

Dear Members of House Education Committee:

I realize that it is important to keep statements to legislators brief. This document has vital information related to HB 2755. I made it as brief as possible, while attempting to convey essential information. I hope you will take the little bit of extra time to read it completely. It presents information that was absent in the highly one-sided testimonials of today's "stacked deck" hearing.

I was heartened to hear that the closure of OSB weighed heavily on the consciences of legislators who voted to close it. It was heart warming to hear the testimony of the sweet and bright young people who testified today about how vision services had benefitted them. Representatives were made to feel that the money was well spent. I can totally understand your need to feel good about your decision. That is only natural, but beware your need to feel good. I hope that you will remain skeptical and inquisitive. What was not explored was the mis-use of funds, the delay in funding, the loss of funds due to that fact, and how many students were NOT served by the fund.

All of the testimony except for that of Michael Wright and mine, was orchestrated by entities who received funding and were supposed to implement BVIS Fund: Regional ESD , ODE & OCB. Except for the students, we were the only testifiers who were not paid to be there. We have nothing to gain from our testimony. I only learned of the hearing the night before and the only time I had to prepare was while driving to the hearing. (This is part of the problem – stakeholders are not informed of important events that impact them. Students did not know of this hearing in order that they might testify - undoubtedly it would differ from those brought by ESD.)

Legislators have a difficult job in that you have to rely on others who are knowledgeable on the topic in question, in order that you will have (hopefully) all the necessary information about the topic on which you are creating law. It is important that you understand that you did not hear from a representative sampling of students today. As I recall, there were about 4 students who testified. Three of them were on the mildest end of the spectrum to qualify as visually impaired. Only one was blind, and a braille reader. He was very articulate and charming. As such, they represent, at most, 30% of students who are BVI. The remaining 70% have much more complex needs.

My question is, how have the other 70% fared and how have they benefited from the BVIS Fund? I would like to know how the remaining 846 or so BVI students in Oregon feel the BVIS Fund has helped them? To get a true picture of how the BVIS Fund has improved things for these students, all of the students' families should be sent a confidential survey, which is designed and administered by an independent source, knowledgeable in the needs of BVI students, outside of the Oregon educational establishment. If you truly want to know how effective ODE and ESD were in implementing the BVIS Funds, you will require an independent survey and it should be monitored more frequently than every 4 years. I would say yearly, or at minimum every two years.

Most of the hearing was devoted to hearing from people brought by agencies who benefit from the funds. We, who challenged that assertion, were restricted to a much smaller amount of time. There is no way I could provide you with this information in 4.5 minutes. The agencies were paid to be there. I took time off from my job, and my very busy life, to be there and to write this. As did Michael Wright. I mention this not to tout my saintliness, but so that you will give due weight to what I say as an advocate for BVI students, with no vested interests – unlike the testimony arranged by the recipients of the BVIS Fund.

Although ODE's representative, Julie York, openly stated that it took them 2 years to start spending the money in the BVIS Fund, the hearing did not explore all the funds that were lost because they were not used or made available to the majority students around the state. Some of the Education Committee latched onto the stories about how quickly and effectively the goal ball program was implemented, as though it reflected the entire BVIS Fund. But the goal ball story was the exception, and had relatively little impact on the majority of BVI students around the state.

OSB had long provided an extensive menu of skills-oriented summer camps, over a period of 6 weeks, for students who normally attended local schools. They were excellent and provided a rare opportunity for students to meet others like themselves. My son attended those for over 5 years and they were excellent. I have not heard of any of these camps having been done, since the closure of OSB. Clare and her mother testified as to how powerful and profoundly important it was to meet others like herself at camp. Unfortunately, Oral Hull does not do camps for people who are more disabled than Clare, as OSB used to do.

There was a gentleman who testified to his "model" sports program and the increase in participation of BVI students. What percentage of the 850 BVI students in Oregon were able to participate in this program, or even knew about it (which I believe was centered in the Portland metro area, not in local districts, contrary to the stated purpose of the bill)?

