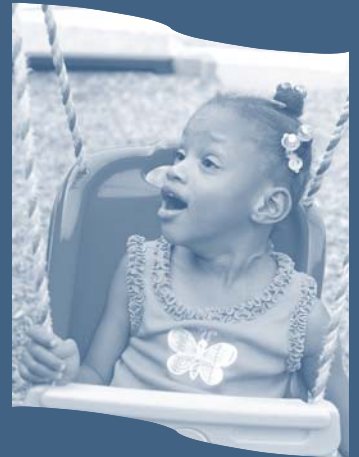


A Troubling Tale:



*Results of Washington's
No Paid Services Caseload Survey*



January 2012

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Recently, the Washington State Developmental Disabilities Council (DDC), with the support of the DSHS Division of Developmental Disabilities (DDD), conducted a survey of individuals on the DDD "No Paid Services Caseload." These are people who are eligible for DDD services, but don't receive a paid service for a variety of reasons. They are the major part of the great "unserved" DD population.

Survey results are alarming. The majority (56%) of those who responded to the survey said they need a service right now. The most requested service is respite care, the primary inexpensive service in the Individual and Family Services (IFS) Program, which is poised for suspension for the second time in a

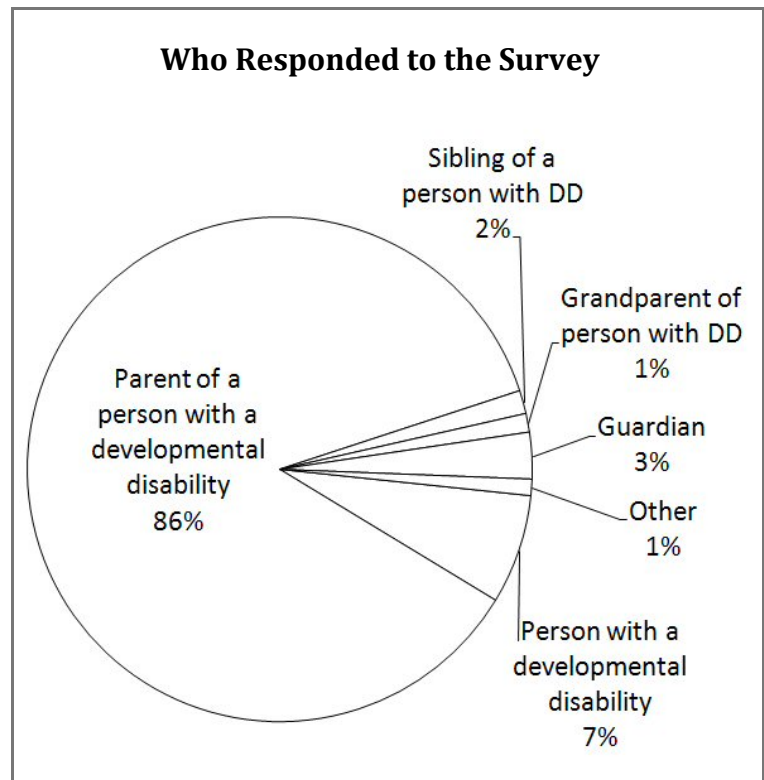
year. The loss of the IFS Program will result in an additional 1,000 people joining the ranks of the "unserved". As families are increasingly tasked to provide all financial, physical and emotional support for their loved ones with developmental disabilities, a little respite from overwhelming care giving responsibilities is critical to family stability.

The No Paid Services Caseload (16,852) is a sizeable segment of the total DDD caseload of 39,000. Over the years, little attention has been given to this group and not a lot is known about them except for the fact that their ranks are growing. In addition, those on the No Paid Services Caseload no longer have a case manager because of a budget cut that took effect January, 2011. These factors led to the DDC's decision to learn more about this group of DDD clients through a survey and two focus groups.

Six hundred seventy people submitted responses to the survey questions (along with 40 pages of written comments). This is considered a statistically valid sample. The Council also conducted two follow up focus groups to learn more about how individuals with developmental disabilities and their families are faring with out DDD paid services.

