if the team decides to pilot the tool in one or a few clinics (around 2-3 developmental navigators deployed in pediatrician clinics that are partnering with Child Haven), they will need to account for the cost required to sustain developmental navigators. However, if the team decides to pilot in say, Odessa Brown, which has developmental navigators as salaried employees of their clinic, the team might not need to incur this cost. This cost for supporting those providing developmental screenings would stay even after the pilot, if the tool is adopted by county or state-level organizations that run developmental navigator programs/support local clinics in conducting developmental screenings.

- **People required to support research, development, and potential iteration of the tool while it is being piloted (and if things need to be tweaked during the pilot).** This means accounting for costs of sustaining researcher and developer contributions during the pilot. The team could think about an hourly pay model as the tool would already be deployed at that point and might require occasional tweeks for which a full-time employee might not be necessary. UW graduate student researcher rates are between $20-30/hour. Involving developers outside of UW to contribute to the tool might incur higher costs.

- **People needed to advocate for the adoption of the tool.** These could be County-level employees or funders (e.g., the Universal Development Screening lead of King County) who are piloting the tool with their developmental navigators or clinics (e.g., Hope Central, Harborview) and early childhood support organizations (e.g., Child Haven, Mother Africa) that act as *“champions who use the tool and then recommend it to their colleagues.”* The team should consider thinking about ways, which need not be monetary compensations, to fund the time and contributions of these “champions” for adoption of the tool.

SCALING

A model of adoption could be looking at small level success at local levels (*"champions who use the tool and then recommend it to their colleagues"*) and then scaling more organically.

- ➢ As with other efforts for making developmental screening more culturally responsive and family-centered, grant funding from state or county organizations might be the way to support the pilot run or even the initial years of adoption of the tool at local clinics. As suggested by public health practitioners leading the universal screening efforts of King County, the team could also explore integration of developmental screening information collected using the tool directly into the recently launched Strong Start, state-wide screening registry. A direct integration could be the "hook" for the new tool to become an important part of state-wide screening efforts which are bound to scale further over the years.
- ➢ After initial success of the tool, the team could look at a more organic dissemination strategy, i.e., spreading the word by mouth and encouraging adoption by more local clinics.

Scaling would definitely impact the cost which would be incurred on the team (or the organization that adopts the product) depending on the amount of human capital involved, which would increase operation costs. That is, it is important to account for how developmental navigators and "champions" of the tool are being compensated as the usage of the tool scales. After one point, grant funding might not be enough to sustain the number of developmental navigators being employed to use the tool. At that point, the goal would be to have organizations (e.g., Child Haven, Best Start, Mother Africa) and clinics (e.g., Odessa Brown) compensate/salary their employees who have now adopted the tool which has made adaptive developmental screening easier for them.

The team required to deliver the tool at scale would include:

- ➢ **County or state level funder:** this could be Best Start for Kids or something like the universal developmental screening coordinator at King County who gets their developmental navigators to use the tool and spread the word, if they like the tool.
- ➢ **Other community partners (e.g., Within Reach, Help Me Grow):** which could help fund and/or encourage adoption of the tool among their partnering clinics.
- ➢ **Individual clinics** that partner with organizations such as Child Haven to get developmental navigators to be a part of their clinics (e.g., Harborview, Sea Mar) or have developmental navigators as salaried employees of their clinic (e.g., Odessa Brown). Developmental navigators would be working within/with patients of these clinics to conduct screenings using the new tool.

- **Developmental navigators:** the people who would be using the tool to conduct developmental screenings. They are the ones who should ideally benefit from using it as it would make the behavior and culturally-adaptive developmental screening process easier for them, i.e., they won't have to think about ways to adapt screening questions on-the-fly.

POLICY BOUNDARIES & CONSIDERATIONS

The team should consider (and potentially leverage) several policy-related things when they explore funding and adoption opportunities.

One important consideration is the limited coverage for developmental screening currently provided by state insurances. Recently, Medicaid funding was approved for covering 5-6 types of developmental screenings. Although this is not much, it is a start. However, to get these screenings covered under Medicaid or other insurances, providers need to use a standardized tool (e.g., ASQ, SWYC) and protocol, not home-grown or non-standardized screening practices. Thus, it is important for the team to think about standardization of their tool (even if it essentially draws from existing developmental screening questionnaires) and consider how long that process would take (e.g., it took ~5 years for SWYC to be standardized).

The team could also consider leveraging other incentive structures set up by the state for promoting family centered developmental screenings as discussed earlier (e.g., $100,000 incentive for physicians for CHW training).

Another thing for the team to be mindful of is that under the Individuals with Disabilities Education Act, children under the age of 3 are federally mandated access to free developmental support services (e.g., speech, occupational therapy). But because developmental delays or disabilities are often not identified until later, i.e., until children start going to kindergarten and are over the age of 3, there is a missed opportunity for both families to access publicly-funded services and for early childhood service providers, who lose on their customer base.

LEGAL & REGULATORY CONSIDERATIONS

The team also needs to consider legal and regulatory things as they continue to develop the tool and look for opportunities to pilot it.

A potential challenge the team could encounter is regarding intellectual property (IP) of their innovation. The innovation consists of: (i) the novel tool that uses IRT and CAT for doing behavior adaptive developmental screening, (ii) existing developmental screening questionnaires (e.g., ASQ, SWYC) which the tool will adapt (or support developmental navigators in adapting), in order to conduct more culturally-responsive developmental screenings. The latter part could be hard to file for IP as the team does not own the existing questionnaires, and are only working towards supporting developmental navigators in adapting them/pulling from various questionnaires using the tool, depending on different cultural and population needs. The team might want to consider an IP only for the system part, i.e. the IRT and CAT-based tool, and not for the adapted questionnaires. Hence, the IP might be for the process of behavior adaptive testing for developmental screenings, even though the tool supports adaptation of existing questionnaires to be more culturally relevant for different populations. The team could take inspiration from SWYC and how they allow for translations of their questionnaire as long as those translations are shared back with the creators so that they can disseminate it to other people as well.

