Colleen Wieck

From: MtnAspens@aol.com
Sent: Thursday, September 02, 2004 10:59 AM
To: admin.dd@state.mn.us
Subject: Please forward to: Colleen Wieck, Executive Director

FROM: Liz Gann, White Bear Lake, 651-777-6357 home 651-737-4005 work

SUBJECT: Waiver Cuts for the Disabled in Minnesota
Attachments include:
- * My letter to Governor Pawlenty
- * Response from Rep. Neva Walker, DFL
- * My response to her response

Is there anything that you know of going on to oppose this? This will inflict quite a hardship on the most disabled people in Minnesota, including my Daughter, Heather.

Regards,

Liz Gann
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Governer Pawlenty:

Heather is 24, and was born with profound brain and other organ damage, due to suffocation during the birth process. As a result, she is functionally blind, deaf, has constant seizures, has a head the size of a 6 month old child, cannot speak or communicate or understand communication, has scoliosis, cannot walk, is in a wheelchair, cannot feed herself, often will not eat and has a feeding tube, is not potty trained and is in diapers, is mentally retarded and functions at 6 months of age although she is 24 years old, and is only about 100lbs.

Yesterday, I received a letter that stated that Governer Pawlenty has withdrawn funding for the most disabled people of Minnesota, and for my daughter Heather, has withdrawn 25% of the funds we use to pay for attendants to care for her, and for special equipment.

Heather will never work. She cannot. She cannot even think a complete thought. She will never be able to take care of herself. All she needs is someone to care for her. She is effectively a 4 month old baby in the body of a 24 year old.

Most of her life, I have provided the 24X7 care for her, either myself, or paid someone else to do it while I work. I am her mother, Liz Gann.

In 2001, Heather finally qualified for a "waiver", which is state financial assistance given to adults who have families who forgo the state home/institution (and the associated expense, saving the state a whole lot of money) and instead, receive about 1/3 of what it would cost the state to support the individual, to live pay for their care. This money does NOT go to the family. This money goes to pay for care for the disabled person. The state has never paid me even one cent. In fact, I still pay for Heather's medical and dental insurance through my company, and the state only picks up the remainder of what my insurance does not cover, usually less than 10%.

I am only able to work because of this waiver. Otherwise, it is so expensive, I would either have to put her in a home (which would more than triple what it currently costs the state), or quit working and quit paying taxes and go on welfard so that I can care for her (which would more than quadruple what it costs the state to care for her).

I am saving the state $100,000 - $200,000 a year, yet the state wants to reduce the waiver it gives me by 25%.

That is simply NOT smart financial planning.
Nor is it humane to take away money from the most horribly disabled of our society.

What are the numbers?

Well, I'm not completely sure, but this is what I've heard.

Heather's 2003/2004 waiver was about $70,000. That covered her day program, her care so that I can work, respite care for her so that I can go away for a rest from time to time, and so that I can do things on the weekend (like shop for her food and provisions, go see a movie, ride my bike, etc. I am unable to leave her alone without skilled care). Otherwise, I provide all her care 24/7.

The state spends between $150,000 and $200,000 per individual in state run group homes or institutions.

The company I work for is still Heather's primary insurer, and the states MA program is secondary.

Now, Pawlenty has cut Heather's budget 25%.

What does he expect? Does he think Heather can care for herself? Does he want me to quit work and quit paying taxes and quit paying her medical insurance and go on welfare so that I can take care of her?

Does he want her to be put into an institution so that the state can DOUBLE or TRIPLE its expenditures for her care?

Did anyone think this new policy through?

The people who are lucky enough to have families who want to care for them, should not be punished like this.

We are the heroes. We are the ones saving money for the state. Yet we are the ones being attacked like this for doing the right thing, and taking care of our family members.

I understand that the state needs to stop spending money. But why take money away for the worst of the worst disabled people in the world?

I don't know a person who, when faced with the state's money problems, would agree to fund a sports stadium or a mass transit train, rather than properly care for the most horribly disabled people on this earth.

What have you accomplished by taking away services for a person who cannot think, constantly has seizures, cannot eat, cannot talk, cannot communicate, has to be diapered, cannot control her bowels, cannot walk, cannot defend her person against abuse, cannot tell people she is hungry or thirsty or being abused.

What have you accomplished?

These people didn't spend more than they brought in, the governement did. These people didn't lose sight of priorities, the government did. These people didn't put the state in the financial position it is in, the government did.

Why is the government now punishing the most handicapped and disabled of our citizens?

People who cannot think because they have damaged brains, cannot walk, cannot eat, cannot control their bodily functions, would die without 24x7 care?

This is who Governer Pawlenty punishes?

Don't tell me we are having budget problems and everyone must suffer.

These people have suffererd enough, and will suffer for all of their lives.

What comes next, reduce the amount we can pay people who assist these people to the point that only felons right out of jail will take the job? Then more abuse and rape of the disabled?

Is that where we are heading?

You need to adjust your priorities, and take money away from projects, not from the most disabled people in our society, not from people whe really CANNOT do ANYTHING to help themselves.

Don't kill my child with your budget cuts!

Liz Gann

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Subj: Dear Liz Gann
Date: 8/26/2004 2:51:25 PM Eastern Daylight Time
From: "Neva Walker" <rep.neva.walker@house.mn>
To: <MtnAspens@aol.com>
Sent from the Internet (Details)

Dear Liz: Thank you for sending me and the rest of the Health and Human Services Policy/Finance Committee members in the House of Representative a copy of your e-mail to Governor Pawlenty. I appreciate learning about Heather and thank you for sharing your story. During the last legislative session, I didn't support any cuts to disabled and plan to be back again in January to work with others to reinstate funding for our most vulnerable citizens.

I admire your strength and courage. Stay strong, Rep. Neva Walker

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Subj: Re: Dear Liz Gann
Date: 8/26/2004 11:20:45 PM Eastern Daylight Time
From: MtnAspens
To: rep.neva.walker@house.mn

Thank you so much. You are the first person to acknowledge my mail.

Even if you take the emotion out of it, and look only at the economic consequence of what has been done here, it makes no sense.

Families who keep family members at home already sacrifice so much, the pressure is so great, it is love that keeps us together.

But we already battle to keep our jobs amid the multiple health problems requiring doctors appointments, hospitalizations and surgeries.

To also take away the money used to pay a good wage to a decent personal care attendant, so that we family-member-care-takers can also earn a living, pay taxes, and pay our and our child's insurance, makes NO economic sense at all.

Please, if you have any influence, try to make these people see what they are doing.

If they take away $10,000 from my budget, that small amount could cost me my job, land my daughter in a state run home, and end up costing the state not only the amount it saved by my caring for my daughter, but also all the taxes I pay into the system, and all the health care costs.

My insurance company through work has paid over a quarter million, I would guess, for my daughters health care as the primary insurer....the state of MN, much much much less, in the 10's of thousands, if that much.

If the budget cuts cost me to lose my job, and my daughter has to go to a home, the state will spend over $150,000 a year, as opposed to $70.,000 a year. That does not sound like