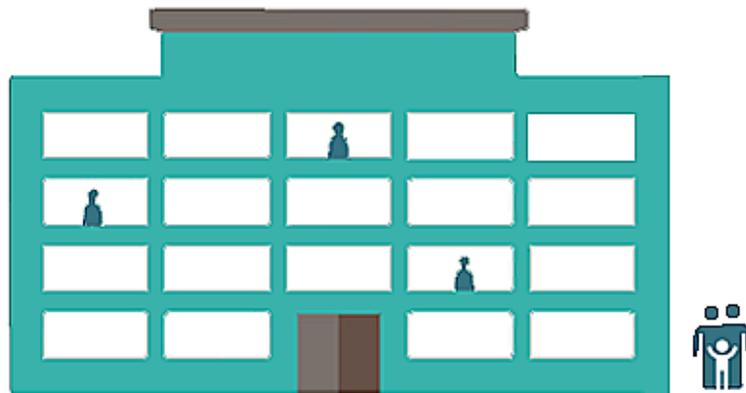




“I Want to Go Home”

Reevaluating DDA’s Children’s Services to Prevent
Hospitalization and Out-of-State Placement



September 2022

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About DD Ombuds

The Office of Developmental Disabilities Ombuds (DD Ombuds) is a private, independent office focused on improving the lives of persons with developmental disabilities in Washington State. RCW 43.3821ⁱ provides the office with authority and identifies its scope. The Legislature authorized DD Ombuds to monitor services provided to people with developmental disabilities, review facilities and residences where services are provided, resolve complaints about services, and issue reports.

Executive Summary

The purpose of this report is to share the stories of youth and their families who have been affected by being stuck in the hospital or have been sent to out-of-state placements. Since youth and families know their needs the best, DD Ombuds believes that directly sharing the stories of families can inform person-centered systemic changes. To prevent youth from getting stuck in the hospital or being sent to out-of-state placements, the DD Ombuds recommends comprehensive community services.

Problem 1: Insufficient In-Home Services Cause Out-of-Home Placements

When trying to find in-home services for an intellectually or developmentally disabled youth, many families have a difficult time accessing the services they need. Then, when children and families are not able to get enough services at home, families say there are not enough early-crisis intervention options to prevent emergencies from escalating. Finally, after family-members work hard for years to try to help their disabled child get their needs met, they decide they cannot keep their child safe at home anymore. As a last resort to get help, family-members take their child to the hospital. By not having services that comprehensively support a whole family, families report that Washington's services are not doing a good enough job at preventing out-of-home placements.

Recommendation 1: Invest in supporting Medicaid-funded crisis intervention services, like WISE, so they can help youth with developmental disabilities.

Recommendation 2: Offer expanded twenty-four-hour, in-home personal caregiving services for youth with developmental disabilities.

Recommendation 3: Fund and create a state-operated personal-caregiving service which has the capacity to serve the number of people who need in-home personal caregiving.

Recommendation 4: Develop and fund an effective cross-systems care coordinator role that can help families across all DSHS-services.

Problem 2: Unavailable Emergency Options for Disabled Youth

When youth with developmental disabilities and their families are in a crisis, there are not enough emergency service options for Developmental Disabilities Administration (DDA)-workers to be able to respond effectively or creatively. Because there is not enough capacity for emergency services, oftentimes, developmentally disabled youth are in unwinnable situations with no choice but to wait, sometimes for almost a year, at medical hospitals. As a result, families say they become discouraged because there is almost nothing that DDA-workers can do to try and help.

Recommendation 5: Collect data on when DDA-providers initiate police interactions for people with developmental disabilities.

Recommendation 6: Expand Intensive Habilitation Services (IHS) so that youth with developmental disabilities have short-term, crisis stabilization options available in-state.

Recommendation 7: Develop policies and procedures that protect youth with developmental disabilities who are at risk of losing their residential placement.

Problem 3: Hospitals Are Not Long-Term Crisis Stabilization

Because acute-care hospitals are not designed to be places for long-term crisis stabilization, youth with developmental disabilities often experience inhumane conditions that are unable to meet their needs. Hospitals are not meant for people to live there long-term and should never, ever replace crisis stabilization services.

Problem 4: Expensive Out-of-State Placements Separate Families

Because Washington does not have enough services for intellectually or developmentally disabled youth, families sometimes make a heartbreaking decision: to send their child to an out-of-state placement. Recently, the number of youth sent to out-of-state placements has increased, which has lead family-members and advocates to question if the conditions at out-of-state schools can meet children’s needs. When youth are ready to come home, family-members still encounter difficulties ensuring that they can get the services they need in Washington. By not investing the money spent on out-of-state placements in Washington, families say youth with intellectual and developmental disabilities are funneled into expensive out-of-state schools and institutions that separate their families.

Recommendation 8: Create a DDA out-of-state caseload for youth with developmental disabilities, with the purpose of helping children return home to their families in Washington.

Recommendation 9: Reallocate the \$13 million a year spent on out-of-state placements for youth with developmental disabilities to services in Washington.

Problem 5: The Need for Trauma-Informed Community Healing

When many disabled youth and families are denied access to services which would give them safety and dignity, they are experiencing systemic-trauma inflicted by Washington’s social service system. To heal as a community, youth, and the families who support them, need agency and structural power to determine their needs, get help when they say they need it, receive kindness when accessing care, and stay in their homes and communities.

Recommendation 10: Develop an accessible, trauma-informed peer mentor program run by and for youth with developmental disabilities.

