



# Protections

## For People with Developmental Disabilities

Working in Harmony with state legislators to provide protections for people with a developmental disability.



## Defend our Right to be Safe, Healthy & Protected!

**HB 2658/SB 6396** would ban PFAS chemicals from food packaging such as microwave popcorn and fast food as we want to keep toxic chemicals out of our children's food.

**HB 2793/SB 6413** would require manufacturers to stop selling fire-fighting foam that contains PFAS chemicals by 2020, greatly reducing the chemicals going into our water supply.

**SB 5448 will** create a policy that says school staff cannot require parents to put their child on psychotropic medications to participate in activities.

**HB 2558** would stop school staff stigmatizing students for attendance, academics or behavior; OSPI would review policy annually.

**HB 2767/SB 5155** would require that schools cannot suspend/expel children in grades K-2, and restricts removal for a day with conditions to plan return.

**HB 1539** would create Erin's Law, which would create a legislative task force to adopt model curriculum to prevent sex abuse of students in schools, especially important for special education.

**HB 2262/SB 6015** allows parents and siblings to receive damages for a person with a disability who is wrongfully killed, acknowledging that the person's life had value.

**SB 5547** expands the services the Office of Public Guardianship can provide to include Supported Decision-making, Power of Attorney, Payee Services.

A few families/guardians (for less than **700 people**) want a Residential Habilitation Center (RHC) placement because they think it is safer than a community setting (where about **80,000 individuals** with DD live); yet the opposite is true! The "**No Excuses**" and "**No More Excuses**" reports document repeated abuse and neglect in the RHCs just in a **one year** period of time. Documented incidents include people receiving no human interactions for hours at a time, being yelled at and ordered around by staff, malnourishment and choking because client's food does not meet swallowing needs. Though a physician is required 24 hours a day, staff often cannot contact one. There are also cases of medication errors, a near drowning, rape and death from improper medical care.

**OPERATING BUDGET: DO NO FUND** the \$21,649,000 requested by the Governor for replacing doors, carpets, vehicles, furniture and other items at the RHCs. It also includes more FTEs and funds to drive laundry back and forth every day between Fircrest and Rainier. The Legislature has added FTEs a number of times to fix CMS compliance issues, yet each year they are still out of compliance. It is time to stop pouring money into the RHCs and build up DD services in the community where there is more oversight and where study after study has shown that people thrive there. **DO FUND** the services for the 47 people who have asked to move out of an RHC and have had to wait because of lack of community funded services!

# Residential Habilitation Centers (RHC)

## Active Treatment: What Does That Really Mean?

### *Purpose of a Residential Habilitation Center (RHC)*

In Washington, there are four RHCs, offering Intermediate Care Facilities (ICF), nursing facility (NF) services, or both. Rainier School in Buckley, Fircrest School in Shoreline and Lakeland Village in Medical Lake are the three RHCs that have an ICF. Yakima Valley School is only a Nursing Facility. These RHCs (along with two others that have closed) were called schools because they were created in the 20<sup>th</sup> century for children with developmental disabilities, as they couldn't attend public schools. A short video created in 1951, Children Limited <sup>1</sup>, shows the origins of our RHCs. Children are no longer admitted and the RHCs no longer function as "schools". Over the years, the RHC residents, and residents' family members and guardians began to consider that the RHC is the client's home – a facility many have lived at into their twilight years.

However, in recent years, the Centers for Medicare and Medicaid (CMS) **has re-emphasized the "intermediate" aspect of institutional care.** That is, **it is the responsibility of the RHC not to house and protect people, but rather to be actively preparing them for leaving the RHC and integrating into the community.** This emphasis by federal regulators is changing the culture and practices in the RHCs. Staff now are being held accountable for engaging the residents in "active treatment", helping residents function with as much self-determination and independence as possible, preparing them to return to society. <sup>2</sup>

According to CMS: "Active Treatment (42 CFR 483.440(a)) refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. The individual's interdisciplinary team must produce accurate, comprehensive functional assessment data and prepare an Individual Program Plan (IPP), which includes opportunities for individual choice and self-management. The IPP must be directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible." <sup>3</sup>

