

DD Awareness Day

March 23, 2011

Introduction

- My name is Philip Pearson, husband of Sandy & father of William, 37, who is on the Medicaide Waiver Wait List
- I retired in 2000 from Bell Laboratories as a director of engineering and we moved to Palm Coast Florida in 2004 where we signed Bill up for services with APD. We have been waiting for 7 years now but understand that there are families with much more need than we have.
- Since it would cost about \$50,000 per year to support my son in a group home, I figure that I would need about \$5 million to generate that amount of income assuming 1% on the money. I don't have \$5 million and I expect that most families don't. The state needs to step in!

5 Messages

- Families already receiving services
- Families on the Wait List
- DD organizations
- Legislators
- & the Governor

Families Currently Receiving Services

- Don't get too comfortable with what you have - services are always vulnerable to attack by those more in need than you are.
- Join your local Family Care Council and Arc to get involved insuring that you may keep your services and help those on the waiting list receive theirs.
- Help those on the waiting list to see that you are allies in the fight to get and keep necessary services

Families on the Wait List

- Don't give up! There is hope. The legislature passed legislation establishing priority based on one aspect of need. This should at least help families with elderly caregivers.
- Don't get sidetracked by your own special problems, thereby splintering the effort
- Work with the FCC, Arc and DD council to identify other ways to prioritize, such as impact on the families so that legislation can be drafted to address this. There are families that have a critical need that are not addressed by the current prioritization strategy.
- Keep organizing and working with the FCC, Arc and DD council to keep the pressure on the legislature to provide required services.

DD organizations

- Work together! Put aside your self interests and work with the other advocacy and support organizations.
- United we stand and divided we fall.

Legislature

- Step up to the plate and work with the families that are here to identify and provide the services that are required. We elderly families need to know that our family members with DD will be taken care of when we die. And this means BEFORE we die, not sometime after.
- The problem is not insurmountable. Although, there are about 20,000 people on the waitlist, there are only about 1,500 people on the waitlist over the age of 45 (aging caregivers). This would cost about \$75 million.
- In my area, 12 which covers Volusia and Flagler Counties, there are about 500 people on the waitlist and 70 people on the WL over 45.
- Therefore, create a study committee for addressing the wait list, create an oversight committee (that includes family members) that addresses how our people are treated and how the monies allocated are spent and work to identify other sources of revenue to support our families with DD members.

Governor

- We elected you!
- We need some help!
- We need to know that our children are properly taken care of when we die!
- Now provide some leadership!
- We vote!