Still Stuck in the Hospital

Background

Since its creation in 2017, the Office of Developmental Disabilities Ombuds Office (DD Ombuds) has received many complaints from adults who get stuck in hospitals who do not medically need to be there. The DD Ombuds' systemic advocacy report, *Stuck in the Hospital*,ⁱⁱ showed why people getting stuck in hospitals is a public health crisis and advocated for investing in community-based services. Later, in 2019, Disability Rights Washington filed a lawsuit, *Murinko v. Strange*.ⁱⁱⁱ The plaintiff, Shawn Murinko, argued that the Department of Social and Human Services' (DSHS') failure to provide meaningful options in the community put him at risk of hospitalization and institutionalization. In 2020, the lawsuit was settled and the Developmental Disabilities Administration (DDA) instated new policy as one of the conditions: Critical Case Protocol (CCP).^{iv} Critical Case Protocol starts a person-centered planning process of someone's DDA services and requires missing support pieces to be incorporated into their service plan. However, even with advocacy by the DD Ombuds and the new CCP policy, adults with intellectual and developmental disabilities getting stuck in hospitals is still a systemic problem. Now, it is a problem that effects youth.

Problem

Recent DDA-reported numbers show that in April 2021, 7 people were stuck in the hospital for an average of 114 days.^v DDA does not share data on the ages of clients who are stuck in the hospital, which means that the number of youth,^{vi} ages 0 to 21,^{vii} who receive DDA services and are stuck in hospitals is unknown. In addition to youth getting stuck in the hospital, there has also been an upward trend in the number of disabled youth who are sent to out-of-state placements who cannot get their service needs met in Washington. To prevent youth from getting stuck in the hospital or being sent to out-of-state placements, the DD Ombuds recommends comprehensive community services that center the right to dignity, humanity, and self-determination.

Methodology

When the DD Ombuds began developing the idea of this systemic-advocacy report, the DD Ombuds noticed that a lot of the media stories about youth stuck in the hospital tend to blame careless family-members and disobedient disabled youth. However, putting blame on individual youth and family-members does not recognize how disabled people may not have their needs met because of problems within Washington's social service system. When Washington's social service system is not able to meet many people's needs, then that means it is a systemic, not individual problem. Instead of individualizing problems, DD Ombuds uses a disability justice approach.

Disability justice, imagined by queer, disabled activists of color, Patty Berne and Mia Mingus,^{viii} is a way to understand how inaccessibility can be solved through collective-organizing. Furthermore, disability justice considers how racial, immigration, and gender injustice affect a disabled person's ability to access the resources they need. With this framework in mind, DD Ombuds works to empower disabled people to defend their dignity and humanity by considering the broader context rather than just a single person's story.

To gather the stories that families shared for this report, the DD Ombuds interviewed youth and their family-members from across the state who were stuck in the hospital or were sent to live at an out-of-state placement. Because parents of disabled youth were relied on to provide most of the quotations for this report, this report is limited in perspectives from disabled youth who *receive* DDA-services. However, despite these limitations, understanding how lacking needed services holistically affects families is crucial to learning how they have been failed systemically. For that reason, the DD Ombuds still feels that parents' perspectives are incredibly important to explain what the roadblocks are for a youth to receive DDA-services in the first place. The DD Ombuds will continue to work on connecting directly with youth to see how they explicitly feel about the services they receive.

During the review process for this report, every person quoted enthusiastically consented to what was written about them, had the opportunity to suggest changes, and

agreed with all systemic recommendations. In the final report, identifying information was removed and every named individual is identified with a pseudonym: this includes, but is not limited to, names, ages, and geographic location. Since families and youth know what their needs are the best, the DD Ombuds believe that directly sharing the stories of families can inform person-centered systemic-changes.

“We Don’t Just Throw Our Kids Away”: Insufficient In-Home Services Cause Out-of-Home Placements

A decade ago, when Ella was about ten years old, she started receiving Out-of-Home Services (OHS) at a “Licensed Staff Residential” (LSR). But before that, Ella lived at home with her brother, Henry, and her Mother, Laura. Laura organized everything for her children, lots of specialized doctor’s appointments, occupational, physical, and speech therapists, personal caregiving schedules, and more. Personal caregiving was an important service because, while she worked a fulltime job on top of being a single parent, Laura needed someone who could take care of her kids. In the end, Laura said, “Everything kept falling back on me to make it happen. ‘Well, Mom needs to do this and Mom needs to do that.’ That’s one of the things that broke me.” Laura wanted to help Ella get her needs met at home, but the services were not there.

What Ella and Laura went through while trying to find at-home services is similar to what the DD Ombuds has heard from many families: unavailable services in the family home as the deciding reason to ask for Out-of-Home Services (OHS). When trying to find in-home services for an intellectually or developmentally disabled youth, many families have a difficult time accessing what they need. Then, when children and families are not able to get enough services at home, families say that there are not enough early-crisis intervention options to prevent emergencies from escalating. Finally, after family-members work hard for years to try to help their disabled child get their needs met, they decide they cannot keep their child safe at home anymore. As a last resort to get help, family-members take their child to the hospital. By

not having services that comprehensively support a whole family, families report that Washington's services are not doing a good enough job at preventing out-of-home placements.

Laura said that organizing services for Ella and her brother was overwhelming. She said, "Behavior technicians could work with Ella, but they weren't caregivers. And they couldn't be left alone with her, so I had to have a caregiver and a behavior tech for Ella and a caregiver scheduled for Henry." Then, when Laura came home from work, she said, "I would see the caregivers sitting there while they watched TV, or they were on their laptops. So, I would make them a schedule, and I would ask them to check it off, so I knew they were at least trying."

It is extremely difficult for family-members to help their children get the services they need to be successful at home. The main DDA program for youth with "challenging behaviors" is the Children's Intensive In-Home Behavioral Supports (CIIBS) Waiver.^{ix} The CIIBS Waiver is supposed to provide wraparound support to families so children with disabilities can remain living in their family home. However, parents say that the CIIBS Waiver is not meeting this goal.^x For example, because the CIIBS Waiver is so complicated, family members need their child's Case Resource Managers (CRM) to explain what services are available. However, when one family-member asked their child's CRM for help, they said that the CRM "would stumble all over it and then not know herself, then tell me that her supervisor would call and explain it to me but then nobody ever would." Even if family-members did know what services to ask for, they were often not able to help their youth access them. A parent said that when they tried to find personal caregiving services for their child, the local agencies were "totally booked solid, like, maybe we'll have something in a couple years." These long waitlists discourage and prevent families from getting help when it is needed right away. Another needed service, not included in the CIIBS Waiver, is twenty-four-hour personal caregiving. Ella needed twenty-four-hour personal caregiving because, Laura says she "couldn't stay up twenty-four-hours per day." The CIIBS Waiver does not offer twenty-four-hour caregiving because it assumes family-members have support-networks who can help when a primary caregiver is not available. However, many of the family-members of youth stuck in hospitals did not have people who

could help at a moment's notice. For these families, the CIIBS waiver is not providing them with crucial, easily accessible services.

