

A Few Stories

1)

I do not know if this will help but here goes. One day I was taking some individuals out on Day Habilitation when I was the Manager at a local Assisted Living Home/Group Home here in the valley when an individual who has mental retardation, fetal alcohol syndrome, bipolar disorder, and intermittent explosive disorder decides to run off in the Wal-Mart Parking lot. He has had multiple arrests for assault, me and a fellow staff member notified the police because we couldn't keep up with him with the other individuals we had with us. We loaded up in the vehicle we were in and went to look for him. At the same time we found him, the police did too. I communicated with the police upon them arriving and they handled the situation perfectly. At first they were on the defense because of the individuals swearing, and aggressive gestures but once I explained his disabilities they calmed and we talked him down together. However, if I had not been there I imagine he would have been arrested and taken to jail because he most likely would have assaulted the police officer.

This could be an example of why educating law enforcement officials could benefit in situations such as this. Once they knew that he wasn't on drugs or looking for a fight they calmed, he calmed and the problem was corrected.

In another story, in the same Group Home I worked with an individual who was a convicted sex offender. He was scheduled to attend weekly court hearings to check on his status and to make sure he was doing well. He has mild mental retardation. Most days at court were great with him leaving happy that he was one step closer to being off parole and on with his life. However, one day he found out that due to a setback (believe it was pornography(violation of his parole)) he had another 6 months added onto his parole. After being dismissed he ran away from us in the parking lot and said he was leaving. After we caught up to him and he began calming down and being talked to he came to realize this is just another obstacle to overcome.

This could be another example of why educating criminal justice officials is important because of situations such as this. If they had taken the time to work through the reasons why and how come he was getting additional time, plus working through his frustration this situation may have never occurred. It could have been much worse, he could have ran into traffic, or hitch hiked, or worse.

Thanks,

Joshua Bicchinella, ILA
Independent Living Advocate

2)

In the more than 10 years I have spent in association with the head and your support group here at Access Alaska, I have seen numerous occasions where people with invisible disabilities due to traumatic brain injuries, strokes and/or brain tumors were thought to be impaired due to the consumption of an intoxicant. After being pulled over by an officer, with flashing lights and quite possibly a flashlight shone in their face and they were definitely impaired. Many people with seizure disorders can have a seizure induced by a strobe light, fluorescent lights and some computer screens can also be a problem. And once a person is in the legal system there is a good chance they will have a difficult time getting appropriate representation due to their inability to communicate what their disability is. Probably my favorite metaphor is comparing the brain to a laptop that has been dropped and still looks the same on the outside, the laptop does not think that there's anything wrong with it and gives everyone that tries to use it an error message.

One member of the head injury support group here in Anchorage (a stroke survivor) reported on his Fourth of July trip to Seward, AK that the local police thought he was drunk because of his balance issues. The officers refused to accept his doctor's note as proof of his disability even after he passed a breathalyzer test. They took him to the hospital for a blood test and put him in jail while they waited two days for the results and the judge to come to town. Another member reports having drank one beer six hours before being stopped by a state trooper and had largely the same experience.

A call came in from a local church pastor that was advocating for a young man with a cognitive impairment that was his family's sole breadwinner. He had been pulled over for weaving in his vehicle, and could not walk a straight line but had passed a breathalyzer test. His car was impounded and he was taken to the clinic for a blood test which he passed. And he was left to bear the cost of paying impound & towing charges in order to get his vehicle.

It becomes even more tragic in cases of child custody and domestic violence as the authorities can become a third-party abuser or a tool of a disenfranchised spouse or domestic partner. I am involved in representing a support group member in this type of case and I am having difficulty in finding the correct attorney for appropriate representation.

On a system's advocacy positive note: the local Anchorage Police Department has implemented The Crisis Intervention Team which was founded in Memphis in 1997 through the efforts of NAMI.

I have been invited to participate in graduation Day presentation on neurological impairments/brain disorders that may present as substance abuse. I was initially invited to present at the state of Alaska Department of Behavioral Services and have presented at five of the last six graduating classes. The information was well received by the paramedics and graduating officers of the 40 hour class. <http://www.youralaskalink.com/news/Crisis-Intervention-Team-Graduation--130899263.html>

This is one of the most important components of developing a long-lasting peer support network: developing empathy in seeing that injustice done to one of us with a disability is being done to all of us. We are much stronger together than alone. Frank Box –IL Advocate/ HISG Facilitator

3)

We know of a young man with a cognitive disability who has a permanent conviction on his record, in court view, that has interfered with and prevented his entry to employment. We currently have him employed, but the conviction is there for all future applications he may make. He is not longer in my program, and he's not likely to come to us for help. He accepts the kind of stuff the world dishes out very quietly.