On the following pages you will find some myths that are held about the No Paid Services Caseload and the findings from the survey that challenge these myths.

The revealed needs and concerns of the No Paid Services Caseload should be a call to action.

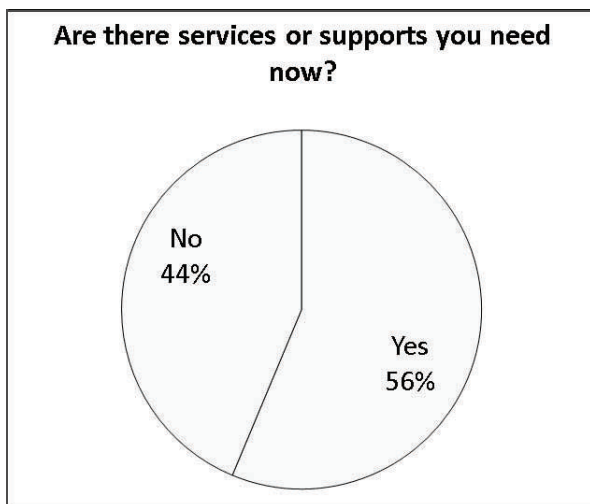


Myth #1:

People on the No Paid Services caseload are there because they need no services.

Our Findings:

In our survey, most respondents stated there are critical DDD services that they need **now**.

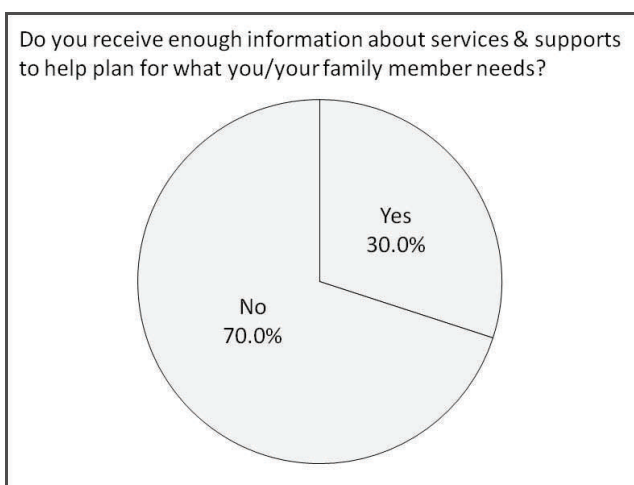


Myth 2:

People on the No Paid Services caseload are getting enough information to plan for themselves (or their family member with a developmental disability) both for now and in the future.

Our findings:

Only a minority of the respondents in our survey stated they received enough information about services and supports to help plan for what they need now. In focus groups, families also reported they need help in planning for the future.



"I feel alone in trying to figure out what to do for my daughter. I know that DDD is out there, but I haven't had any useful information from them or any assistance. I am left wondering WHAT does DDD do? I am exhausted and just keep trying to keep treading water with the daily needs of my child. Isn't there anything out there to help parents?"

-Survey respondent

"We are in information limbo. I am aware that my daughter may be eligible to receive services now, and in the future, but we don't know what they are."

- Survey respondent

"As aging parents it is difficult to do future planning or transitioning to independent living.... It is difficult to stay on top of the information and follow-up without a case worker to prompt, etc."

-Survey respondent

"I am concerned about my daughter's future and who will care for her when I am gone. I would like to have access to legal services so I can figure out a will and think about guardianship when she turns 18."

