

## **Online Complaint to DD Ombudsman – May 6, 2019**

### **Seattle, WA**

#### **Please describe the concern or complaint.**

Kevin has spent the better part of the past 6 months in the hospital - ER, SECU, medical floor and now back in the ER in a small, secured room with a small plexiglass window that he is let out of a couple of times a day to use the bathroom and shower.

Kevin had been at Fircrest for several years but moved back to his home community in a group home about 5 years ago. He did very well. Last Fall he became more agitated and assaulted caregivers and I believe a housemate. He was taken to the ER and it was found that his ammonia level was extremely elevated (drug reaction possibly) He seemed to stabilize but the group home refused to take him back home. Kevin became more and more agitated and his family thought they would try to take him back to their house. That lasted about 4 days before Kevin become more agitated and assaulted his parents - he had been asking to go back to his house. The police came and took him back to the hospital.

During this stay, there were some medication changes and DDA did agree to work on finding emergency respite and having behavioral specialists work with Kevin - but this was a temporary fix until they could find an agency and get staffing to provide supported living for Kevin. Kevin's guardian had requested many times to have him go back to Fircrest for stabilization and she is continually told that is not an option - there are no beds there.

Kevin moved to the crisis respite about March 11 and family was told he could be there until the 28th as long as Kevin "behaved." This is the message I received from Kevin's mom on April 1 " The respite bed was going to end March 28 and DDA was going to send him to our home or the hospital. The behavioral analyst was as worried as we were about Kevin coming to our home because he was very vocal about not wanting to come to "mom and dad's house". Thank goodness our legislators called DDA and requested for them to keep Kevin in a stable situation until a group home was found. DDA has rented a small apartment/suite and Kevin is there with the same staff he has been with at the respite bed. We are hoping we can find a home soon so he can be in a more stable/permanent situation. He is doing well at the new place. on Tuesday a received a call from Kevin's case manager letting me know that they have decided to rent a place at the embassy suites and have the same staff that was working with Kevin for the last 12 days to take care of him until May 15 or until the group home gets staffing together to take over.

April 29, 2019, Kevin's mom asked be about this new police "catch and release" in which those with a history of assaultive behavior are only "on hold" in the ER and are not provided any therapeutic services.

Once they are admitted, or even if they are ever admitted, they remain in the emergency room area and only treated as emergency patients. No tests, no consults, no imaging, no therapies, nothing is done for them. They remain "on hold" until DDA or family take them out. Kevin is still having outbursts, ended up at the ER and even though the staff at the respite place think that is something physically wrong with him, the hospital refuses to do any especial testing or consults. The (respite) staff suspects possible seizure activity, but the hospital refuses to have neurologist consult. "

I asked Kevin's mom if any labs had been drawn and she said a CPK was the only one that was abnormal - This lab result indicates there is some tissue damage/breakdown - it is something that should be investigated to figure out why it is so high - it appears from what I have been told that it is basically being ignored.

The crisis respite place will not take Kevin back and if the group home can find a place and get staffing they may be able to but there appears to be no progress in this area.

Kevin's mom asks about Fircrest over and over again and their answer is "no beds available" in any of the RHCs in WA state. The hospital said today that they were talking someone in DDA about finding an RHC outside of the state.

According to Kevin's mom, his condition is deteriorating, he continues to try to escape and has injured about 7 hospital staff.

Here is a post that Kevin's mom made on my advocacy blog today about what is going on:

## **Time/Date of when the complaint occurred:**

Here is a post that Kevin's mom made on my advocacy blog today about what is going on: The complaint refers to a time period - not a specific day. Fall 2018 - May 2019

Kevin's hardships continue

Kevin was under the care of Holly community Services since the end of February. This is a great organization that cares for disabled individuals and does it in a professional and compassionate way. Despite the fact he was enjoying life, he continues having outbursts. His caregivers suspect some physical issues or possibly seizure activity, since Kevin acts strange before he has a meltdown (blank stare like). We are unable to know what is going on due to his limited language skills.

