

Developmental Disabilities Life Opportunities Trust

c/o Ed Holen

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Invest In

LIFE



Growing Your Options

Developmental Disabilities
Life Opportunities Trust

Washington State Developmental Disabilities Endowment Trust Fund

Annual Report 2004

FROM THE CHAIR



In 1999, along with Margaret-Lee Thompson, George Walker, and many other advocates; we worked with the legislature to establish the Developmental Disabilities Endowment Trust Fund (Life Opportunities Trust). We were convinced it would meet a need recognized by many families that included a member with developmental disabilities. With George as its first board president, the Life Opportunities Trust came into being and grew steadily. As George's successor in the board presidency, I am excited by the opportunity to extend the Trust's benefits to many more whose lives can be helped.

Like others who helped establish the Life Opportunities Trust, I am the parent of an adult with developmental disabilities. I have worked alongside many other parents to advocate for supports to help adults with disabilities afford to live a fuller life than SSI and Medicaid provide. We are very grateful that Washington state legislators, spearheaded by former Senators McDonald and Wojahn, provided this option. We are determined to make sure every person who is interested in the future of a child or an adult with developmental disabilities hears about the Life Opportunities Trust and has an opportunity to enroll.

The Life Opportunities Trust is doing well. Keeping management costs to a minimum and making the enrollment process as user friendly as possible have been keys to the Trust's success. This has been made possible largely because of the dedication of the Developmental Disabilities Council staff and the Arc of Washington staff, who each play a valued role in the successful administration of the Trust.

Enrollment is continuing to grow. The Arc employs a small, dedicated staff to explain the benefits of the Trust and provide "hands-on" help for families during enrollment. The only problem is that the staff can only reach and help a small number of new families each month. To this end, the Board is exploring new methods to expand the Trust's ability to get information to families and facilitate enrollment without adding to staff. Among the ideas are: producing a DVD or video presentation that describes the program as well as a web-based, step-by-step enrollment guide to help families complete required documents. Another innovation we are considering is a program to encourage financial advisors to provide information about the Trust to their clients; as well as links to foundations and other organizations to assist our efforts to expand information on the Trust's availability.

I am very pleased with last year's performance by the Trust and expect to report even better results in our next annual report.

TRUST FUND CONTINUES HISTORY OF GROWTH, POSITIVE RESULTS

“We’ve come a long way these past five years, and we have even more exciting plans for the future,” said Trust Fund Administrator Ed Holen of the Developmental Disabilities Council. “Success is the result of dedication and hard work by many people from the program’s earliest days.”

First, skilled advocates and strong friends in the legislature led to authorization of the Trust and a generous investment of state dollars to be used as matching funds for early enrollees. The legislative action in 1999 was only the beginning for the special needs trust for people with developmental disabilities. Every year since then has seen important progress.

The arduous process of creating legal documents, establishing an enrollment process and getting the word out to qualified individuals and families took many months of hard work. There was a major challenge getting out the message that trust investments could be made for the future benefit of people with developmental disabilities without jeopardizing Medicaid or SSI funds.

While actively involved since the beginning, it wasn’t until December 2003 that the DD Council took over full management of the Trust from the Department of Community, Trade and Economic Development. Since then, the Council has worked closely with the Trust Fund Board Members, staff of the Arc of Washington State who are responsible for enrollments and the Washington State Investment Board to ensure the trust is well managed and yields positive results for enrollees. This coordinated team has also worked to ensure information is readily available and enrollment in the trust is as straightforward as possible.

To help with this goal, a website for the Life Opportunities Trust was launched, and a brochure and step-by-step handbook was published last year. Staff has also held seminars and informational events throughout the year for families to get more information and provided advice over the phone to people with specific enrollment questions.

Visit the DDLOT website at <http://www.ddlot.org> for more information.

“We are so pleased with the success of the fund to date,” said Janet Adams, Trust Fund Board Chair. “This trust is a rare opportunity and something every family with a child with a developmental disability should consider.”

