Agency Recommendation Summary

Children with developmental or behavioral disabilities benefit greatly from early intervention, but fewer than half are identified before starting school, when interventions are most effective. In order to ensure all children are appropriately screened for developmental delays and receive critical early intervention services, the Department of Health (DOH) proposes creating a statewide data system to track developmental screenings and delays identified in children, and assist with care coordination and early intervention.

Fiscal Summary

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<th>Operating Expenditures</th>
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<td>Obj. J</td>
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### Package Description

Washington faces several obstacles to ensuring all children are appropriately screened for developmental delays and provided early intervention services so that they enter kindergarten healthy and ready to learn, including:

- Service providers have no way of knowing a child’s screening history.
- Agencies and stakeholders involved in providing screening and services to children are not coordinated. They cannot easily share information on a child’s screening or early intervention history.
- Researchers and program managers have few data regarding screening because such data are scattered among many providers with separate data systems.

Families struggle to find resources and connect to services that improve developmental outcomes. During the past biennium, Washington’s Medicaid program shifted policies to more closely align with the American Academy of Pediatrics (AAP) Bright Futures recommendations for age appropriate screenings. Washington’s Medicaid program began reimbursing providers who bill for screening in January 2016. Projects to train health care providers in using validated screening tools have spread across the state, but there is no statewide method to capture the screening data and allow communication and referrals across the systems and ensure all children are screened according to Bright Futures guidelines, and those children with developmental or behavioral conditions are referred to and receive early intervention services well before entering Kindergarten.

DOH requests funding to build a Universal Developmental Screening (UDS) data system.

All UDS stakeholders, including families, health care providers, child care providers, community organizations that serve families, and state agencies would benefit from a statewide UDS data system that will document periodic screening and developmental delays identified in children, and assist with coordination of care.

Screening and prevention/early intervention are important investments for long term health outcomes. The return on investment is highest in the early years of life. Every $1 spent on early childhood development screening and treatment saves $17 in health and societal costs.
Developing a Universal Developmental Screening Data System

DOH envisions that the UDS data system would capture all screening, diagnosis, and intervention services for Washington’s children and provide the platform for the data and analysis component. The system will allow health care providers to submit, either manually or through their Electronic Health Records, UDS data from children they have screened. A variety of users (e.g., a child’s healthcare provider, parents, early learning centers, and schools) would have access to view appropriate levels and types of data in accordance with privacy laws. This request will pay to build the system in a test environment, test and refine the system, train providers to use the new system, and launch it.

To determine the functionality needed and propose a design for the UDS data system, DOH staff have completed extensive research that enabled the agency to develop recommendations about the business functions of such a system over the past two years. DOH staff developed a business case, conducted key information interviews with a wide variety of stakeholders (pediatricians, early intervention specialists, early education providers, and parents), completed a legal analysis with the help of the Attorney General’s office to document how a system like this could function across the different sectors of health and education, and worked with IT experts to create a conceptual diagram and the system business requirements. Lastly, DOH staff worked with an IT business analyst and internal DOH IT experts to estimate the cost of building and maintaining the UDS data system.

Staff explored other approaches, including utilizing existing screening and intervention data by other systems, or purchasing an off-the-shelf UDS data system. However, these options failed to meet the needs of the stakeholders involved (early learning providers, healthcare providers, social service providers, educators, and families).

In fall of 2017, DOH submitted the UDS data system into the inter-agency HITECH 90-10 Medicaid Match program, which would significantly reduce the cost of building the system. This application was approved in April of 2019. It is expected that the UDS data system will remain in approved status for 90-10 Federal to State Medicaid Match through September 2021. The state currently has the opportunity to build this system at a significantly reduced cost (savings of $1,460,000 in FY 2020 and $547,000 in FY 2021). In order to take advantage of this, DOH must be able to complete construction of the system by fall of 2021. After that point, it is unclear what Medicaid matching would be possible.

Assumptions and Calculations

Expansion or alteration of a current program or service:
The UDS data system would be a new to the Department of Health and builds on several years of work
to increase screening, referral, and early intervention services for developmental and behavioral conditions among young children.

These funds would be used to leverage available federal match dollars to create, test, implement and maintain a Universal Developmental Screening database that would align with agency goals regarding interoperability needs so that the system can exchange information with other data systems containing child health data (e.g., the IIS, Clinical Data Repository, Child Health Intake Form Automated System, and Birth Defects Surveillance System).

**Detailed assumptions and calculations:**
The UDS data system developmental costs are one-time. The request would pay to build the system in a test environment, test and refine the system, train healthcare providers to use the new system, and launch it.

The proposal also includes an ongoing cost for an FTE to maintain the database, provide technical assistance, coordinate with HMG, provide training, etc.