Kevin has been taken to the ER twice in the last month, this last time on April 24, and has remained there since then. I raised several concerns to the ER doctor but little did I know about the new policy adopted in St. Joseph Hospital called "social admissions", or just "ER hold". This means that Kevin, or any other patients in his situation, will be kept on hold for indeterminate time at the ER and will only receive emergent care that addresses threats to life. Individuals like my son and others will not be admitted, just "held". I was not told that this time or during his last admission.

This situation is so terribly sad! Due to my child's severe autism, he is not able to participate in group/individual therapy sessions. This also disqualifies him for admission to the hospital's mental health unit where he could possibly be stabilized with the right medications. With the implementation of "social admission", testing and consults that could help him and others are no longer available.

After talking with several hospital employees (off record), they expressed their concerns that patients on ER hold are not getting therapies or other medical care (non-emergent) that are necessary for their wellbeing. Last week I also received the devastating news that the respite bed was no longer available for my son due to his behaviors. I approached the Hospital and requested a written copy of the new policy so I was able to get more information of what kind of care was available for my son. After many attempts to get a copy of this new "policy", none of my phone calls were returned for days.

Finally, last Friday, I received a call from the ER manager. She was very kind and let me know that I was mistaken (me and many of the hospital staff): "no new policy has been implemented". It never happened, was never a proposal... no meetings took place to plan for it. Also, she informed me, she will be my main source of information from now on. I raised my concerns regarding what I perceive as discriminatory practices against the mentally ill and disabled patients. During our friendly conversation I was advised to find help for my son out of state.

I am grateful for the caregivers at St. Joseph Hospital (MDs, RNs, CNAs, and security). They are caring professionals that face difficult situations daily. My son has assaulted seven of them during this admission and for that that I feel so very sorry. I am ashamed of the systems which have left behind the most vulnerable people in our society. DDA/Washington state is closing all the specialized centers where people like Kevin were able to go and get stabilized under the care of psychiatrists, behavioral specialists and other well-trained professionals. Their treatments were done under a more humane environment. On top of this, I have been researching the nationwide movement in Hospitals of "catch and release" approach that makes the situation of this already at-risk population worst.

My son sits in a small room 24/7 under lock, only let outside to take showers or use the bathroom. This is completely necessary to keep those safe around him, but nevertheless, is still inhumane. He attempts to escape any time he sees an opportunity and I can only imagine what a terrifying nightmare this

situation must be in his 5-year-old mind. "Caged like an animal" due to the lack of resources, this is DEVASTATING for him and those of us who love him.

## **What do you think will solve the complaint?**

I think that we, as a state need to realize this abuse that is occurring. We do have the space at the RHCs but due to some political issues and inaccurate information (what I believe to be inaccurate information) there has been no attempts to increase funding or services at the RHCs for those who actually need the services.

Regardless what one believes about "all people can live in the community" and want the RHCs closed, there are many for whom the RHC is the least restrictive environment and one in which therapeutic services can be provided. People are not locked in small rooms are treated like caged animals but are treated as people who need care and help.

## **What would you like the DD Ombuds to do?**

I would like the DD Ombuds to investigate this situation - is this "catch and release" policy one that is happening state-wide.

Push for better wages for supported living caregivers and assistance with housing to be able to have people like Kevin live in the community.

Also, out of state is not an option that should ever be brought up when we do have the resources in our state and it is a goal to keep people in their communities. Look at exception to rule issues and grant admittance to an RHC for the very least so that Kevin is not locked in a prison-cell.

Look at his psychiatric/neurology issues and ensure he is receiving appropriate medical care.

## **Describe the steps you have already taken to solve the problem, if any.**

Kevin's mother and I are in contact often regarding our sons. They were housemates for a few years while both of them lived at Fircrest. We try to get this information out for others to become aware of

what is happening behind closed doors. WE want to be stakeholders in the care and support issues related to people with significant support needs who also happen to have some sort of IDD