Trust Board Members

Janet Adams, Chair

John Ederer

Ron Meltzer

Philip Ruggles

Margaret-Lee Thompson

Wanda Thompson

George Walker

ABOUT WSIB

The Washington State Investment Board (WSIB), created in 1981 to manage the long-term assets of the state, is comprised of 15 members – 10 with voting rights and five without. Its mission is to invest with integrity, prudence and skill to meet or exceed the financial objectives of those they serve.

In 2004, the WSIB invested \$57.25 billion dollars for 33 funds, including such major funds as 15 state employee retirement plans, four state insurance funds for injured workers, and 14 permanent and other trust funds. More than \$7.3 million is invested for the Life Opportunities Trust, which was placed under the WSIB investment management in 2000.



Solid Returns in 2004

In 2004, the Washington State Investment Board, responsible for investing both public and private trust funds, invested more than \$7.3 million for the Life Opportunities Trust.

Public funds (state money) and private funds (individual and family funds) are invested differently. Public funds have an investment mix of 22.5% fixed income, 12.2% U.S. equity, 24.1% cash portfolio and 41.2% TIPS portfolio. Private funds are invested 60% in stocks and 40% in bonds. The stock portion is expected to track the performance of the Dow Jones Wilshire 5000; and the bond portion is expected to track with the Lehman Aggregate Bond Index.

The Trust's public funds have posted returns of 6.2% since inception in June 2000, 6.5% for the past three years, and 5.7% for 2004. Private funds have posted returns of 9.8% since inception in July 2002 when families began making personal contributions, and 9.1% for 2004. Both sources of funds are outpacing inflation and 90-Day T-bills by several percentage points, yielding sound results for stakeholders.

WSIB objectives for the DDLOT are to:

- 1) maximize return at a prudent level of risk based on identified investment time horizons,
- 2) ensure sufficient income is available to fund the expected needs, and
- 3) invest in a manner that will not compromise public confidence in the program.

By the Numbers

Last year, the Trust welcomed 169 new enrollees, a 90% increase in a single year. Of those, 63 were Trust I accounts established by parents and guardians; and 106 were Trust II accounts set up by individuals with developmental disabilities. The total enrollment is 336, with 165 as Trust I accounts and 171 in Trust II accounts. Also, 29 additional people are on the enrollment payment plan, which allows them to make payments toward the \$600 enrollment fee while holding a slot for them when they have saved enough to receive the maximum of state matching funds.

Filling Fast

In 2000, the state invested \$5 million to cover the matching dollars for private contributions. The number of slots receiving state match for enrollment fees or private contributions is limited to the amount of the state's initial investment plus earnings. When these state funds are exhausted, enrollments may continue but without the currently available, generous match.

Currently, Trust managers estimate there are 900 to 1,000 total matching slots available. With 385 of those already taken or reserved as of March 1, 2005, the fund is approaching half full. Enrollment rates are climbing as more families learn about the Trust. The Trust is encouraging eligible people to complete their enrollments as soon as possible so they can take advantage of the 100% state match of the enrollment fee and the 25% state match of private contributions.

"We're filling up quickly, and unfortunately when we're full many families will lose out on this great opportunity," said Deputy Trust Administrator Clare Billings of the DD Council. "We are continuing to try and reach families to help them learn more about the Trust and to encourage them to invest for the future needs of their children."

"Never has the early-bird-gets-the-worm analogy been so appropriate," said Janet Adams, Board Chair. "Of course we will look for additional ways to add value to the Trust, but we can't be sure that we will ever have a way of getting families such a tremendous benefit as the match now provides."

| By the Numbers | 2004 | Total |
|-----------------------|-------------|--------------|
| Trust I | 63 | 165 |
| Trust II | 106 | 171 |
| Total | 169 | 336 |



DISBURSEMENTS AND HOW FUNDS MAY BE USED

Financial advisors all say investing is meant to be a long-term endeavor. It takes time for investments to grow, which is why it's best to start early.