In addition, "In 1988, when the current ICF/IID regulation was implemented, it was viewed as a great step forward in promoting a focus on the actual outcomes experienced by consumers. The field of DD is increasingly emphasizing supporting individuals in their own homes and communities, rather than placing people in facilities. In addition, services in virtually all States are placing increased emphasis on person-centered planning and person-centered services that focus on the preferences, goals and aspirations of each individual and on supporting them in reaching their personal goals." CMS says that the revised survey protocol actually gives facilities more freedom in the way it implements active treatment services. The survey now centers on the fundamental requirements that produce outcomes for individuals. It focuses on observations of staff/resident interaction and on interviews with residents which show the outcomes of active treatment. <sup>4</sup>

### *Active Treatment versus Specialized Services*

When a person enters an ICF, the IPP created for them must include an active treatment plan. For a NF, a Preadmission Screening and Annual Resident Review (PASARR) is done as well as a Level II evaluation. The PASRR considers community services first. Specialized Services may be included for "individualized" services not included in the NF daily rate. These services can include working on communication skills, feeding devices, mobility aids, a transition support specialist to help the person return home, habilitation, or long term care daily living supports like cueing and other individualized services. <sup>5</sup>

The State must either identify practically available types of services that will meet the Level II individual's needs, or not admit that person to NF. Services are delivered by providers specially qualified in DD and ordinarily are not the NF staff. They may help also facilitate transition out of the institution.

CMS mandates that **"states will comply with federal PASRR rules; persons with IID will be served in the most appropriate available setting, and if admitted to a NF, will be supported & served rather than warehoused. NF admission is permitted only if needed and if services and supports are available to meet the stated need."** <sup>5</sup>

Only a small percentage of people with DD would appropriately be placed in NFs. This group would include those individuals whose physical condition requires skilled medical care on an inpatient basis that cannot be provided in an ICF or in their home.. <sup>6</sup>

<sup>1</sup> <http://www.arctrustfund.org/About-Us.html>

<sup>2</sup> Developmental Disabilities Administration 040 - M2 - TA - ICF-IID Habilitation Requirements Agency Submittal: 2015-17 Final 2017 Sup

<sup>3</sup> [https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/ICFMR\\_Glossary.pdf](https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/ICFMR_Glossary.pdf)

<sup>4</sup> <https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/Downloads/R94SOMA.pdf>

<sup>5</sup> [http://www.pasrassist.org/sites/default/files/attachments/Specialized\\_Services\\_guidance\\_11Sep2013.pdf](http://www.pasrassist.org/sites/default/files/attachments/Specialized_Services_guidance_11Sep2013.pdf)

<sup>6</sup> [www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Paper-Based-Manuals.html](http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Paper-Based-Manuals.html), Publication 45, Section 4395

# PFAS in Fast Foods, Compost & Fire-Fighting Foam! HB 2658/SB 6396 AND HB 2793/SB 6413

**Working in Harmony** with state legislators to protect children and adults with developmental disabilities and not expose their often fragile immune systems to chemicals in their food and water.

**KOMO News**—by Connie Thompson, January 29, 2018

## Health advocates urge state to ban widely-used non-stick chemicals in food packaging

A bill under consideration in Olympia would ban certain non-stick chemicals that are widely used in food packaging.

The chemicals are man-made compounds called PFAS chemicals.

PFAS chemical are used to coat paper and cardboard so that food liquids and grease won't seep through the wrappings or containers.

Local consumer and health advocates say PFAS have been linked to cancer and other health risks. They say the same chemicals that make non-stick food packaging can stick to our food, and stay in our bodies.

When you eat popcorn that's popped in a typical microwave bag for example, local consumer and health advocates say there's a good chance you're also consuming toxic, non-stick chemicals used to keep the popping oils from leaking.

According to researchers at Toxic Free Future, a non-profit science and consumer advocacy group in Seattle, 100% of microwave popcorn bags recently tested likely contained perfluorinated non-stick coatings. Perfluorinated chemicals are part of the PFAS chemical group.

"They're the same industrial chemicals that are used in stain-proof coatings on your furniture and your carpeting or waterproof coatings on your jackets," said Toxic-Free Future spokesperson Ivy Sager-Rosenthal.

Perfluorinated chemicals are found in all sorts of food packaging, including muffin and sandwich wrappers, butter wrappers, french fry boxes and many take out food containers.

But health and safety advocates say the non-stick chemicals migrate from food packaging to the food- and pose a serious health risk- especially for children. And the chemical migration increases when introduced to heat.

Proponents of SB 6396 and its companion bill HB 2658, say laboratory testing has found the chemicals damage the liver and kidneys, cause developmental delays, and reproductive problems.