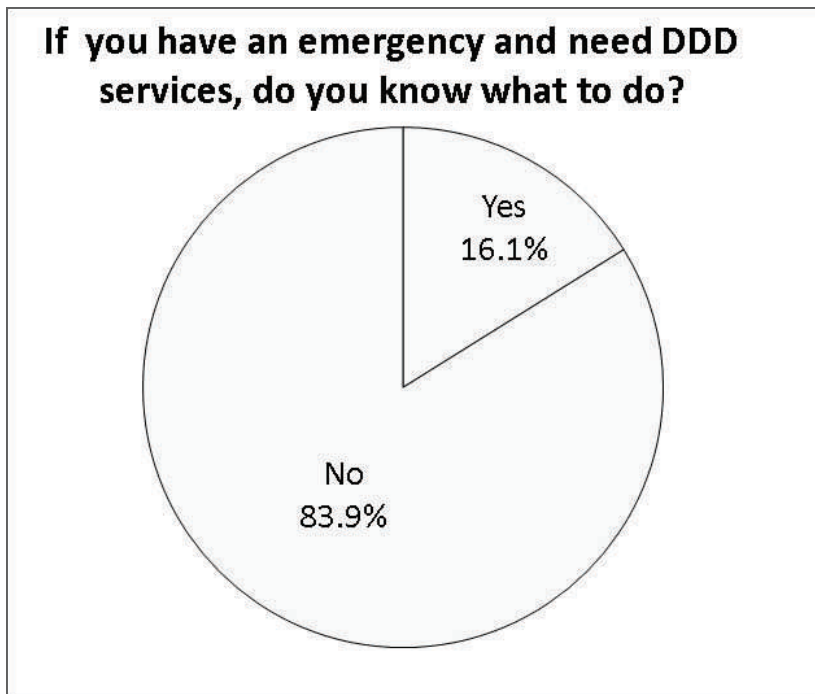
-Survey respondent

Myth #3:

If people on the No Paid Services caseload need emergency help from the Division of Developmental Disabilities, they know how to get it.

Our Findings:

Our survey shows that only a small minority of those surveyed knew what to do to if they needed DDD services in a crisis.



Additionally, in focus group sessions, some participants reported they contacted DDD for emergency services and didn't get a response.

Other participants stated that since they weren't getting anything from the Division anyway, they wouldn't even consider calling DDD if they had an emergency where they needed help.

"I have no clue how I could contact DDD in case of an emergency."

- Focus group respondent

"I called the number I was supposed to call to get help, the 800 number. It has been six months and I still haven't heard back from them."

-Focus group respondent

"My husband got brain cancer this year and is undergoing chemotherapy and will be out of work soon...We want information about getting respite for my son in case my husband needs emergency care as we don't have relatives around. I am the sole caregiver for both of them."

- Survey respondent

"My son has both Downs and Autism and I am the only other person in the home I NEED help, a break and I do not qualify. I am so tired and stressed. I call DDD and no one ever calls me back.."

-Survey respondent

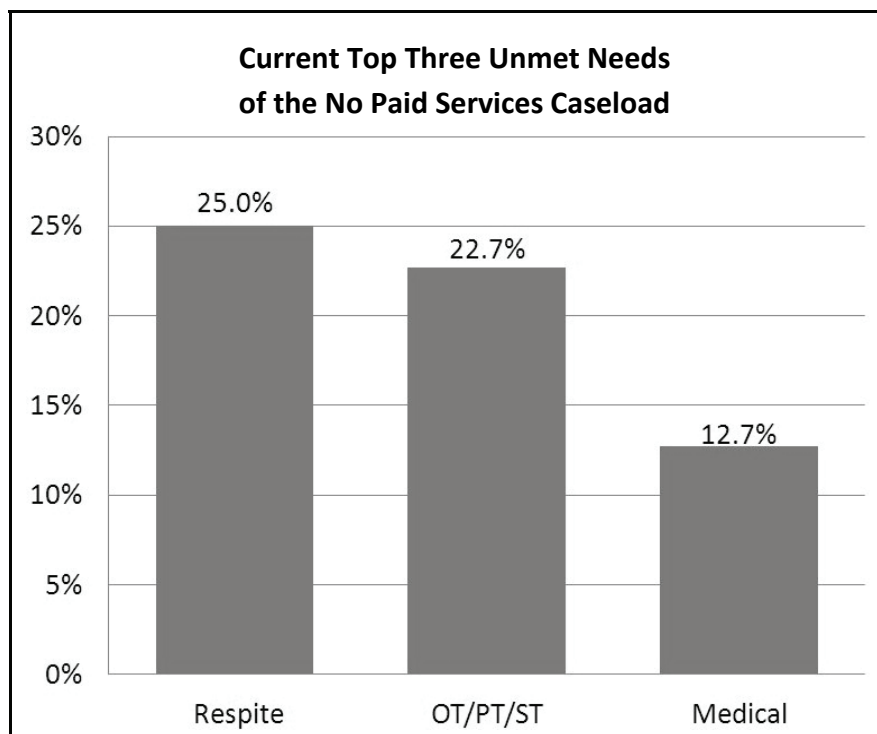
Myth # 4:

The needs of the No Paid Services caseload are so large that there is no way to even begin to meet their needs.

Our Findings:

In our survey, the most frequently expressed current needs were respite and assistance with medical and therapy costs. (See chart below)

Even a limited amount of respite helps families continue to provide care and helps families stay together. This benefits both families and taxpayers by reducing the likelihood that an out-of-home placement will be needed.



In our focus groups, parents expressed frustration with the unrelenting demands of caring for a child with developmental disabilities when no respite care was available. Even a couple of hours of respite a day was seen as a way to provide better parenting, both for the child with a developmental disability and other children in the household.

* Therapies—Occupational therapy, physical therapy and speech therapy.

“I have only had three hours away from my daughter since she was born five years ago Her behavior is so extreme (due to autism) that no one in our social network can care for her. This is taking a huge toll on my marriage.

- Focus group participant

“I think services need to be more uniform. Some families with low income get a large number of services while family like ours, where we make a little more money can’t even get the least expensive services like respite. We pursued emergency services three years ago during a very difficult time where we were considering putting our son in a home and still couldn’t even get respite, which would have been a huge help.”

-Survey respondent

“Respite care is a big challenge for families in general..... The only time we, parents, get a break is if one or the other of us takes the kids for an occasional evening (six per year) from family members. Our family members are also not overly fond of watching the kids due to their conditions.”

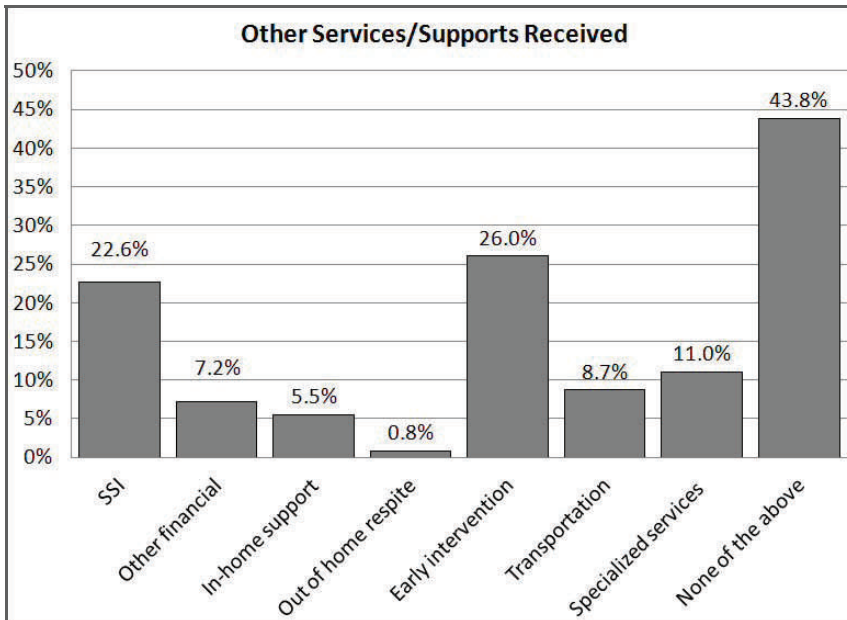
-Survey respondent

Myth #5:

People on the No Paid Services Caseload receive other services that help meet their needs.

Our Findings:

A large number of respondents indicated they did not receive other sources of funding typically thought of in conjunction with a disability.