The same is true for investments in the Life Opportunities Trust. The fund was created to help families with individuals with developmental disabilities save money for the future without negatively affecting a person's asset levels and risking the loss of Medicaid or SSI funds. Also, some individuals have set up Trust II accounts because they've received money from a legal settlement or have received gifts of money that would put their SSI or Medicaid eligibility at risk.

While the intention of the fund is to create a resource for future support, many individuals find they have special needs now. Several people have used their private contributions for medical needs. One person was able to purchase a special hearing aid that Medicaid did not cover. Another, who was transitioning to a new health insurance plan, lost his prescription coverage for a short time and was able to use Trust funds to pay for an emergency supply of critical asthma medication. Still another person used the money to pay for a root canal.

Other people who have taken early disbursements have used the money for a variety of things like furniture, community activity fees, pre-paid funeral arrangements and bills like cable television or telephone charges that are not considered "food and shelter" expenses under SSI.

All funds dispersed come from private contributions because none of the enrollees

are fully vested. In addition, the corresponding state matching funds are also removed from the individual's account.

Changes in SSI Rules

The Life Opportunities Trust operates under Federal rules for special needs trusts. To comply with these rules, all disbursements must go through a determination process. Funds cannot be used to pay for things that another resource, like insurance, SSI or Medicaid should cover. This has created some challenges in the past because SSI is meant to cover food, shelter and clothing. As of March 9, 2005, a rule change at the Social Security Administration allows trust holders to use their private contributions to purchase clothing, which was not an option previously.

"While we want to encourage all enrollees to consider disbursements carefully, this rule change will help," said Patti Bell, Trust Fund Manager with the Arc of Washington State. "Most people wouldn't dream of paying for food, shelter and clothing for \$564 a month, yet that is what people with developmental disabilities have been expected to do. Allowing clothing purchases from Trust funds will provide some needed relief."



WHY YOUNG FAMILIES INVEST

Investing in the Life Opportunities Trust has special advantages for families with young children or pre-teens. Not only do younger families have more time to allow their investments to grow, but also they can use these funds for school-to-work transition assistance.

Families investing the minimum amounts when a child is young will have Trust resources available to pay for some or all of the transition services a child will need when he or she graduates from high school.

“With thousands of students waiting for employment dollars and a tremendous state budget deficit year after year, there are simply no guarantees transition will ever be adequately funded,” said Lori Flood of Bothell “That’s why we invested in the trust now while our son Christopher is younger (age 14), so we can be sure he will get the help he needs when he needs it.”

For enrollment or account information, please contact Patti Bell at 888.754.8798.

LIFE STYLES

Chrispins Set Up Trust for the Treats

When Jim and Rita Chrispin of Olympia heard the Legislature in 1999 was working on a bill to establish a trust fund for people with developmental disabilities, they were eager to get involved. The long-time advocates were already thinking about the future for their son Alex, 23, who has a developmental disability. They weren’t quite sure what to do about investments; and planning for when they were no longer able or alive to care for Alex was a difficult task to approach.

“We were concerned because you can’t leave anything to your children or it may jeopardize their SSI,” said Rita. And while Jim and Rita, who are 59 and 53 respectively, have plenty of time to plan for the future, they wanted to do something early to help ensure Alex had enough money for the special things that make life particularly enjoyable for him.

For example, Alex has an affinity for Mylar balloons, magazines and trips to McDonald’s. The SSI money he gets goes toward food and shelter. Mom and dad buy the little treats he enjoys now, but when they are gone, the money for these treats will not be available without a special trust fund.

The Chrispins knew that they could hire a lawyer to set up a special trust on their own, but the Life Opportunities Trust made it much easier for them to invest. And with state matching funds, the Chrispins are able to leverage more dollars with their investment.

“This was the right thing for us to do – prepare for when we’re not here,” said Rita. “Our family is in Ohio and Indiana. There is no one here to take care of Alex when we’re gone. But we know that through this Trust, the money will be there to provide him with the little things he likes.”

The uncertainty of life inspired the Chrispins to set up a Trust account long before Alex needed it. They invest about \$25 a month and add extra money when they have it. Knowing the money will grow and be there for Alex gives the Chrispins a strong sense of security.