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Gov. Chris Gregoire  
PO Box 40002  
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Dear Gov. Gregoire,

I have just finished reading the final draft of the recently released final draft of "The Feasibility Study for the Closure of State Institutional Facilities, Part III, Residential Habilitation Centers." It is wildly inaccurate, is based in ideology, not fact, and will result in the following sequelae:

- 1) It will **NOT** save money, contrary to the predictions of it's authors.
- 2) It **WILL** result in damage and death to the people moved during central central core facility closure. The attempted Fircrest closure of 2004 was instructive in this regard, and is discussed below.
- 3) It **WILL** result in lawsuits and multiple damages against the state of Washington, such as those that were awarded after the attempted Fircrest School closure.

To find out what is **REALLY** going on, continue reading.

The state of Washington, from about 1970, made an **ideological decision** (based neither then nor now on fact) that all mentally retarded people should live in the community, would thrive in the community, and could be better managed at lower cost in the community. This notion, coinciding as it did in time with the civil rights and other similar movements then nascent in the culture, won wide currency with many Departments of Disability across the country. Some major teaching centers, for example, The Yale Child Study Center, disagreed, but were shouted down in the general hubbub.

Since that time, with now generally acknowledged research on cost and clinical outcomes notwithstanding, Washington's Department of Developmental disability continues to cling to their original notion, prodded strenuously by effective parent lobbyists like Margaret Lee Thompson, with whom I am sure you are acquainted. ( The parents who are most active in the movement to close the state centers are most often parents of children who DO do well in the community, and are frequently Down's syndrome children and adults. Down's sufferers are statistically most often (although not always) mild or moderately retarded, and many often have shortened life spans because the disorder is often accompanied by significant heart malformation.) RHC residents, on the other hand, are primarily profoundly retarded, medically fragile, or have significant behavioral impairments. Community parents generally tell legislators that there are many RHC eligible people living successfully in the community. This is not true. There are a few, and the successfulness of their living is open to question. The people who NOW, as opposed to 15 or 20 years ago, live in the RHCs, are very difficult to care for, **and the cost is about equivalent in any setting.**<sup>1</sup> <sup>2</sup> Washington State's OWN DATA indicate this, and Norm Davis, one of the

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<sup>1</sup> see for example, Walsh, et al, "Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research," Mental Retardation, Volume 41, Number 2: 103-22, April, 2003. Updated in 2009 by lead author Kevin Walsh, with conclusions found to be valid.

<sup>2</sup> Mitchell, Braddock, and Hemp, "Synthesis of Research on the Costs of Institutional and Community-Based Care," Volume 17, Number 2: Fall, 1990.

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current study authors, has said so publicly. Washington's tenacious retention of their ideological position in the face of now well accepted financial data is telling.

In order to cling to their preconceived ideological bias, Washington State hires people and institutions to write it's reports just as a good attorney hires an expert witness: they know what the conclusion will be before they receive the report. Such was the case with the current authors, Davis Deshaies. Although it does not appear as part of the final draft, the preliminary draft showed at its conclusion a summary of states for whom they had previously done work. No surprise : all were states who were seeking to close their state centers.

Davis Deshaies' conclusions and data recitations are about what one would expect. In fact, one should be happy, I guess, that they even admit (recommendation #5, p 3.7 [the] "...community supported living provider network [would] require substantial refinancing and increased capacity in order to support people leaving the RHC's in an equal or better fashion." is at least a beginning. That they do not include any of the costs involved in the "upgrade" and "expansion" in the presented cost tables that detail the projected savings in the living situations is not a surprise. They do not figure in the much richer staffing patterns which they themselves indicate are essential in the care of RHC residents (page 3.11), nor the higher staff reimbursement rates which they themselves say are needed (page 3.46) either, nor the costs of the MYRIAD OTHER SERVICES WHICH ARE PROVIDED IN AN RHC BESIDES HOUSING AND BASIC DAILY CARE is no surprise either.

As with the HCBS waiver that supports community care, much of the cost of RHC based care is federally reimbursed. Currently, Linda Rolfe (Director of the Division of Developmental Disabilities) puts the federal reimbursement rate at 62.8%. (Public verbal communication.)