Lastly, Laura repeated how much work it was to keep up with all of Ella's services. Laura was responsible for understanding and interpreting DDA's gigantic bureaucracy, keeping all of Ella's medical appointments scheduled and up to date, organizing multiple caregiving schedules, training Ella's caregivers, medically caretaking Ella and her brother, and holding the personal caregivers accountable for following through on Ella's behavior plans. And the services that Ella was getting were still not enough. Because of confusing bureaucracy and how hard it is to access needed services, disabled youth do not get what they need to grow, thrive, and succeed in their communities. Meanwhile, many family-members reported becoming completely overwhelmed. They believed they were parental failures; in actuality, the services were not meeting the whole family's needs.

As Ella grew older, she started to self-harm. Without personal caregivers who would engage with Ella, it was Laura's responsibility to make sure Ella was not seriously hurting herself. To help Ella and Laura, and other families in the early stages of a crisis, families need services before an emergency gets too big. However, the responses that parents received from CRMs when they asked for help indicated that CRMs did not understand the problem or respond efficiently. When the same parent, who was told personal caregiving waitlists were over two years long, asked for more services, they were told by their child's CRM "He gets caregiver hours, why don't you use them?" Another family-member described that their child's crisis slowly grew from a "mole hill into a mountain" while they waited for help:

When I started calling for help through DDA we only had a mole hill. It could have been fixed with a little bit of help, but now we got a mountain. My son does not deserve to have to go through what he has for the last nine months because there's no resources.

If CRMs responded to calls for help by quickly referring families to the resources they asked for, they could help deescalate and be responsive to a family's unique needs.

An early-crisis intervention option that CRMs could refer families to is Wraparound with Intensive Services (WISe).^{xi} WISe eligibility is broad, but family-members say that WISe

eligibility coordinators told them that their disabled children were not eligible because of “cognitive incapability” and being “nonverbal.” By not serving youth with disabilities, family-members report that crisis intervention services are not helping an important population.

Without enough services and caregiving support, Ella’s self-harm became worse. Then, one holiday weekend, Ella’s caregivers fell through. Laura explained:

That caregiving agency, it was their policy not to schedule people on holiday weekends. Then, my other one caregiver who was always there for me called in sick. So, I was sitting on the floor with Ella so she wouldn’t be hurting herself. I got up, I got my bags, and I took her to the emergency room at Children’s’. I told Ella that I can’t. I can’t take her home.

Laura says she did not decide to take Ella to the hospital carelessly. Instead, she decided to after years of begging for help and not being able to get Ella what she needed. She explained, “It’s, you know, it’s not—it’s not something we take lightly. We don’t just throw our kids away and don’t want them. It’s an anguishing roller-coaster that gets you to that point.” When Ella and Laura arrived at the hospital, a nurse pulled Laura aside and whispered, “This is probably the best thing you could’ve done because they would’ve given you the runaround for a really long time. They wouldn’t’ve really helped you unless you did this.” The nurse was right.

After Laura brought Ella to the hospital, DDA-workers explained voluntary Out-of-Home Services (OHS) to Laura.^{xii} OHS usually means facilities called “Licensed Staff Residentials” (LSRs) that are like supported-living for adults, but parents can keep custody of their child. Laura said that it felt like “finding a hidden door” because she could still stay in Ella’s life while ensuring her needs were met, like twenty-four-hour personal caregiving. However, the longer that Ella lived at the LSR, the less that Ella and Laura were able to be a part of one another’s lives. For example, when Laura asked staff at the LSR what Ella’s day looked like, she was given vague answers. Laura also could not visit Ella as often as they both would have wanted because the LSR was several hours drive away. Ella’s services at the LSR came at an incredibly high price.

From the beginning, Ella should have been able to get the best in-home supports. Out-of-home placements get intellectually and developmentally disabled children twenty-four-

seven services, but at the cost of having to be removed from their family homes. By not having enough accessible at-home services, families say that OHS becomes the only option to get youth more support. However, as the next section will show, even OHS can fall apart. When youth placements collapse, besides the hospital, there are very few emergency options.

“There’s No Place!”: Unavailable Emergency Options for Disabled Youth

A few days before Owen’s Licensed Staff Residential (LSR) closed for good, Nora, Owen’s Mother, received a phone call from his Case Resource Manager (CRM) telling her that she needed to make sure she had an emergency plan for Owen. Unaware of what was about to happen, Nora called her mother, Teresa, to ask for advice. During the phone call, Teresa told her daughter not to worry and that if an emergency happened, CRMs are there to “tell them where to go or what they needed to do to solve the problem.” Teresa recalls, “Silly me, I thought he was the emergency plan.”

When an emergency did happen a few days later, Nora and Teresa assumed Owen’s CRM would be able to help.

Unfortunately, there are not enough emergency service options for DDA-workers to be able to respond effectively or creatively to crises. Because there are no options, DDA-workers ask family-members to take their child home, even though families do not have enough services to keep their child safe. Finally, when DDA-workers do meet with families to try and help, families say they become discouraged because there is nothing that the DDA-workers are able to do.

A few days after the first phone call, Owen’s CRM called Nora again telling her she needed to pick up Owen from the Licensed Staff Residential (LSR). Immediately. Owen’s CRM explained that an emergency had happened at the LSR and it needed to close for a few days but would reopen soon. Confused, Nora and Teresa called Owen’s CRM back for advice. Teresa and Nora explained that Nora could not pick Owen up, youth were not allowed in her affordable-housing complex and her apartment did not meet Owen’s access-needs. Affordable-

housing rules on visitors and environmental modifications are incredibly strict and rule violations can result in eviction. Nora also knew that her home was too far away from the high school where Owen loved to go to art class and swim. They told Owen's CRM that if Nora brought Owen home, they would both lose their housing and Owen would not be safe. Nevertheless, Nora and Teresa said that Owen's CRM told them that they needed to "step up" and use Nora's "natural support-system." Teresa retorted, "Look, I am her support-system and I can't do it!"