I can tell you that my son and I never heard about any of the sports camps or goal ball events, except after the fact. During the period after the bill was passed and the time that my son, Morgan, aged out of school district services, we had extreme difficulty getting appropriate services for him in the school setting. It took over a year for Morgan to get a device like the one that Jesus Ortiz has. And that was after I filed a complaint with the Office of Civil Rights. During that period, when he was in a classroom with other sighted students, he did not have a device. Most people cannot understand him when he talks. Since he was 4 years old, he has always used an SGD (speech generating device). The SGD allows him to communicate by speaking what he types on the keyboard. His device had broken and he had no means of communicating verbally when he went to school, (other than his speech, which they could not understand) because he was not provided a device for most of the school year. When students were given worksheets in class, there was no one there to read the braille he produced, on the antiquated Perkins Braille. Other students received immediate feedback on their answers, and were able to correct their information in the classroom. We were told that my son would have to wait 2 weeks for the vision teacher to read his work and give him feedback. As well, he would have to wait up to 2 weeks, to get his school hand-outs in braille. While other students could do schoolwork at home, because they did not require special equipment, my son was told that he could not have equipment at home. For this reason and more, I withdrew him from that classroom, when I saw that nothing would be changed and he was distressed. Some of his educational program involved the use of the computer and he was denied the request to have an audio screen-reader provided to him at home, so that he could access his computer (designed for the blind user, it reads the on-screen visual cues and allows commands to be made without a mouse). Finally, in November 2011, Morgan was provided the braille embosser that we had been asking for since September 2009. This is just one story, but I am sure there are many more. I think it is important that you hear them. This not more the norm than the exception.

It is also important for you to know that during the school year of 2009-10, when I was stunned by the failures of Morgan's school to provide the basic necessities for learning and functioning in the school setting, I got connected with others in the BVI community, through networking that occurred around opposition to HB 2834. When I posted a question on the email list, seeking resources, it turned out that Michael Wright was on the same email list. I did not know him, but he said he worked for NWRESD. He suggested that ESD could do an assessment, and that might help establish what my son's needs were. I dismissed his comment as yet another empty gesture from an ESD employee (as in my experience their "assessments" are limited by what they choose to provide). And anyway, we didn't need an assessment. We knew what he needed and were not able to obtain it. A couple years later, I learned he had been fired for offering me that advise (as well as similar advise to a couple other parents).

I later came to learn more about Michael Wright. Michael Wright, fresh from losing his job at OSB, came to NWRESD with enthusiasm for bringing services into the 21<sup>st</sup> century for blind students in Oregon. He quickly learned that ESD wanted no part of his suggestions and advocacy for blind students. He was shocked when he saw that blind students were unable to take the OAKS test because they were not provided with braille equipment that would allow them to take the tests

alongside their sighted peers. When he suggested that the state purchase braille embossing equipment that would remedy the problem, he was scoffed at. In 2011, when NWRES D realized that they might be in trouble for not implementing the BVIS Funds, they decided to go ahead and by that equipment he had recommended they buy. He also advocated for the acquisition of braille embossers to be placed in any schools where there are students who use braille, in order that they could get their school work at the same time as their sighted classmates, rather than waiting 2 weeks for a centralized location to produce the teaching material in braille for him. This equipment can be used by any teacher and does not require a specialized teaching degree. I was amazed to hear Angel from OCB, talking about BVI Funds to be used for a centralized location to produce braille, as if it is a new innovation. ESDs have used a centralized braille resource for years, called OTMC (Oregon Textbook & Media Center) and it is very inefficient. Localization of braille production, with current technology is what is needed.

Michael Wright also had suggested that the funds be used to purchase socket Bluetooth adapters for students to use with their refreshable Braille displays, so that information could be transmitted from a SmartBoard in real time. He suggested the use of the iPad for both blind and low vision students, since it was quite apparent that Apple had made them highly accessible for blind users. They had learned how accessible the iPad was back in 2008, when a technology fair was held at OSB. His suggestions were frowned upon, as it did not match the modus operandi of ESD.

One of the accomplishments, cited by Julie York of ODE, was the repair of some Perkins Braille machines. That made me chuckle inside. Those should have been thrown away or donated to some museums of antiquity long ago! Many students, including my son, find those antiquated machines onerous to use. The BVIS Fund should be used to fund contemporary equipment, not repair quirky outmoded equipment.