**Moving from an RHC has a high mortality risk for an RHC resident.** When Fircrest downsized in 2004, the mortality rate was 10%. DSHS denies this; in order to be counted as a death attributable to a move, one must actually die in transport. Even the one man who died 10 hours post transport from Fircrest does not count as a move related death under the DSHS system. I was so alarmed by what I believed then, and believe now, to be the actual mortality risk, that I PERSONALLY followed up on three<sup>3</sup> of the six deaths to make sure that they were directly attributable to the move itself, and did not occur incidentally. They did not; all were directly related. DSHS is correct when they say that they "died of natural causes" (they were not murdered) but again, all of the deaths were directly related to the move. **When people die, and you cover up that your administrative action or decision was responsible, have you carried your commitment to your ideology too far?**

Even when people do not die in moving, the results of the move itself can be highly damaging. In the course of writing this letter, I spoke to a professional guardian at Fircrest who sued on behalf of five of his wards after the 2004 Fircrest move under Washington State's Vulnerable Adults Act. Three of the wards were awarded more than \$100,000.00 each in damages; the others were awarded lesser amounts.

Once moved, death rates for RHC residents are much higher in the community that they would be had they remained in the RHC. In a seminal article out of UC Riverside, Strauss and Kastner<sup>4</sup> found that among 1,800 California institutional residents moved into community settings, mortality was 67% higher in the first two years following discharge than would have been expected had they remained in the institution, and 88% higher the year after that. This finding is similar to Linda Rolfe's (Director, Division of

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<sup>3</sup> I am now seeking data on the other three people who died after being moved; so far I have been unable to find out anything about these three individuals.

<sup>4</sup> Strauss, D. and Kastner, T. "Comparative Mortality of People with Mental Retardation in Institutions and the Community. American Journal on Mental Retardation, Volume 101(1), 26-40, 1996.

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Developmental Disabilities) publicly stated position that the success rate for moving people to private facilities was “very low” when the people involved had both severe physical and intellectual disabilities.

D. Davidoff (2009)<sup>5</sup> sheds light on the increased mortality and morbidity for transferred residents in his discussion about the great difficulty of recreating medical settings in different venues. He is exploring the reasons why two different medical facilities, both following the same federal protocols, achieve such variable results for infection control of indwelling blood lines and for response results for emergency ‘crash’ teams dealing with high risk patients. Davidoff would argue that EACH RHC has a distinct cultural setting, built over many years, of people with common skills, sharing for the most part a common set of values about the level of care to be delivered there, in a certain community. He would argue that one can not AND SHOULD NOT assume that that culture can be replicated anywhere else. He would be completely unsurprised that in transferring residents from RHCs to MULTIPLE community settings (even with the same programs) that the results are so variable and often so disastrous.

In the community, life can be quite dangerous for the ex RHC resident. Many newspapers have run exposes of real community conditions, particularly for the nonverbal. Some living situations are good, but sadly, many are not, and they can change without warning with the altered desires or life circumstances of the community home operator. A particularly heart wrenching expose ran in the Oregonian, on November 11, 2007. In an article entitled “After Fairview,” author Michelle Roberts found that one in five of those out placed after Oregon RHC Fairview’s closure in 2000 were physically abused or mistreated by their caregivers in community settings. I have on my desk now a letter from a sister and guardian detailing the abuse and injuries her severely retarded sister suffered in multiple group, foster, and adult care homes in Washington State before finally coming to live (successfully) at Rainier.

**In place of RHC’s, then what do Davis Deshaies, then, propose?** They propose an undefined sort of community care which will be at least as expensive as RHC care (and sometimes more expensive), and using the RHC staff as vaguely defined “community consultants.” Whatever for? The Virginia “Centers of Excellence” model is better.<sup>6</sup> RHC staff are very good at what they do--caring for the profoundly mentally and behavior impaired--why not let them continue doing what they are doing? It makes much more sense to open the doors of the RHCs to those in the community who need their services but who haven’t been able to obtain adequate care in their communities. Dental care is often particularly difficult to obtain, for example, because mentally retarded patients are often very frightened and require unique sedation before procedures, which needs to be combined with seizure and other sorts of medication in atypical dosages. If community homes and private family home members want to obtain “consultation” from RHC caregivers, that, too, could easily be combined with the ongoing care of RHC residents.