For a child to receive OHS, a primary caregiver must sign an "Out-of-Home Services Acknowledgement:"^{xiii} if OHS end, family-members agree to pick up their child right away. There is an important contradiction here: how can a family-member instantly take their child home if it was so unsafe that they had to ask for OHS? Even though family members explain why bringing their child home would be unsafe, DDA-workers are obliged to follow their organization's policies. This frustrates family-members because it is not responsive to their child's needs.

Family-members said that taking a child home was not safe for physical and health reasons. For example, because their child had lived at an LSR for many years, one parent did not live in a house that was wheelchair accessible anymore. When this parent told their child's CRM that their child's wheelchair could not fit through any of the doors, the CRM said that the youth just needed to be able to get through the front door; it did not matter if they left again. The same parent did not know how to use their child's current medical equipment but was told by their child's CRM that did not matter either because they could have figured it out. Other parents were worried if they took a child home who was self-harming or suicidal, they might kill themselves. When a crisis happens, DDA-workers should be able to offer safer, better options to families.

Teresa, Owen's Grandmother, begged Owen's Case Resource Manager (CRM) to do something, explaining why it was not safe to bring Owen home: "I never insulted him even when he was telling me he didn't know anything. At the end of it, I did say, 'Look, I know this is not your fault, but I'm just really frustrated about all this. We need help, we need help!'" The

next morning, Nora and Teresa say they received a phone call from a DDA-Supervisor telling Teresa to stop abusing her employees.

During the phone call from the DDA-Supervisor, Teresa and Nora asked for more information on what crisis options DDA had available. Instead, the DDA-Supervisor repeated what Owen's CRM had already told them: "Listen, Nora. You are his parent, and this is different now. He's your responsibility and you need to take him!" And so again, Teresa said to the DDA-Supervisor, "She doesn't have any place to take him, there's no place!" Nora and Teresa were upset because they felt they were being asked to risk Nora and Owen's safety. Meanwhile, they did not even know if Owen still had a home at the LSR. Nora apprehensively agreed to stay with Owen at a hotel while the LSR was closed, but with the expectation that it would reopen soon. Sadly, there were not any crisis options for Owen or the growing number of other children in Washington who are experiencing a placement, behavioral, or psychiatric crisis.^{xiv}

DDA's OHS program is small. Families report that when they tried to ask for OHS for their child, there were frequently no spots available, or an available spot was on the other side of the state. Another option, for youth having behavioral crises, is the DDA-funded crisis program called Intensive Habilitation Services (IHS).^{xv} However, there is only *one* IHS facility that can help only *three* children at a time for the entire state. A state-funded crisis service, Children's Long-term Inpatient Program (CLIP), only has ninety-four beds for the whole of Washington.^{xvi} To add perspective, "on any given day, an average of 33 Washington children are in emergency departments, hotels or acute care units waiting for a long-term bed...wait times range from one to four months."^{xvii} Because there are not enough spots, crisis services are hard to access; none of the families in this report could get their child into IHS or CLIP. This means that, because there are no other places for youth to go, hospitals become the only option.

While Nora was staying with Owen at the hotel, she said that because "Owen was out of his comfort zone, he became upset, and he didn't understand why he wasn't at home anymore." Meanwhile, Nora, who is low-income, paid a thousand dollars for the hotel room.

When the day the LSR was supposed to reopen passed, then the next day, and then the next, after three days, Nora realized that help was not coming for Owen. Hoping they could get Owen help, Nora and Teresa called and reported themselves to Child Protective Services (CPS). During the phone call, Teresa remembers that “The guy from CPS who we’re dealing with says take him to the hospital. And I’m like, ‘To the emergency room? What would they do?’”

On the advice of the CPS social worker, Nora and Teresa took Owen to the hospital. When they arrived at the emergency room, the on-duty nurse took Owen to a room that would eventually only have a bed on the floor and a chair. Nora and Teresa hoped, now that Owen was at the hospital, “Well, maybe something’ll happen now.” Soon, meetings started with hospital social workers, Managed Care Organization (MCO) representatives, and DDA-workers who arrived at the meeting week after week to say the same thing: there was nothing they could do. Meanwhile, Owen waited, and waited, and waited. Because there are no options, youth wait in the hospital, sometimes, for months.

When someone, like Owen, is “socially-admitted” to a hospital, it means they do not have a medical reason to be there, but there is nowhere they can go. Social-admits at a hospital are extremely expensive, *The Seattle Times* states “one day...costs \$1,670”^{xviii} and costs “exceed \$20 million annually.”^{xix} This is partially because insurance companies cannot reimburse hospitals for their costs if there is no medical reason for someone to be there.

When a DDA-client is stuck in the hospital, typically, DDA-workers organize “transition planning” meetings to organize all the workers who can help and gather resources to get someone the services they need as soon as possible. However, there are rarely any services these workers can offer, and youth and their family-members have their hearts repeatedly broken. For months, meetings happen where, sometimes, over a dozen different workers can offer a child nothing. One parent, when remembering the meetings for their child, explained how painful they were:

Very few people came up with any solid ideas. It was more like, “Well, we can’t do this, it’s your job! No, it’s your job! Get it off the desk!” In the meantime, my kid just got sicker and sicker.

What good does that do the kids? Sometimes, there are twelve to fifteen people involved in meetings on my child. So everybody can attend meetings and say, “We can’t do this and we can’t do that?” And my kid, his case kept jumping up from a regular case manager to the supervisor, to the regional supervisor. Up, and up, and up, and up, and up to where you’re dealing with the highest up. And they’re in on the meetings and they don’t want to do anything.

