LTSS Trust Commission Feedback Sessions Summary
Extending Coverage to Individuals Who Became Disabled Before the Age of 18

Three feedback sessions were held in September 2020 to engage affected stakeholders for the Long-Term Services and Supports Trust Commission's recommendation to the Legislature or the appropriate Executive Agency on whether and how to extend coverage to individuals who became disabled before the age of 18. Individuals from the following organizations were in attendance, along with DSHS staff and one LTSS Trust Commissioner.

- Arc of Washington
- Developmental Disabilities Council
- Developmental Disabilities Ombuds
- People First
- Self Advocates in Leadership (SAIL)
- Traumatic Brain Injury Council
- Washington Association of Area Agencies on Aging
- Washington Business Association
- Washington Initiative for Supported Employment (WISE)
- Washington State Independent Living Council

The sessions introduced disability and business stakeholders to the intent of the Long-Term Services and Supports Trust in comparison to the existing landscape of services for adults who became disabled prior to the age of 18. Stakeholders strongly recommended extending coverage to workers who became disabled prior to the age of 18, which would require a statutory change. The following concerns were discussed regarding the lack of LTSS Trust coverage for people who became disabled prior to the age of 18, including concerns about disability not being defined in the statute.

Solvency and Intent

The original intent of the LTSS Trust Act was to provide insurance for a future risk and address the needs of the vast majority of older adults who would not be able to afford long-term services and supports in their senior years. Utilizing the LTSS Trust to fund an existing need requires additional actuarial modeling to understand the impacts. Actuarial modeling on the current LTSS statute requires a 0.55% premium to cover the expected cost of services (assuming the SJR8212 ballot initiative passes; otherwise a 0.66 premium).[1] In September 2020, a draft actuarial analysis indicated that to cover this population, the premium rate required would increase by roughly two percentage points to 0.57% (or if SJR 8212 fails, one percentage point from 0.66% to 0.67%).[2] This increase would require the average worker to

[1] Note: The statutory premium rate is 0.58%. Some margin will be needed between the premium required to cover expected costs and the statutory premium rate to cope with uncertainty around the range of factors that will drive program revenue and costs over the coming decades.

[2] It is assumed that extending coverage to people with disabilities that onset prior to age 18 will increase benefit spending in the early years of the program. If SJR8212 passes, the Trust will be able to invest its reserves in equities and earn a higher average return over the long term. The decline in reserve levels due to higher benefit spending (on individuals with disabilities that onset prior to age 18) in the early years would result in lower investment income over the long term as well. As a result, the effect on premium required to pay benefits over the long term is higher if SJR8212 passes than if it fails.

contribute approximately $5-$10 more per year to the Trust ($5 if SJR8212 fails, $10 if it passes). Modeling parameters will be referenced in the final report.

<u>Defining Disability</u>

With disability not defined in the current statute, exclusion of individuals disabled prior to the age of 18 has the potential to exclude even those workers whose childhood disability did not correlate with an LTSS need. The initial actuarial modeling assumed exclusion would apply only to individuals with an intellectual or developmental disability who would likely have had an LTSS need in youth that would continue into adulthood. This means that the cost of covering people with other disabilities in childhood (besides an intellectual or developmental disability) is already included in the 0.55 rate. This fact helps explain why covering the remaining disability population costs only a projected 0.02 percentage points. But with disability not defined in the statute, exclusion of people "disabled" before the age of 18 could extend to individuals whose disability in youth did not prove to be lasting or did not correlate with an LTSS need in adulthood, or to individuals who experienced an accident in youth from which they later recovered, as the scenarios below will render clear.

Uncovering records from decades earlier for these unclear situations for every individual who applies for LTSS Trust benefits in older age would be administratively extremely difficult and costly, as would uncovering records for a narrower definition, which would likely be proposed in agency rules. There are many different agencies that determine disability in youth, including the Developmental Disabilities Administration, the Social Security Administration, Washington Disability Determination Services, the Division for Vocational Rehabilitation, and others, especially if including diagnosed behavioral health conditions. Systems to uncover these records for every individual who applies, whose records are likely 50 years old or older, would need to be set up and uncovering these records to exclude people could cause significant delays in determining eligibility for LTSS Trust benefits.

<u>Inequity for Workers with Disabilities</u>

The LTSS Trust Act provides a benefit for workers who have paid in. Washington is one of the top states in the nation for employment of individuals with developmental disabilities. Although LTSS services in Washington are consistently ranked high in comparison to other states, there are gaps in Medicaid LTSS due to limited slots in HCBS waivers, federally required income and resource caps, and other restrictions on receiving services. The workgroup found excluding individuals with disabilities who have worked and contributed to be inequitable and shared significant concerns about this aspect of current law. Scenarios under the current statute that shed light on these inequities are highlighted below.