**To get rid of the RHC’s , which is their goal, what do Davis Deshaies need to do?** First, they need to stop using the RHCs for respite care, even though these are often the only appropriate, adequate beds available for the job. Forty out of Fifty states KEEP RHC’s, partly to provide this much needed respite and crisis care. Sending retarded people to jail when in crisis is not the answer; neither is forcing them into any open bed in the system. (Davis-Deshaies “Zero Refusal” policy. page 3.6) Even if these “Zero Refusal beds” are somehow “special,” the state has a poor history of discriminating carefully about who goes into which bed. And what if, God forbid, all of the available “special” beds were full? One thinks of the group home fire, for example, where a fire setter was placed in an empty bed in a community group home near Fircrest, setting a fire that caused multiple deaths. Or the case of James Cushing, a young man discharged from Rainier who had done well there, but who had panicked in the community, was

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<sup>5</sup> Davidoff, F. “Heterogeneity is not always Noise: Lessons from Improvement.” Journal of the American Medical Association, 302(23), 2580-2586, 2009.

<sup>6</sup> <http://www.nvtc.dmhrsas.virginia.gov/RCSC.shtml>

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bounced from group home to group home, finally had no place to go, and then killed a woman on Queen Anne Hill.

The people whose family and wards are in the state centers love their being there, and do not want to move. Moving them, if one uses honest figures, does not "free up" monies to help others. My sister, Margit, does not "use too many services" because she is greedy, she uses more services than someone with a lesser impairment because she is much more impaired. I LOVE IT that she lives in a large facility with lots of staff that can watch her and watch each other--she is much safer that way. Abuses and any neglect are quickly seen, reported, corrected. (Not that I can say this has happened with Margit--staff love her, and she loves them.) Margit can't tell me what happens, so unless someone else sees and tells me, I have no way of knowing what's going on. RHCs have real surveys, not "Quality Assurance" audits that talk about self esteem and similar issues. (Nothing against self esteem, here. Again it is an issue that is appropriate to consider with a less impaired population.)

1. **What is needed is problem resolution that deals with the real facts, real people, and not with ideology.** Please don't be fooled by a report that includes lots of fancy graphs that don't tell you very much when you really look at them, and leaves out all the numbers you would try to find out yourself if you had time to do a proper literature review. Don't be misled by false claims that "everybody's doing it." Everybody's NOT doing it, and even if they were, what Washington State needs to do is what's right, not what's trendy. Abraham Lincoln was right when he said, "If the end brings me out all right, what's said against me won't amount to anything. If the end brings me out wrong, ten angels swearing I was right will make no difference."

Thank you for your time and attention.

Sincerely yours,

Anne F. Eddy

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*I enclose as a kind of appendix a detailed description of my sister, Margit's, condition and care, in order that you may understand why she, and others like her, are neither nursing home eligible nor candidates for a group home, family home, or foster care. With a chronological age of 63 years and a mental age of 18 months, she is too "bright eyed" for an MR nursing home, while her physical condition is much beyond the scope of any usual community non medical facility. Except in an RHC, she (they) don't fit in anywhere.*

Margit has many medical conditions, all of which have to be managed with no input from Margit, not an easy task even for doctors who are experienced in this sort of medicine. She has a swallowing disorder, which necessitates that everything she ingests, even water, be thickened or thinned to to consistency of apricot juice. She has a seizure disorder, which is managed both "in house" and also by the UW Seizure Clinic neurologists, who visit the campus every three months. The Rainier docs have told me that our folks do badly with community management of their seizures: Rainier seizures are more severe, more difficult to manage, do not respond to the regimens commonly used on the community. Margit's disorder was caused by the birth injury that caused her profound retardation; I suspect that the same is true for most Rainier residents.