His alcoholic father asked that he accept custodial responsibility so the dad could get bailed out of jail. Of course the son agreed. There was no advocacy or prevention of court assigning him the responsibility: I did not know about the issue until after the conviction.

Conviction occurred, predictably. Dad got out of jail, drank. No way that an adoring son who had lived his life away from dad in foster care would or could confront the father. No skills for that. If he had, what chance would he have of influencing active alcoholic dad? So dad got, predictably when drinking, into a fight and was arrested. Son was arrested and convicted, summarily, of neglect of custodial duties. I think he was 19 at the time.

I have written, called and approached all the legal entities I can think of, including public defenders, convicting magistrate, clerk of court, and an attorney that had previously worked for Alaska Legal Services. It's a conviction that is WRONG as the day is long. But . . . oh, too bad. None of us can do anything about it now. So let's all go home to our comfortable homes and families. We won't be contacted when future employers eliminate this young man as a candidate. We won't even have to think about the damage it will continue to do in his life.

Somehow, we managed to keep him from being arrested to serve the time required by the conviction. Warrants stopped being issued. I don't even know how that happened, but I was scared to death for this kid to have to go into FCC at his tender age. I think we need a few more 'mistakes' in the legal system to clear that record of conviction

4)

Last year, one of our deaf consumers was at a friend's house drinking on post (where she lives). She went to her car and started it since it was January and cold outside and got in the back to sleep. A "friend" called the MP on her. Apparently, MP tried knocking on the back window, but since MS is deaf, she didn't hear them. They also opened the door and apparently directed her to get out, but again, since she is deaf and did not hear them, she did not wake up, did not move and was unable to follow their instructions. So for her, the only recollection she has is being grabbed out of the back of the vehicle. She stated it was very dark and she had no idea it was MP. She began swinging her arms because she thought she was being attacked.

She said that in court, they lowered the charges because they looked at the video of what happened, but she was still charged with a DUI and Assault 4. I have no idea if she was given accommodations for her disability in court, or if she really knows what charges she was being given. She can read lips, but that does not mean she shouldn't have had a translator available. They suspended her license, I think gave her suspended jail time and a smart start for her car for (6?) months.

I've also gone to court with her for a protective order. I can tell you that they have accommodated her by using the relay system to do English to text translation, however, a mess up in translation last time we were in court, almost caused her to say "OK" to dropped the protection order.

5)

Focusing on the hidden disability

Fetal Alcohol Syndrome will affect every aspect of their lives for as long as they live

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By CHRISTINE SCHMID

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When Margaret and Lester Hunt's five adopted adolescent boys moved into their home in 2001, four of them chose to take new names to symbolize their new lives.

One no longer wanted to share an identity with his biological father, so he changed his name to Jake. Another wanted to assume the name of his adoptive father and grandfather and became Lester Allen III.

"They wanted to leave their past behind," said Margaret Hunt. What the boys couldn't leave behind is the fact their mothers drank alcohol while the boys were in the womb. All five boys are diagnosed with some degree of Fetal Alcohol Syndrome - a disease that will affect every aspect of their lives for as long as they live.

"I know that when they grow up they're going to see what their friends have - apartments and cars - and ask why they can't have it too," said Hunt. "I just have to tell them that when their mom was pregnant, she drank alcohol, and it damaged their brain."

Problems associated with Fetal Alcohol Spectrum Disorders

- learning disabilities
- problems with memory
- behavioral problems
- poor judgment
- brain damage
- heart and kidney problems
- mental retardation

Source: Health and Social Services office on Fetal Alcohol Syndrome

FAS is caused by one thing only: a mother drinking alcohol while pregnant. Unlike those of crack or cocaine, the effects of alcohol on a developing fetus last a lifetime.

When the Hunts adopted the boys - from two separate families - they did not know of their new sons' brain damage.