- *<u>Meet Calvin, whose car accident in youth has lasting impacts, yet he has not accessed formal services.</u>*

  Calvin has a car accident at age 17, which leaves him with a broken neck and traumatic brain injury. After months of rehab, he no longer needs assistance with activities of daily living, previously provided by his family. He leaves home and enters the workforce at age 18 as a customer service representative and begins paying .58% of his wages into the LTSS Trust. He has some trouble maintaining stable work due difficulties with attention, memory, communication, and difficulty controlling anger. Calvin also has chronic pain *that sometimes leaves him in bed for days, relying on support from his sister who lives nearby. He is not receiving any Medicaid LTSS services. Despite these challenges, Calvin has maintained work for at least 500 hours per year for the last three years and wants to continue working.*

If he applied for LTSS Trust benefits, DSHS would first need to determine whether Calvin was disabled prior to the age of 18, which would exclude him from benefits. Because Calvin did not access formal services, it would be nearly impossible for the LTSS Trust to obtain medical records from his youth to determine a diagnosed TBI or broken neck that had lasting impacts on his health. If Calvin's days in bed became frequent enough due to chronic pain, he could benefit from the LTSS Trust while he spends any resources he has to make him eligible for Medicaid. If the services he accesses through the LTSS Trust helps him develop strategies to manage his chronic pain, he could avoid using Medicaid and he would not be subject to spending his resources down, nor estate recovery for services used.

- *Meet Naomi, whose disability in youth does not correlate with long-term care needs in adulthood*

  Naomi is born deaf. She goes through the state Disability Determination System (DDS) as a child and is determined to be disabled. She received Supplemental Security Income (SSI) from Social Security for her disability as a child (her SSI would include Medicaid/Apple Health). Throughout her public schooling she was identified as disabled and received Individualized Education Program (IEP) services to support her disability. She went to college and received services through her state college's Student Disability Services Office due to her disability.

  On graduation with a degree, she qualified for and received employment supports through the state Division of Vocational Rehabilitation (DVR) due to her disability. She obtains full-time employment as a computer engineer and is very stable in her career. After becoming employed, Naomi loses her Social Security benefits due to her high income, so she no longer qualifies for Medicaid/Apple Health and has to seek coverage on the Health Benefits Exchange. She pays in to the LTSS Trust at .58 per $100 dollars for ten years due to her stable career and full time employment. At a point in the future she needs LTSS services due to issues that arise unrelated to her deafness. Naomi cannot access the LTSS Trust for resources to support her LTSS needs due to her diagnosis of "disability" as a child.

- *Meet Sofia, whose monthly Medicaid waiver service gives her access to personal care and Apple Health medical coverage*

  Sofia is a 22-year old with autism (diagnosed at age 8), whose mother has invested in the DD Endowment Trust Fund. She is eligible for DDA services and has been receiving personal care at home to assist with getting ready for school. Her mother pays a co-pay each month for $100 worth of occupational therapy services before Medicaid will pay. Sofia is starting a new part-time job with assistance from DDA employment services. She will pay .58 for every $100 of wages she earns toward the LTSS Trust. Her DDA services *are not impacted and she is establishing a work history that could meet the hours requirement to become qualified after three years of work.*

As Sofia earns income, she risks making too much money to continue to qualify for Medicaid LTSS. She may utilize Healthcare for Workers with Disabilities, which keeps her on Apple Health with personal care benefits without regard to income or resources, however, her occupational therapy benefit is only available if she does not exceed resource limits. If she had an accident that prohibited her from working, she would no longer be eligible for HWD. If LTSS Trust coverage was available, she could use it to continue occupational therapy and her mother would not have to pay $100 toward her care each month, nor would Sofia be subject to estate recovery. Although $36,500 is a limited benefit, she has worked and earned it like any other Washington worker.

<u>Background & Relevant Law</u>

The LTSS Trust Statute (RCW 50B.04) requires the LTSS Trust Commission to provide "<u>recommendations on whether and how to extend coverage to individuals who became disabled before the age of eighteen, including the impact on the financial status and solvency of the trust</u>. The Commission shall engage affected stakeholders to develop this recommendation." These recommendations are due January 1, 2021.

RCW 50B.04.010 defines:

- **"Qualified Individual"** as a person has paid the long-term services and supports premiums required by RCW 50B.04.080 for the equivalent of either:
  - (a) A total of ten years without interruption of five or more consecutive years; or
  - (b) Three years within the last six years.
  - (In both cases a year of vesting requires at least 500 hours of work.)
- "**Eligible beneficiary**" as a qualified individual who is age 18 or older, residing in the state of Washington, <u>was not disabled before the age of 18</u>, has been determined to meet the minimum level of assistance with activities of daily living necessary to receive benefits through the trust program, as established in this chapter, and who has not exhausted the lifetime limit of benefit units.

Premium assessment: The Trust is an earned benefit based on social insurance contributions, or premiums. The initial premium rate is 0.58 percent of an individual's wages. Premium assessment begins January 1, 2022.

Eligible beneficiaries—Determination—Services and benefits.

- Benefit payments begin January 1, 2025.
- A qualified (vested) individual may become an eligible beneficiary by filing an application with DSHS and undergoing an eligibility determination which includes an evaluation that the individual requires assistance with at least three ADLs.