Margit is wheelchair bound, has no use of her legs, no reflexes in her lower legs, and requires two very able bodied and skilled people to do transfers. Soon, according to the Rainier physician who recently examined her, she may additionally require a special motorized sling. Many of these special adaptive devices can be fabricated at Rainier, and they make many similar devices because many people need them, and need modifications of those that are already existing. Currently, Margit uses a special toilet seat back (even though she is incontinent), and the existent device has been modified many times with more and more seat belts and padding because she can sit neither safely nor comfortably on a regular toilet seat.

In order that she retain for as long as possible the function that remains in very upper parts of her legs, back, and in her upper body, Margit uses a "Standing Table" prescribed by OT three times a week on her cottage. (OT also supervises the chair's use.) Margit can no longer bear weight, and so she "hangs" vertically in this device, which stretches out her spine and lower joints. She is not crazy about this procedure; to keep her entertained and co-operative, the staff paint her fingernails during the time required, which fascinates her. Margit, because of needing to undergo this procedure, is now the proud owner of more colors of nail polish than practically any other person on the planet.

As noted and implied above, Margit is incontinent and diapered. (It is not unusual in an incontinence management program to try to use the toilet , especially for bowel movements on a managed schedule.) She is also chronically constipated, which is medically managed, and also sometimes needs to be manually evacuated.

Again as noted above, Margit is wheelchair bound, and requires two person transfers. She has scoliosis, and her back is collapsing. One of her vertebrae is shattered, and she has multiple discs. She is in chronic pain, which will increase, and which can not be corrected. Managing her pain is a constant balancing act, in which the goal is pain relief on the one hand, but the avoidance of excessive sedation on the other. Also because she is wheelchair bound and her movement is limited, bedsores are a constant threat. So far her skin is intact and clear, which speaks volumes about the quality of nursing care she is receiving.

She has kidney disease, and is prone to urinary tract infections. Because she is difficult to bathe, she is bathed on a sort of a special mechanical lift, allowing thorough cleaning of her perianal area, which can not be achieved with normal bathing or showering. Rainier School obtained or constructed this lift for her, which greatly reduced her number of UTIs.

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She also suffers from essential hypertension, has had bilateral cataract repair, has survived bowel cancer, has neurologic hematomas, has had a broken leg (when she was ambulatory her balance was very poor, resulting in falls.) Her heart function is good, and she suffers from nothing from which I anticipate her death in the near to moderate term.

As you would expect from her mental age, she is non verbal. This means that she can not follow directions, can not respond to important information, for example, "Fire!" can report nothing that has happened to her, for example abuse, or serially missed physical therapy appointments.

She is almost unable to entertain herself, and is hugely reliant on the staff who care for her, who continually speak to her kindly (she doesn't understand the words, but hears the kindness,) scribble with her (she is not interested in the scribbling, but she loves the interaction,) give her magazines (she doesn't look at the magazines, but enjoys the motoric sensation of flipping the pages,) polish her fingernails. Several times a week they take her and her housemates in a specially modified van for rides; sometimes in good weather they will take her for rides on the three person tricycle I bought her which has had to be modified several times in the Rainier workshop to accommodate her always worsening physical condition. She "does her laundry," an extremely time consuming process in which she and a staff person very slowly put articles of clothing first in the washer and then in the dryer. I'm not sure she has any idea what she's doing, but I know she loves the cheering that accompanies the completion of the task. She also "cooks."

Margit also "works," or at least used to, at the Thrift shop run by Rainier school at Bonney Lake. Her job there was to sort jewelry. I have no idea whether she sorted any jewelry (all the time sheets I saw had to do with the number of feet she traveled in her wheel chair) but Margit LOVED work. She got to get dressed up in HER jewelry (five to 10 necklace strands were her absolute minimum) and see customers, some of whom would greet her by name. Although it was strictly forbidden by federal and state regulations, some would even rub her head, an activity which Margit particularly enjoys.

And what would Margit do without all of this manufactured activity? Nothing. She would sit in the special power easy-chair I bought her, hang her head, and grind her teeth. One hour after another, without end. She can not think of anything to do.