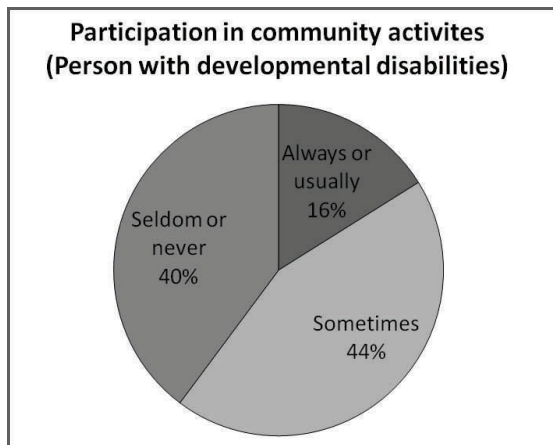


Myth #6:

Communities are helping to fill in the “service gap” by including people with developmental disabilities in community events and activities.

Our findings:

Regardless of community intention, most individuals with developmental disabilities and their families report they experience little participation in community activities.



“It would be nice to have a straight answer as to the possibility that my daughter may qualify for Social Security benefits. She went without glasses for three months because we simply could not afford them and insurance did not cover the cost. I ended up getting some help financially from family to pay for them. I feel somehow she is being left out of benefits that are owed to her. She not only has a vision impairment, she is also profoundly deaf.”

-Survey respondent

“Friendship groups for peer group interactions are needed in my area.”

- Survey respondent

“Community involvement with employment opportunities, health activities and other outside resources would be beneficial for everyone concerned.”

-Survey respondent

“We need programs, resources and volunteers that help build communities toward positive acceptance and inclusion of our special populations.”

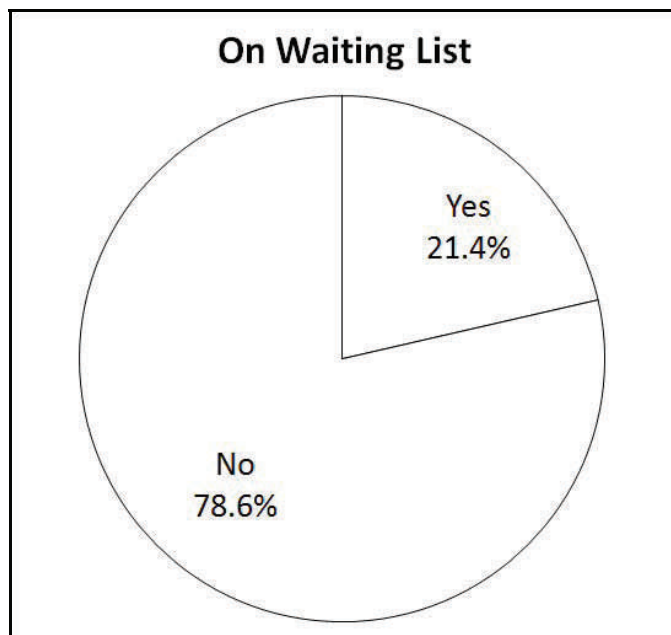
- Survey respondent

Myth #7:

People understand what being on the No Paid Services Caseload means.

Our Findings:

Families don't appear to know what being on the No Paid Services Caseload means. In the survey, a majority of respondents reported that they weren't currently on a waiting list. Focus group participants expressed the sentiment that they felt being on the No Paid Services Caseload implied they were on the waiting list for (an undetermined) something.



The 21.4% of respondents above think they are on a waiting list for:

- Individual and family support, primarily respite (80%)
- DD Waiver (40%)
- The Voluntary Placement Program (10%)

In reality, only about a third of the No Paid Services Caseload is on any waiting list.

“Our son was on the wait list for family support dollars from 2000 until it was no longer available in 2010. Being on a wait list for ten years is not a wait list.”

- Survey respondent

“We were approved for DDD, but it is currently frozen. The letter we received in the mail was very confusing.”

-Survey respondent

“I would like to know how far down the wait list we are.”

-Survey respondent

“I’m very uncertain what role DDD has in our son’s case. Are we on it and “just waiting” for services or are we no longer on DDD? We get varying answers whenever we have called. I would love more clarity from DDD.”