**ONE TIME COSTS for UDS**
In 2016, staff contracted with a Business Analyst to design the system and provide cost estimates for the build. We have used this estimate with a modest adjustment to account for increased interoperability needs so that the system can exchange information with other data systems containing child health data (e.g., the IIS, Clinical Data Repository, CHIF, and BDSS). The estimate is $1,622,000 in FY 2020 and $608,000 in FY 2021 to build and test the system and include personnel and IT contracts. FY 2020 includes 1.2 FTE and $1,500,000 in IT contracts associated with the build, FY 2021 estimate is $608,000 and includes 1.0 FTE and $500,000 in IT contracts. However, these costs are eligible for up to 90-10 federal to state match. Therefore, DOH only requests state funding of $163,000 in FY 2020 and $61,000 in FY 2021 for these costs for a biennium total of $224,000. The cost savings under the 90-10 federal to state match are $1,460,000 in FY 2020 and $547,000 in FY 2021.

**ONGOING COSTS for UDS**
Ongoing costs for operating and maintaining the system and customer interfaces are estimated at $2,230,000 per biennium. The breakdown is as follows:

9.5 FTE ongoing for staffing and maintenance of the UDS program at a cost to the agency of $1,101,000 per FY. This includes staff to provide ongoing customer service for system users, including coordination and follow-up services, clean data and data analysis support, database management, and an epidemiologist for data analysis and program evaluation. Hiring will be phased, beginning in FY 2022.
This also includes hosting and maintenance costs for the contractor at $200,000 per FY. Maintenance and on-going program costs are not eligible under the 90/10 and DOH is asking for the full $2.2 million per biennium.

Total cost for FY 2020 $162,000, FTE 1.2; FY 2021 $61,000, FTE 1.2; FY 2022 and ongoing $1,101,000 per FY, FTE 9.5.

Workforce Assumptions:
See FNCal attachment for FTE detail.

Strategic and Performance Outcomes

Strategic framework:
This proposal is linked to the Governor’s priority for healthy and safe communities by ensuring children are screened for developmental conditions. Data suggest that screening and early interventions improve health outcomes and mitigate the negative impacts of developmental delays. The proposal also relates to the priority for a world class education because a successful screening, referral, and early intervention system improves children's school readiness and education outcomes. The proposal also supports the agency strategic plan of the Healthiest Next Generation (HNG). HNG aims to “ensure all children have appropriate developmental screenings and access to services.” This is exactly what this proposal aims to accomplish. This would increase agency funds by $223,930 in the first biennium and $2.2 million in the 2021-2023 biennium utilizing new General Fund State dollars.

Performance outcomes:
This proposal will support Results Washington Goal 1.1c: Increase the percentage of infants and toddlers with developmental delays who substantially increase their rate of growth in social-emotional skills from a baseline of 57.50% in the 2012-13 fiscal year to 67.25% by December 2019.

By ensuring all children are screened and, where appropriate, provided early intervention services, we can help achieve this goal.

Other Collateral Connections

Intergovernmental:
None.

Stakeholder response:
Some parents may be uncomfortable with having their child’s UDS information in a statewide database. DOH believes that by being transparent in the use of the data and the security of the data, along with the added conveniences DOH intends to build into the system, (e.g. can access immunization records at the same time as UDS information and easily share information with child care as well as health care
providers) DOH can alleviate these concerns.

This request is closely linked to services and supports that would be identified through developmental screening. There is a broader need to coordinate services that address the social determinants of health, but the UDS database will be more narrowly focused. Pilot sites should have the ability to do an assessment of effective strategies for connecting existing referral systems, (e.g., 211, Within Reach, Child Care Aware, Healthcare) which would be valuable and informative to policy conversations on the broader state infrastructure required.

Furthermore, this proposal would potentially reduce disparity gaps and improve outcomes for priority populations. This proposal would have a positive impact on communities of color. The UDS data system would serve all children regardless of a child’s socio-economic status or other factors, it would help improve health equity and decrease health disparities. Children living in poverty may be at a greater risk for developmental delays. Therefore, early periodic screening may assist in identifying delays that may be mitigated by early interventions. According to a 2015 HHS Author Manuscript, “racial/ethnic and language disparities exist in the diagnosis and treatment of early childhood [developmental and behavioral] conditions. For instance, compared to other children, African-American and Latino children are less likely to be diagnosed with an autism spectrum disorder (ASD), and are more likely to be diagnosed at older ages and with more severe symptoms.” Ensuring all children are screened will help close that diagnosis gap, and providing support to link those identified with early intervention services will help children achieve their greatest potential.

**Legal or administrative mandates:**
None.

**Changes from current law:**
None.

**State workforce impacts:**
None.

**State facilities impacts:**
None.

**Puget Sound recovery:**
None.

**Agency Questions**

Did you include cost models and backup assumptions?
Yes.

**Reference Documents**
IT Addendum

Does this Decision Package include funding for any IT-related costs, including hardware, software, (including cloud-based services), contracts or IT staff?

Yes

1F Create Developmental Screening Tool IT Add.docx