It’s not even—it’s not a kid to most of these people who are making decisions for this child. Never even met him. They know nothing about him. Nothing. And it’s like, they’re going to make such life altering decisions for a kid, you should at least come meet the child. I think he—he’s a human being! It’s a person, it’s not just some number or some case—it’s a real person in there.

When there are no options for a youth stuck in the hospital, it is painful for families to attend meetings where workers cannot offer anything. Even if a DDA-worker is doing their best to try and get a youth services, there is nothing they can do if there is simply nothing available. Being stuck in the hospital is an expensive, grueling process that makes children with intellectual and developmental disabilities and their families feel uncared for and neglected.

For the months that Owen was stuck in the hospital, Nora slept next to him every night, she said, “I would wake up, I would go to work, and I would come back to the hospital.” Eventually, Owen happened to get a spot at a Licensed Staff Residential (LSR) that Teresa says he was “lucky” to get. However, the new LSR was hours away from Owen’s family. Because there was nowhere closer, Nora accepted the LSR spot on the condition that DDA would help her visit Owen. However, after Owen moved in, Nora says DDA did not follow through on helping them visit one another.

When there are no services to help youth who are in a crisis, until a spot somewhere becomes available, youth with intellectual and developmental disabilities are in unwinnable situations with no choice but to wait at the hospital. Meanwhile, family members look for help from workers who do not have any services available to suggest. One of the reasons good emergency options are so important is because hospitals are not meant to provide long-term crisis support. The next section shows why hospitals are terrible emergency placements and do not always meet a youth’s needs.

The Last Time He Went Outside: Hospitals Are Not Long-Term Crisis Stabilization

Audrey took her teenaged son, Karter, to the emergency room because she was scared that she could not keep Karter or herself safe. As of writing this report, Karter is still stuck in the hospital and has not been outside for 274 days. When Audrey begged hospital social workers to let Karter out of his room for a short walk, she was told no because it would be a liability issue. Audrey pleaded, “Can you let him walk around on the roof so he’s not leaving the building?” “No.” Because acute-care hospitals are not meant to be places for long-term crisis stabilization, when intellectual or developmentally disabled youth are stuck, they are not able to get services they need.

This is not the first time that Karter has been stuck in the hospital. A year before, Karter stayed at the hospital for three-and-a-half weeks. Audrey says, “Every single day the hospital tried to convince me to take him home and every single day I had to say no. And then, they basically just pushed him out the door because, ‘Well, he’s stable and you’ve got a safety plan in place.’” A year later, Audrey says Karter was back at the hospital with everything worse than when it started. Other family-members also cited hospital-workers trying to discharge a youth before making sure they had services they needed at home. Oftentimes, if family-members could not find services, they would refuse to bring their child home. Consequently, hospital-workers threaten to report family-members to Child Protective Services (CPS) for abandonment.

Hospitals clash with parents on whether refusing to pick up their child is abandonment. On one hand, parents want to make sure their child has what they need to come home safely. On the other, hospital boarding is expensive and hospital-workers need beds to be rotated quickly so they can treat the next patient. As a result, family-members said that hospital social workers were not always kind in their attempts to have them pick up their child from the hospital. For example, one social worker threatened that they had authority from the hospital’s lawyers to put a youth in an ambulance, have the paramedics drive them home, and then drop

them off on the curb. Ultimately, hospital-workers are pressuring the wrong people. Since hospitals are required to ensure a safe-discharge^{xx} for all patients, they should direct their advocacy towards systemic change and helping a youth get the services they need to live in the community. However, as previously mentioned, finding services for youth with intellectual and developmental disabilities is not easy.

Over the past 274 days, Karter needed services at the hospital to teach him skills that could help him safely discharge. However, Audrey says she was told that because Karter is in the hospital, he does not qualify for his DDA-waiver services until he leaves the hospital again. Simultaneously, because there is no medical reason for Karter to be at the hospital, Audrey said she was told he does not qualify for insurance-funded treatments. Until he leaves the hospital, Audrey says Karter does not qualify for anything.

DDA's waivers are federally funded through Home and Community-Based Services (HCBS).^{xxi} Waiver participants "waive" the right to get services in a medical or institutional facility and choose to receive services in the community. However, waivers have a key condition that complicates how youth can access services: waiver services cannot be duplicated if someone is getting a similar service through their insurance-provider.^{xxii} Normally, when someone is sick and needs to go to the hospital, it is paid for by insurance. What does this mean for youth who are stuck in the hospital and need services? When youth are living at hospitals, they are not living in the community anymore; HCBS waiver funding cannot be spent on services in a hospital. Because a youth is not technically admitted to the hospital and is only "socially-admitted," families report that their child's insurance-providers said they do not qualify for insurance funding either. This means youth cannot receive services from their waiver or insurance, leaving them with no options.

At the hospital, Karter lives in an eight-foot-by-eight-foot room with no windows. Audrey says that not being able to go outside, run, play, and be a kid changed Karter completely. While DDA-workers try to find a place for Karter to go, he waits until someone can do something to help. Very few people grasp the severity of what it means for a person to be stuck at a hospital for months, so it is important to know *exactly* why being stuck in the hospital

is inhumane. Hospital policies often do not allow children to leave their rooms or go outside. A parent said their child's hospital room reminded them of a cage: "He couldn't be a kid. He couldn't go outside, he couldn't do anything. And then, when he did try and go out, the nurses would say, 'Go back to bed.'" If a youth is lucky, maybe they will have a television in their room, but otherwise, they have nothing to do all day. Another common complaint from parents is that their children are over-medicated. Audrey said, "They increased Karter's antipsychotic. Twice. They've added a bipolar med. And I understand that it's because they're not a pediatric psych ward and don't have the ability to deal with him the way they need to. But where's his quality of life?" Other youth who were stuck in the hospital also experienced physical restraints and social isolation from being in the same room all day with nobody to talk to.

While writing this, Karter is still stuck at the hospital. However, Audrey shares that after five months, the hospital moved Karter out of the emergency room:

Now, he has a room with a window and he loves the window. He's spending a lot of time just staring out the window and laughing. I feel like he's experiencing a freedom he hasn't got to have for quite some time.