They want state lawmakers to ban PFAS chemicals in food packaging in Washington.

But whether it's microwave popcorn or other non-stick food packaging materials, representatives of the chemical industry call the proposed ban too far-reaching and the concern unnecessary.

Jessica Bowman is a spokesperson for the FluoroCouncil, which represents the fluorochemical industry worldwide. She testified at a January 29 public hearing in Olympia.

"We respectfully oppose this bill for the following reasons: The bill would restrict all PFAS unnecessarily and without full consideration of their actual use and safety," said Bowman.

The American Chemistry Council argues on its website that the use of the PFAS in food packaging "is highly and rigorously regulated."

If Senate Bill 6396 passes- the state Department of Ecology would have to first determine whether there are safer alternatives to PFAS chemicals in food packaging and present its findings.

If that assessment is accepted, a statewide ban would take effect in 2021.

**HB 2658/SB 6396 No PFAS in our Food Chain through Toxic Wrappers and Compost!  
HB 2793/SB 6413 No PFAS in our Water Supply through Fire-Fighting Foam!**

For More Information Contact:  
Laurie Valeriano, 206-200-2824  
Nick Federici, 360-481-1936  
Diana Stadden, 253-576-6351



# Protections For People with DD



## **Toxic Free Future without PFAS HB 2658/SB 6396**

Many people can't imagine a night at the movies without popcorn. Or go a month without a burger, never realizing that our health could be threatened by Toxins hidden within the bag or the wrapper. We need all nonstick PFAS chemicals out of the food we eat!

## **Prevent Sex Abuse HB 1539**

When children are in school they count on the teaching staff to keep them safe. Parents send their kids to class every day without a second thought. Today we know that we need a way to identify if something isn't right and who to tell. Teachers, parents, and young people need the tools to stay safe. We want a curriculum developed to support families and school staff.

## **Wrongful Death HB 2262**

Family, and Friends make our lives worth living. What would we do with out them? What If they were suddenly gone? How could we replace them? The family of people with disabilities who often spend their lives loving and supporting their relatives, have invested countless hours and finances to enrich the lives of people who often don't have the resources to take care of their sometime complicated and lifelong needs. Families are deeply emotionally invested. It would leave a horrible void if that loved one was gone.

## **Supported Decision Making SB 5547**

SAIL believes that there needs to be choices when someone is in need of Guardianship. Full Guardianship is not always appropriate. Maybe a person only needs help in only 1 or 2 areas. In that case supported decision making makes sense, and it saves money. People are using just what they need and not giving away all their rights.

## **47 people are waiting Budget**

The RHC's are a dangerous lonely place to live! There have been incidences of choking resulting in death, a near drowning and rape. People are being yelled at or being ignored for hours. There have been many medication errors, and there are still 47 people who have been waiting to leave the Institution for over a year. This must stop, people want to live in the community. Stop pouring millions of dollars every year into unsafe environments. Set our people Free!

## **Service Dog Definition HB 2822**

Adopts the federal definition for service animals and creates a civil infraction for misrepresentation of a service animal.

## **Jury selection HB 2398**

Prohibits discrimination based on the presence of any sensory, mental, or physical disability or service animal.

**Legislative Valentine Bingo  
For People with  
Developmental Disabilities**

	<b>HB 2658</b> PFAS Chemicals in Food Rep McBride		<b>HB 2448</b> DD Property Transfer Rep Senn
<b>HB 2822</b> Service Dog Defined Rep Steele		<b>HB 2262</b> Wrongful Death Rep Santos	
	<b>HB 1539</b> Erin's Law Rep McCabe		<b>HB 2558</b> Don't Stigmatize Students Rep Kirby
<b>HB 2793</b> Fire-Fighting Foam Rep Petersen		<b>HB 1239</b> Records for SS Appeal Rep Sullivan	

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	<b>SB 6396</b> PFAS Chemicals in Food Sen Wellman		<b>SB 6360</b> Improve Transition Services Sen O'Ban
<b>SB 6163</b> Telemedicine Collaborative Sen Becker		<b>SB 6015</b> Wrongful Death Sen Hasegawa	
	<b>SB 6237</b> Personal Needs Allowance Sen Keiser		<b>SB 6549</b> Dental to age 13 For DD Sen Rolfes
<b>SB 6413</b> Fire-Fighting Foam Sen Van De Wege		<b>SB 6221</b> ABLE Act Sen Walsh	

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