Testimony for HB1053

I am writing as a parent of two special needs children. My wife and I are both in favor of maintaining the ability of family to work as staff in the Self-Direction Program. In many cases, outside staff are unwilling or unable to work the hours that are necessary to support disabled individuals – for example think about the 2-3 hours first thing in the morning before an individual departs for school or work. If they need help with ADLs during that time, it is very difficult to find an outside individual who will come for such a short, early shift. In that case, family is often the only option to providing service to the disabled individual.

In addition, many families find that one or more family member is unable to hold down other employment due to the many demands (medical, scheduling, planning) that they are performing for the disabled individual. In that case, it seems only fair that allowing them to be a paid employee should be allowed. This situation is extremely common in the disabled community, because caring for a disabled family member is extremely taxing and draining. There are often disruptions to sleep schedules for the family member as well, due to medical or behavioral issues of the disabled individual.

For all of these reasons, we ask that you vote to solidify this right for families. It's already the rule, but voting it into a law will give families a breath of relief, for one less thing to worry about for the future.

Thank you.