Hospitals are not meant for people to live there long-term and should never, ever replace crisis stabilization services. As the next section will discuss, not having enough services in Washington means that a disabled youth might even have to go to another state.

"I Want to Go Home": Expensive Out-of-State Placements Separate Families

It is a Monday afternoon in June. It is rainy in Washington, where Brie, Michael's Mom is, and Michael says it is boiling hot at his out-of-state placement. Michael and Brie are at their weekly twenty-minute Zoom call. It has been less than a week since his first visit home to Washington. Michael is excitedly telling his Mom about how he went on a fieldtrip to the dinosaur museum, just finished nine books in seven days, and is looking forward to baking his favorite cake together the next time he visits, Brooklyn Blackout Cake. Michael's face starts to

shift, and he raises his arms to cover his head. Brie notices and asks him, “Your face is really sad all of a sudden, is there something that’s making you feel sad?” Michael peeks out from behind his arm and whispers, “I miss you, Mom. I want to go back home.”

It has been fifteen months since Michael left his family in Washington to live at an out-of-state placement. After a terrifying police encounter when Michael was almost arrested, Brie says she decided to ask Michael’s school district for help finding an out-of-state placement. Brie says that, even though Michael had about twenty police interactions in the past, this was the only time Michael was ever threatened with an arrest. Brie attributes this to her family being white and outwardly passing to others as having class-privilege. There were no services for Michael in Washington, so an out-of-state school that was two-thousand miles away and cost \$300,000 dollars a year was the only place he could go. Because Washington does not have enough services for intellectually or developmentally disabled youth, families sometimes make a heartbreaking decision: to send their child to an out-of-state placement. Recently, the number of youth sent to out-of-state placements has increased, which has lead family-members and advocates to question if the conditions at out-of-state schools can meet children’s needs. When youth are ready to come home, family-members still encounter difficulties ensuring that they can get the services they need in Washington. By not investing the money spent on out-of-state placements in Washington, families say youth with intellectual and developmental disabilities are funneled into expensive out-of-state schools and institutions that separate their families.

After seeing Michael’s tears, Brie took a deep breath. She began to tell Michael how, after he left, she sat in his room and held his stuffed animals and she was giving his pets his love every day. Michael smiled widely and told Brie, “I want to chain myself around the fence post, so they can’t haul me away from the house.” Brie looked back at Michael through the computer screen, smiled slightly, and said, “I know, buddy. Nothing about this is going to be forever.”

As the number of disabled youth sent to out-of-state placements grows, more families are experiencing painful separations. Family-members are angry that it seems like more state-

resources are spent on sending their kids out-of-state, than helping them stay at home. Instead of spending money on out-of-state placements, parents felt that the money should be re-allocated to services in Washington.

In 2020-2021, Washington school districts sent eighty students to out-of-state placements. In 2016-2017, there were nearly four times fewer students sent out of state.^{xxiii} The price tag is steep: \$13 million altogether and as high as \$315,000 per student.^{xxiv} Family-members felt outraged after hearing this number, especially, after not getting the services they needed at home. When a family-member was told how much an out-of-state placement costs, they said, “If they have a home and they’re wanted in the home, why not take a little chunk of that money and put it towards behavior support?” What matters more than the cost, is that youth at out-of-state placements do not want to be there, they want to be home with their families. During the call with Brie, Michael kept repeating the same demand: I want to go home.

Brie is worried about the conditions at Michael’s school. Brie says she snuck the books that Michael read last week into his luggage; books and music are against the school’s rules because they encourage “behaviors.” After Michael arrived at the out-of-state school, Brie says Michael lost weight because school staff would not make him sensory-friendly food and he was only allowed to eat what staff gave him.

Brie says that school staff told her that involved parents are abnormal for the school. She says, “I am in-contact with the school at least a couple times a week. I make the psychiatrist call me at their visits. I make the pediatrician call me. I recently found out that that’s not normal and they were annoyed with me that I was constantly in their face.” During a meeting with Michael’s support team at the school, a doctor told Brie that “Well, once they live here, we take care of them, and the parents don’t participate in any of that.” Brie replied, “Well he’s my son, so anything you do with him, you’re going to need to call me about. He lives with you, but he is my son.”

This is not even the first time Michael has left Washington. Three or four years ago, Michael was suicidal, but left Washington because no psychiatric services would treat him

because of his Autism. Brie says bringing Michael home was hard. Washington providers and schools would not work with him because, as Brie said, “they didn’t know how to take care of kids that have been in facilities.” To make matters worse, Brie says that because of rules and policy, Michael came home with no community-based services. This means that Michael could not access any DDA-services he was receiving before leaving Washington and still needed. Brie says, “That’s the first time Washington failed him.”

Like getting services when a youth is stuck in the hospital, it is hard for youth at out-of-state placements to come home with services in place. There are a couple ways that a disabled youth can lose their DDA-waiver. First, if a youth’s out-of-state placement is funded through insurance,^{xxv} they are living at a medical-facility. By living in an insurance-funded medical facility, a youth waives their right to live in the community and their DDA-waiver. However, if the funding for an out-of-state placement is coming from a child’s school district,^{xxvi} they are still living in the community and can keep their waiver. The second way a youth can lose their DDA-services is if DDA does not consider them a Washington resident.^{xxvii} When a youth is at an out-of-state placement, the determination for Washington-state residency is up to DDA’s discretion. If a youth loses their DDA-waiver before returning to Washington, they must go through the entire onboarding process for DDA-waiver services all over again. When youth cannot get DDA-waiver services to help them transition home, they are not getting the services they need; youth not being able to get services is the same thing that causes out-of-state placements. Without a way that youth can keep their waiver eligibility, rules and policies create barriers that make it harder for families to reunite with one another. Brie said it plainly, after all the therapy Michael received at the out-of-state school, “He had nothing. He came home with nothing.”

