

## Testimony RE: Complex Care Add On

I want to thank the Chairman and fellow members of the House Committee for the opportunity to speak to you today about the Ohio Department of Developmental Disabilities proposed budget, specifically the need for increased waiver reimbursement for complex care needs.

*My name is Francine Ris. I am here today as the parent and guardian of my 28 year old daughter with severe cerebral palsy. Her name is Amanda and she is a gift to me and the community. Although she is very bright, she is non-verbal, non-ambulatory, requires a feeding tube, and is considered total care. I have spent my life focusing on what Amanda can do and staying positive both for her benefit and mine. But today I think it is important for you to hear what Amanda cannot do to understand why I support a complex care add on for providers.*

Imagine how much time it takes you to get up in the morning and leave for work. 30 minutes? An hour? Then picture this... You wake up at home and are lying in a hospital bed enclosed on all four sides so you don't fall out. You make an unintelligible sound to get the attention of your support person so you can get your day started. They come in, chat briefly, change your brief and then you are left alone while they go to the kitchen to get your three morning medications ready which include a muscle relaxer. They return and take ten minutes to administer the meds through your feeding tube, but first apply medication around the g-tube stoma and change the dressing to keep the site dry and healthy. You point to the tv because, although you lack significant control over your body, you were blessed with the ability to partially use your left hand and arm. Your provider reads through the tv channels and shows, and you choose a program you enjoy so that you have something to listen to while your staff goes back to the kitchen and gets the next round of meds ready along with your liquid nutrition. About 20 minutes later your provider returns with a feeding pump attached to an IV pole that has two bags hanging from it. One bag has your breakfast in it and the other one lets the air out of your stomach so you don't get distended. They give you your next round of meds through your g-tube which include a prescription strength pain reliever and an anti-depressant. Then they hook up your feeding pump to your g-tube which runs over an hour. They already primed the line and set the rate and dose in the kitchen. While this is running, your provider gets your communication device since this is your voice. And then you talk about your wants and needs and go over your schedule for the day. Since you cannot program the device yourself, your provider takes on the responsibility of making sure that your device is programmed and updated daily. It's a pretty high tech device like the one that Christopher Reeve and Stephen Hawking use. You like it because it opens up your world but it takes a lot of strength and effort to use it. Sometimes it's easier to use your unique modified sign language to convey your message. Since you can't walk, sit up, or roll over on your own, your provider uses a ceiling lift to get you out of bed, first making sure that the sling is positioned perfectly so that you aren't crooked or chafed from the strap that got too close to your neck. Then you are lowered onto your manual or power wheelchair that has been custom formed and fitted to your body due to severe scoliosis and weakness on your right side. After you are settled in your wheelchair, your provider buckles your seat belt, unlocks the brake, adjusts the handle and helps you finish getting cleaned up and dressed. On certain days you use your shower chair first, but that's another story.

And imagine you are lucky enough to have a modified van so that you can go places including doctor appointments and therapies. You have to trust your provider will know how to operate it and secure the tie

downs to your chair or use an EZ lock to keep you safe to go places.

This is just a fraction of the life that my daughter, Amanda, lives with. As you can see, there is a lot of skill and knowledge that go into supporting someone with complex needs. The quality of life for someone with severe CP like Amanda will inevitably be affected by the quality of care. The need for more skills, education, and experience from the providers is paramount. Turnover is harmful. But it's a difficult job. So to ensure hiring these individuals and retaining these individuals to support this population is the reason I am asking you to support the complex care add on.

Thank you.

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# WITNESS INFORMATION FORM

PLEASE COMPLETE THE WITNESS INFORMATION FORM BEFORE TESTIFYING

DATE: March 14, 2017

NAME: Francine Kis

ORGANIZATION: \_\_\_\_\_  
(IF APPLICABLE)

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ARE YOU REPRESENTING: YOURSELF ☒ ORGANIZATION ☐

DO YOU WISH TO TESTIFY ON  
LEGISLATION (BILL NUMBER): \_\_\_\_\_

SPECIFIC ISSUE: \_\_\_\_\_

SUBJECT MATTER: DODD budget/complex care add on

DO YOU FAVOR ☒ OR OPPOSE ☐ THE ENACTMENT OF LEGISLATION REGARDING THIS ISSUE?

PLEASE GIVE A BRIEF STATEMENT OF THE GROUNDS ON WHICH YOU FAVOR OR OPPOSE SUCH ENACTMENT:

Increased waiver reimbursement will ensure hiring and retaining qualified providers for the most vulnerable population

WILL YOU HAVE A WRITTEN STATEMENT, VISUAL AIDS, OR OTHER MATERIAL TO DISTRIBUTE?

YES ☐ NO ☒

(IF YES, PLEASE PROVIDE COPIES TO THE CHAIRMAN OR SECRETARY)

HOW MUCH TIME WILL YOUR TESTIMONY REQUIRE? 5 minutes