"We were told the boys were not diagnosed with FAS," Margaret Hunt said. But because of her background in social work, she was able to diagnose the boys unofficially only a few weeks after they arrived in her home. "When I got the boys I started taking them to all their checkups with various doctors," she said. The doctors found a cotton swab in one ear and a bug in another in one of her sons. The cotton swab had been there for two years, doctors estimated.

"The FAS pulls into that," Hunt said. "He didn't have the coping skills to say his ear hurt or feels funny. He just didn't know how to say it."

Other signs of FAS for Hunt were when her sons said they would do something - what they had been told to do - then did something completely different. They also took an abnormally long time to do simple daily tasks such as eating breakfast.

"There's just a lot of little things," Hunt said. "These kids, they look normal."

Hunt's diagnosis was confirmed when she talked to the families of her sons, who confirmed the likelihood that the mothers drank during pregnancy. A full psychiatric evaluation in Anchorage made the diagnosis official.

Hunt's adopted sons face a situation typical of many who suffer with FAS: They look and act much like normal boys their age in social situations, Hunt said.

"Anywhere we go I have people tell me, 'Your boys are so well-behaved,' " said Hunt. Though some of them struggle in school, all of the Hunt boys have areas such as art or sports or math at which they excel.

The normal appearance and average intelligence of many who suffer from FAS is part of the syndrome's elusiveness, said Dan Dubovsky of the federal Substance Abuse and Mental Health Services Administration's FAS Center for Excellence. He was in Juneau last week speaking at two conferences on substance abuse and FAS, one sponsored by the Alaska Department of Health and Social Services and the other by the city-run Juneau Recovery Hospital.

"(People who suffer from FAS) sound OK if you're just talking to them," Dubovsky said. "Often they have normal IQs, and the majority don't have mental retardation."

Because of the normal appearance of people with FAS, many people think the contrary or disruptive behavior of FAS patients must be purposeful, Dubovsky said.

"When really, the bottom line in any setting - home, school, job, treatment, corrections - the bottom line is they just don't get it," he said.

People with FAS suffer from low adaptive functioning - the ability to apply knowledge appropriately in a given situation.

"It's the difference between learning a skill and adapting to use that skill," Dubovsky said.

Dubovsky illustrates this difference with stories of his son Bill, an FAS patient he adopted when Bill was 6. Bill was hit by a car and killed last fall at the age of 28, but Dubovsky's 22 years with his son gave him an intimate knowledge of FAS.

When Bill bought his first car, Dubovsky warned him not to get a speeding ticket, because if he did, Bill wouldn't be able to afford the increase in insurance rates and would lose the car.

"So when Bill was pulled over for a speeding ticket, and the officer went back to his car to write up the ticket, what did Bill do? He remembered that I said he would lose the car if he got a ticket, so he just pulled away," Dubovsky said. Bill then was arrested for fleeing from an officer.

Though fetal alcohol syndrome first was identified as a clinical condition in 1973, it is by no means "new," said Dubovsky. References to the birth defects associated with mothers who drink alcohol date as far back as the Bible, when an angel told Samson's mother not to imbibe wine or strong drink during Samson's gestation.

FAS is considered one of three Fetal Alcohol Spectrum Disorders, FASD, which is a newer term for the broad range of disorders that can result from consuming alcohol during pregnancy.

Knowledge of FAS and FASD is very limited, Dubovsky said.

"We do know that it is 100 percent preventable," he said. The disease is caused by the consumption of alcohol during pregnancy, and the child of any woman who drinks during pregnancy is at risk.

"I don't like talking about high-risk populations," he said. "My approach is that until somebody can show me that there is a whole population that is at risk, we need to talk about high-risk behavior."

The fact that the effects of alcohol on a fetus last a lifetime "doesn't mean we can't do anything to help," Dubovsky said. The medical establishment is just beginning to study treatment options for FAS.

With proper treatment, including one-on-one monitoring and sometimes medicines such as anti-depressants and mild stimulants such as Ritalin, people with FAS can lead lives that highlight their strengths.

"They tend to be very likable, very friendly," Dubovsky said. "They tend to really have a strong desire to be helpful. There are a number of them who have many strengths. What we need to do is build on those strengths."

As for the Hunts, they have no regrets about the children they adopted, Margaret Hunt said.

"These guys just ... they sparkle," she said. "There is so much love and care in them, and they want you to be happy. They want to see you smile."