Expensive out-of-state placements take youth with intellectual and developmental disabilities away from their families. Washington-state needs to reinvest and reevaluate how it allocates money spent on out-of-state placements so youth can receive care at home. By not investing in Washington services that give meaningful choice to youth and their families, the

upward trend in youth who are placed at out-of-state facilities could continue to increase, along with all the harm it causes.

As Brie tells Michael what they will do together when he visits in August, a door opens, and it is the end of their twenty-minutes together. A muffled voice tells them that Michael's time is up. Brie rushes to tell him, "Michael, you seem extra sad today, if you're feeling really sad tell someone or ask to call me again, do you promise?" He nods quickly and replies with an abrupt "Goodbye, Mom." The computer screen goes dark.

"So, for fifteen months, twenty minutes a week and three visits. That's all we get."

"Lonely and Scared": The Need for Trauma-Informed Community Healing

According to Deanna, Max's Mom, Max has been to the hospital thirteen times and has had twenty-three police interactions. Police usually took Max to the hospital, but the hospital always discharged him immediately for not meeting treatment criteria. For the nineteenth and twentieth police calls, the police charged Max with felonies and took him to juvenile-hall where he spent seventeen days. Despite all the other youth in this report, who are white, having similar incidents, Max, who is Black, was the only one who the police arrested.

When Max came home after being sent to juvenile-hall, his Mother, Deanna, and him were driving down a highway. While Deanna drove, she warned Max that, as a disabled Black person, he needed to be more careful or "the police will come back and take you to juvie or the hospital." Max panicked, thought he was going to have to go back to the hospital or juvie, and grabbed the steering wheel. The car veered off the side of the road, missing trees and getting stuck in a ditch. When the police arrived this time, they asked Deanna, "You know the routine, what do you want us to do?" Deanna replied, "If this doesn't meet criteria for a hospitalization, I don't know what will." The police took Max to the hospital. Again.

One of the first times the police took Max to the hospital, the hospital-staff called Deanna and said, "Okay, he doesn't make criteria, come in and get him." I said, "No. I'm not coming and getting him. He's there for treatment, the police brought him for treatment, you

treat him.’ And the charge nurse said, ‘So, you’re abandoning him?’ I said, ‘I am not abandoning him.’ ‘Well, if you don’t come pick him up, we’re going to call the police on you and you’re going to be charged with abandonment.’ I said, ‘Do what you gotta do.’ They were saying this right in front of him. Max learned a new word. Abandonment.”

Previous sections explored how disabled youth cannot access at-home services, crisis intervention, what it is like to be stuck in the hospital, and the pain families experience because of out-of-state placements. However, this report has not discussed how these situations cause systemic traumas to youth and their families. To heal and repair these systemic traumas, youth with intellectual and developmental disabilities are asking for trauma-informed community healing that centers their right to dignity, humanity, and self-determination.

At the hospital, Max was committed to the psychiatric ward via the Involuntary Treatment Act.^{xxviii} While Max was at the hospital, Deanna says he was attacked by other patients, because the hospital-staff said his vocal stims “agitated them.” The hospital-staff moved him to an isolated area of the ward, “for his own safety” and Max was not allowed to participate in group therapy. This left Max feeling lonely and scared.

Family-members and youth say not being able to get their needs met has been a traumatizing experience. For example, family-members felt anxious and suicidal from pressure by social service workers to get their child out of the hospital. A family-member confided, “This whole thing and pressuring me to find a solution pushed me to the edge. I had to go to triage for a week because I was thinking of suicide.” Family-members also say that, after being stuck in the hospital, intellectually and developmentally disabled youth experienced personality-changes and new triggers. A family-member said their child “Would sometimes cry. He was not his giggliest self, he wouldn’t smile.” Deanna says that, after being in the hospital, Max cannot be around loud noises and crowds anymore. The biggest trauma that youth and families shared was feeling upset and abandoned. Youth and families expected that, at the worst moments of their lives, they would have gotten help. Instead, families say they received inadequate services, inhumane treatment, and isolation. By not providing families with the necessities they need, Washington’s social service system is causing harm to the people it is

supposed to help. Deanna said the system taught Max that “For the longest time, no matter what he did, nothing was going to happen. What are you doing to these kids? Nobody, I mean, absolutely nobody is doing anything to help these kids or to try to do anything to turn their life around. Their life is disintegrating. And nobody seems to care.”

Staci K. Haines, co-founder of generative somatics,^{xxix} defines trauma as “experiences, series of experiences, and/or impacts from social conditions that break or betray our inherent need for safety, belonging, and dignity.”^{xxx} For an individual, Haines says that traumas cause a person to become separated from society and their community. For a collective of people, Haines says, systemic trauma is “the repeated, ongoing violation, exploitation, dismissal of, and/or deprivation of groups of people of people.”^{xxxi} This means systemic trauma is caused when one group of people has the power to gatekeep the means of safety and dignity from another, less powerful, group. Haines says that “violations that occur frequently, and across many communities show us that there is something in the social and economic fabric that actually supports, or allows for, their occurrence.”^{xxxii} In other words, the way that social services are administered is traumatizing, because they do not enable disabled youth to receive resources that allow for safety and dignity.

One way for youth and families to regain the safety, belonging, and dignity they have been denied, is to ensure that youth have access to the services they are asking for. For individual healing, youth and families say they need to be able to talk about and process their traumas. Family-members worried that current DDA-waiver services did not have opportunities for this: “They need to have robust trauma counseling and not just behavioral modification. They need to be talking to our children, figure out what’s going on, and helping them put words to what they’re feeling. Because my son didn’t have the words, he couldn’t tell me he was mad, or sad, or angry.” To heal as a collective, youth want to connect with other disabled peers. Max felt nervous describing how he felt when he was at the psychiatric ward and juvenile-hall. Deanna and Max sat together as she helped Max explain how the worst part of being stuck in the hospital was feeling lonely and scared, with nobody to talk to: “Max was telling me if he just had somebody that he can pick up the phone and call that might have

helped him. Or if some other child wanted to call and talk to him and he could tell that kid a little bit about what he's gone through or how he felt." By connecting as a group, disabled youth can make movements towards regaining a sense of community, which could eventually be a space to make demands to realign systemic power.