Secondly, the tool and organization administering developmental screenings must be HIPAA compliant. Although this requirement may seem obvious, organizations outside of WA that were working towards culturally-inclusive and universal developmental screening reported on how they were informed of this requirement for the longest time and then it took them a while to get HIPAA-compliant, which delayed the pilot of their community-driven family resource coordinator program.

Third, if in the long run the team does want to support interoperability across multiple clinics, public health organizations, and early childhood services, it is important for them to be mindful of ethical considerations arising on all sides (e.g., HIPAA on the clinical side, FERPA on the education side).

FINANCIAL MODELS & SUSTAINABILITY

The team might want to explore a non-profit or hybrid model for getting their innovation funded and adopted. Below are funding opportunities for different stages of research, implementation, and deployment of the tool.

Research & Development

The initial research and development of the tool, which involves working together with pediatricians, developmental navigators, and parents among other stakeholders. can be funded by academic grants such as by NSF or NIH. This is already being done by the team.

Proof of Concept, Pilot, and Early Years of Adoption

Next, proof of concept work as well as pilot run and initial years of adoption can also be supported by grant funding from state or county organizations. There are multiple state and county level organizations looking to support efforts for making developmental screening more culturally responsive and family-centered. For example, Best Start for Kids King County Department of Community and Human Services/ Developmental Disabilities and Early Childhood

Supports Division (DCHS/DDECS) released a Request for Proposals (size of grant: $250,000 – $500,000) to fund Family & Community Developmental Screening Programs in King County, with the goal of partnering with groups and organizations that wish to make developmental screenings more: culturally rooted, family-centered, relationship-based, and strengths-based and inclusive. Exploring such a partnership to support proof of concept and early adoption of their tool could be a viable option for the team.

Moreover, as suggested by public health practitioners leading the universal screening efforts of King County, the team could also explore integration of developmental screening information collected using the tool directly into the recently launched Strong Start, state-wide screening registry. A direct integration could be the "hook" for the new tool to become an important part of state-wide screening efforts and move from proof of concept testing to state-wide implementation.

After initial success of the tool, the team could look at a more organic dissemination strategy, i.e., spreading the word by mouth and encouraging adoption by more local clinics.

After Proof of Concept Work and Initial Adoption Phase

After the pilot and early years of adoption, the team could explore a for-profit or hybrid model.

They could explore what it takes to get state insurance (e.g., Medicaid) to cover developmental screenings using the new tool. Currently, Medicaid covers only a few screenings (3 development centric, 2 autism centric) but the team could work towards "standardizing" their tool – because current Medicaid coverage requires that developmental screenings are done using standardized questionnaires such as ASQ, SWYC, or M-CHAT – and explore ways to get Medicaid to cover more screenings. Past developmental screening questionnaires such SWYC took around 5 years to be standardized. However, depending on how the tool is designed (i.e., it draws from existing standardized screening questionnaires vs uses a whole new screening questionnaire which requires to go through the standardization process again), the time taken to standardize it for medical insurance coverage could vary. Thus, the team should come back to this phase after they have completed the research and development phase and know for certain how their tool is designed. Moreover, as mentioned earlier, if the team is able to get a "hook" into the Strong Start, state-wide screening registry, the standardization procedure to achieve medical coverage might be easier (or, the team might already have done the work needed to standardize the tool in order to get their results integrated with the Strong Start registry). Further investigation of what integration into the Strong Start registry looks like should be done by the team to determine these nitty-gritties.

Early childhood service providers could also benefit from the inflow of families who use the tool and get referred to their services early on (i.e., as early as a delay or disability is flagged). The tool could also help reduce any time wastage from waiting for referrals to make their way through, or children with delays coming in late (after their delay or disability has progressed) which might make it harder, requiring more time-commitment from the service providers. The team could explore a model where early childhood service providers could be potential payers of the tool.

The team could explore various modes of funding, with grant funding to support the research & development and initial phases of adoption. As the team looks at scaling into more local clinics and potential state-wise adoption of the tool, they could explore a funding model that is a partnership between the payer (e.g., state insurances) and providers (e.g., clinics, early childhood service providers), where the goal is to direct families to the service providers at the earliest/right when delays or disabilities are identified. If the tool is able to get more families who need early intervention for an identified developmental delay to service providers before their child turns 3, these services could be publicly-funded as part of the Individuals with Disabilities Act.

Moreover, it might be appropriate to acknowledge that the team is working on a lifestyle business and this is how big it can get. The goal here is not necessarily to look for VC funding or private insurance coverage because the focus is access and equity. It might be best to focus on state insurances (e.g., Medicaid) and potential partnerships with (i) local clinic providers, (ii) community organizations (e.g., Help Me Grow, Child Haven, Mother Africa, CISC), and/or (iv) early childhood state/county-level organization/funders (e.g., Best Start for Kids) that do developmental screenings.

Going forward, I would also recommend the team to explore developmental screening models followed outside Washington State. While the developmental navigator program might be unique to WA, other national and international-level organizations (e.g., Help Me Grow, United Way) have parallel programs or roles (e.g., community health workers, patient advocates, community representations, family care coordinators) in other states, also working towards making developmental screening more culturally-appropriate.