-Focus group participant

“I am feeling completely lost as a parent trying to help my son. At first DDD offered to help him but then we didn't hear back for more than six months. My letters were unanswered. I am confused. Why is the system this difficult to negotiate?”

-Survey respondent

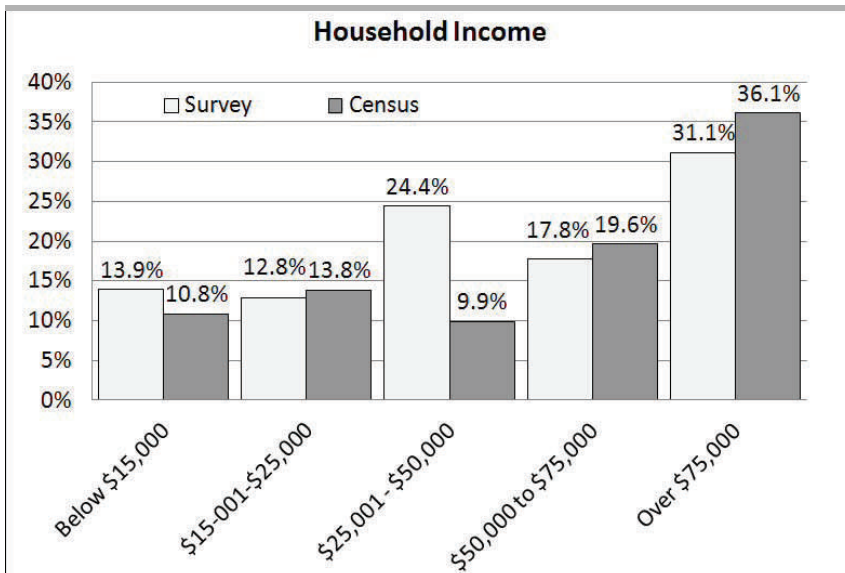
Myth #8:

Persons on the No Paid services caseload are not receiving paid services because of their higher income, so they don't need DDD services.

Our Findings:

While it is true that the families of people with developmental disabilities who are not receiving services report a higher annual income than those families who do (see chart below), their reported income is comparable to income figures reported for all families in Washington State.

Those on the No Paid Services Caseload also express confusion about when family income is considered for services and when it isn't. Some focus group members stated that they know families who are higher income but receive services because of being on a DDD waiver. They assume those families are getting everything they need, regardless of income. Others stated the only way they believed they could get help would be to impoverish their family so their family member with a developmental disability would be eligible for services.



At this point as far as I can tell, the only way I can get services is to divorce my husband, and maybe then we'll get help. It seems unfair that I would need to destroy my family to get a couple of hours of respite care a day."

-Focus group participant

"We think we are on the waiting list for family support/waiver, but have never received confirmation or information about when/if we might receive such funds. We are a PRIME example of a middle class family falling through the cracks. We make "too much" to receive any worthwhile support, but definitely not enough to cover all our son's medical expenses comfortably. We are strong advocates for social programs, but our personal experience has been abysmal."

-Survey respondent

About This Report

This report is a result of a collaborative effort between the Washington State Developmental Disabilities Council and the Washington State Department of Social and Health Services/Division of Developmental Disabilities. Data analysis and the report were completed by the Washington State Developmental Disabilities Council.

Special thanks to those who completed the survey and the focus group members who provided valuable information that supplemented our findings. Thanks also to those who worked behind the scenes to ensure the survey and report were completed, including: Janet Adams, Shannon Manion, Serena Segura, Lisa Weber, Donna Patrick, Linda West and the many advocacy and parent support organizations who encouraged individuals and families to participate.

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About The Washington State Developmental Disabilities Council

The Governor-appointed Washington State Developmental Disabilities Council (DDC) works to plan and promote comprehensive services for individuals with developmental disabilities through system change activities, advocacy and capacity building. For more information about the Council, visit the Council's website at: www.ddc.wa.gov

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