Many years ago, I asked NWRES D if there was something more user-friendly than the Perkins Braille, on which my son could produce braille. He had low muscle tone and it was hard for him to press the keys with the necessary strength. The Perkins Braille is like an antique manual typewriter (do you remember those?) and is very idiosyncratic. The user has to press the keys very hard in order to produce the embossed braille. I thought surely there must be an electronic version, on which one could lightly touch the keys and produce braille (a braille version of an electronic typewriter). NWRES D told me none existed. I didn't believe it and visited some out of state schools for the blind and found that there was, in fact, an electronic braille embosser that was much easier to use than the Perkins Braille. It was called a Montbatten Braille. In September 2009, I requested that Morgan's Montbatten Braille (that he had had since 1998) be repaired or replaced. This request was refused, until, finally in November 2011 NWRES D realized it needed to spend the BVIS Fund and purchased some braille embossers, which they allowed Morgan to borrow (cited above top of p 3) until he completed the program 7 months later.

During today's hearing, after I stated that the BVIS Funds were misappropriated when used to pay for students to go to an out-of-state school for the blind, Rep. Huffman stated that HB 2834 was for funding the OSB students and he was not aware of testimony during those hearings, of local students who had experienced inadequate services. If any of you missed this testimony, I hope you will listen to the recordings of the hearings. I myself heard a preponderance of testimony as to the inadequacy of local districts to serve students at the local level, and that was why we were assured that HB 2834 would help to remedy that problem. Indeed, it seemed to me that became the rationale for closing OSB – to distribute the funds from OSB across all students in the state.

A lot of the testimony that I heard today, extolling how the BVIS Fund had been used, was talking about things that should have been provided through other means anyway. What I mean is that if Jesus needed the refreshable braille PDA (personal digital assistant) to do his schoolwork alongside his sighted peers, his IEP team would have determined that. If the IEP team determined that, then they were REQUIRED to provide it. In order for him to do his schoolwork, he WOULD need such a

device. Therefore, it is a misapplication of funds to buy a student equipment that was required to be provided by his school district.

Someone else mentioned that the BVIS Fund was used to pay for the SWEP (Summer Work Experience Program) sponsored by OCB (Oregon Commission for the Blind). This too is wrong use of the funds. Angel Hall testified how the BVIS Fund paid for SWEP. And SWEP couldn't have happened without it. SWEP has been running for many years and funding has always been provided by OCB, long before the BVIS Fund came along. The point I am making is that it seems to me that there is some mis-use of funds in that the BVIS Funds should not be used to fund things that were already and should have already been funded through another pre-existing avenue. I think that is illegal. This is sleight of hand with funds – sometimes called “cost shifting”.

Clare Johanson and her mother lauded the Oral Hull Camp, which was the one thing cited as the most profoundly meaningful and helpful thing she experienced as a result of the BVIS Fund. Oral Hull has been doing those camps for years. It so happens that Michael Wright told Oral Hull about the BVIS Fund and suggested to them that they might be able to get financial assistance through BVIS, to help fund some students going there. But NWRES D did not create the program, they funded something that already existed.

About the Advisory Board – I think it was Angel Hall who suggested that someone from ESD should be on the board. I do not believe that is appropriate. The board should be independent of educational and other government entities who are implementing the use of the funds. Stevenson suggested that there should be one less parent on the board. I strongly disagree, especially with the reason he gave (“their emotions about their own child interfere with their objectivity”). I think representation of 2 parents on a board of 8 is a reasonable number, given that they know best (if it is a knowledgeable parent who stays informed) what the hurdles are for students and their families. However, I would like to note that Clare's mother, Laura, offered to be on such a board. She is the parent of a student on the mildest end of the spectrum of visually impaired. If a parent of such a child were on the board, you would need to have the other parent on the board be someone who has a child with multiple disabilities and complex needs. It is my understanding that 50% of the BVI students in Oregon are such students. There might need to be more than two parents, just to get a decent representation of the different levels of needs and challenges within the population.

If vision screening is removed from the bill, I would suggest that HB3000 include a provision that mandates insurance companies to cover the type of screening that is required, to determine visual impairment. Normally, insurance companies do not cover this type of screening. It's not the same as the screening where you read an eye chart.

One more thing that I would strongly recommend is that an independent advocacy group be created, comprised of dedicated vision instructors, such as Michael Wright, who can provide true assessments and recommendations of ways to help all blind students in Oregon, without fear of reprisals for living up to the ethics of their profession, as instructors of the blind and visually impaired.

Thank you for thoughtful consideration of this important matter.

Sincerely,

Therese Gorman-Steward