



MEASURE: HB 2646
EXHIBIT: _____
H BUSINESS & LABOR
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SUBMITTED BY: Beth Kessler

February 19, 2015

To: House Committee on Business and Labor

From: Beth Kessler, Oregon Consortium of Family Networks

RE: Support for HB 2646 Amendments

Chair Holvey, Members of the Committee:

On behalf of the Oregon Consortium of Family Networks (OCFN), I would like to offer our support for Senator Chris Edwards' amendment to HB2646, enabling parents to access unpaid leave in order to participate in their child's disability support planning meetings.

OCFN is a statewide collaboration between seven networks of families raising children with intellectual and developmental disabilities and the communities in which they live and represents more than 7,000 families and community partners. For many of these families, disability supports are a lifeline that allows them to keep their children safe, healthy, and living at home. Each family has an individualized plan specific to their needs. This requires completing eligibility assessments, needs assessments, and finally annual planning. Each step has mandated documentation, conversation and timetables. It is not an easy process to navigate the systems these families find themselves directing, and yet it is the families' vision for their child that determines how available supports will be used. Their perspective is vital.

This process is a necessary burden, and with increased Federal regulations, the burden is growing. Community Developmental Disability Programs (CDDP) service coordinators provide case management for children's developmental disability services. They work with families to comply with Federally required deadlines while responding to the reality that parents may not be able to take time off work. This often means lunchtime, evening or weekend meetings, and still it can be challenging to manage this balance. Compliance with deadlines is not always possible and the burden on families to find additional time in already overwhelming weeks is harmful. In some cases, this even leads to gaps in services for these families.

As described in the Wingspread Report published by the Administration on Developmental Disabilities in 2011, "For individuals with intellectual and developmental disabilities (I/DD), the role of family is unique and often central in the support and care provided across the lifespan. Family members play key roles in identifying and securing opportunities for their family members to participate in meaningful ways within their community and ensuring access to self-determined lives."

Please support Senator Edwards' amendment so parent participation in annual disability planning for their children can have the same safeguards guaranteed other Oregonians.

Sincerely,

Beth Kessler, on behalf of the Oregon Consortium of Family Networks

