I emailed all panelists asking for their talking points (if possible). This is what Arzu emailed me:

 WAAC 2018 “Lived Experience Panel” Talking Points from: Arzu Forough, President/CEO Washington Autism Alliance and Advocacy

All of my comments were impromptu, I had copies of the questions and the overview of the session printed out as my visual queue. An overview of my comments from my recollection:

I introduced myself as a parent of two young adults with intellectual and developmental disabilities who are both also diagnosed with autism, one is also diagnosed with severe Tourette's Syndrome.

I added, what's led to most traumatic experiences for our family and those that we serve at Washington Autism Alliance & Advocacy is:

-the complete lack of crisis stabilization services

(I offered an example—representing several families, including a friend who is a social worker at a prominent area hospital, whose son was recently tied to a gurney for 7 hours because there was no available space in the Emergency Room, psychiatric units, or DDA crisis beds.

Parents took him home instead of the attempt to access medical care further traumatizing him. They’d rather have him at home and unsafe than putting him through guaranteed trauma going through the crisis triage system which is NOT designed for individuals with IDD.   Mom said she knew her son was traumatized by this experience and she will not put him through that again if she can help it.

(What I didn't mention yesterday is that this parent is covered with dark purple bruises from bite marks and other physical aggression that she sustained during a cycle of escalation, trying to keep her son from self-harm. Her son outweighs her and is much taller than she is. )

-shortage of CFC/personal care and Respite providers, especially for individuals who have challenging behaviors

-cuts to behavior supports, leaving individuals with inadequate or NO behavior supports.  It’s like taking someone’s wheel chair and not replacing it.

-Limited access and cruel wait times for Applied Behavior Analysis and other recommended supports—especially for our cultural and linguistically diverse and rural populations.

I added that I could go on but that several people in the room are living it as family members and clinicians.