Because so many youth and families encounter difficulties when trying to access services they need, Haines would say that "there is something in the social and economic fabric that actually supports or allows"^{xxxiii} for this "deprivation." When many disabled youth and families are denied access to services which would give them safety and dignity, they are experiencing systemic-trauma inflicted by Washington's social service system. To heal as a community, youth, and the families who support them, need agency and structural power to determine their needs, get help when they say they need it, receive kindness when accessing care, and stay in their homes and communities. Until disabled youth have their needs met, they will continue to ask for their rights to dignity, humanity, and self-determination.

Recommendations

Crisis Intervention

Recommendation 1: Develop an accessible, trauma-informed peer mentor program run by and for youth with developmental disabilities.

Problem: Many youth with developmental disabilities experience isolation, loneliness, and traumas due to not being able to have their needs met. Family-members worried that existing services did not provide youth an outlet to be able to heal and talk about how they are feeling.

Solution: Create a trauma-informed peer mentor program run by people with developmental disabilities for youth with developmental disabilities to create a space where disabled youth can heal together as a community.

Recommendation 2: Invest in supporting Medicaid-funded crisis intervention services, like WISE, so they can help youth with developmental disabilities.

Problem: Family-members of youth with developmental disabilities said that their child was turned away from early-crisis intervention services, like Wraparound with Intensive Services (WISE), because of their disability. This left youth with developmental disabilities unable to access important mental health services.

Solution: Because WISE is a Medicaid-funded service, WISE must provide equally beneficial services to everyone. If WISE, and other crisis intervention services, do not have the expertise to provide equal benefit to youth with disabilities, then WISE needs funding support. Investing in crisis intervention services would enable these entities to hire or train workers who have the skill to provide accessible services to disabled youth.

Recommendation 3: Collect data on when DDA-providers initiate police interactions for people with developmental disabilities.

Problem: In Washington, DDA does not track how often providers are using police in lieu of appropriate crisis interventions. Having collated data would help indicate when providers are

not trained in appropriate de-escalation techniques and do not have access to resources they may need to offer better services.

Solution: DDA needs to start tracking the frequency of provider-initiated police interactions in lieu of appropriate crisis de-escalation. If specific providers have high rates of police interaction for the people they serve, then it should be an indicator for additional training and resources to replace an over-reliance on police.

At-home services

Recommendation 4: Offer expanded twenty-four-hour, in-home personal caregiving services for youth with developmental disabilities.

Problem: The most-requested service that family-members of youth with developmental disabilities asked for was increased hours for personal-caregiving. Primary-caregivers cited feeling unsupported, while youth with developmental disabilities did not receive the caregiving attention they needed.

Solution: To fix this, add expanded twenty-four-hour in-home personal-caregiving services to the CIIBS Waiver so youth can stay in their family home. With expanded personal caregiving services, youth with developmental disabilities can receive around-the-clock support and family-members will not experience burnout.

Recommendation 5: Fund and create a state-operated personal-caregiving service which has the capacity to serve the number of people who need in-home personal caregiving.

Problem: Current personal-caregiving agencies are private companies and have prohibitively long waitlists which do not enable families to get the services they are entitled to. The lack of available personal-caregiving services contributes greatly to a family-member's choice to request Out-of-Home Services (OHS). Even if a youth does have enough caregiving hours, the hours are useless if family-members cannot find a provider to fill them.

Solution: Fund and create a state-operated personal-caregiving service which has the capacity to serve the number of people who need in-home personal caregiving. To attract applicants, offer competitive salaries, wages, and benefits to incentivize employees to continue in personal-caregiving as a long-term career and to maintain the workforce.

Recommendation 6: Develop and fund an effective cross-systems care coordinator role that can help families across all DSHS-services.

Problem: Family-members of youth with developmental disabilities are overwhelmed by the amount of work to coordinate their child’s services. Without the help of a professional, DSHS’ bureaucracy is prohibitively complex for a family-member to navigate which can lead to burnout. Consequently, youth with developmental disabilities are not able to access the services they need to succeed, grow, and thrive in their family homes.

Solution: Develop and fund a cross-systems care coordinator role that can help families across all DSHS-services. Family-members want and need help from a cross-systems care coordinator who can actively educate family-members on all available services, communicate and organize services across organizations, and facilitate cross-systems and wraparound care coordination. Most importantly, a care coordinator role would be able to help a family use Washington’s social service system as a system and not as disconnected services.

Out-of-Home Services

Recommendation 7: Expand Intensive Habilitation Services (IHS) so that youth with developmental disabilities have short-term, crisis stabilization options available in-state.

Problem: In the entirety of Washington, there is only one DDA-funded short-term crisis option for youth. Furthermore, Intensive Habilitation Services (IHS) only has the capacity to serve

three youth at a time. Only having one IHS facility for the entire state does not meet the demand for youth who need short-term emergency placements.

Solution: Fund and create more IHS to serve youth who need short-term crisis stabilization services.

Recommendation 8: Develop policies and procedures that protect youth with developmental disabilities who are at risk of losing their residential placement.

Problem: Critical Case Protocol (CCP) protects adults with developmental disabilities who receive supported-living services if they are at risk of losing their placement. However, youth with developmental disabilities do not have a similar policy that protects them when their placement is at risk. This leaves much of the crisis-response management up to the discretion of the DDA Case Resource Manager and does not adequately protect youth.

Solution: Develop a policy, similar to Critical Case Protocol (CCP), that protects youth with developmental disabilities who are at risk of losing their residential placement.

Out-of-State Placement

Recommendation 9: Create a DDA out-of-state caseload for youth with developmental disabilities, with the purpose of helping children return home to their families in Washington.

Problem: When youth with developmental disabilities want to return to Washington from their out-of-state placement, they are not able to resume the same services they had before they left. Not having in-state services set up before a youth comes home is risky because their care needs are not being met; the entire reason that a youth was sent to an out-of-state placement in the first place.

Solution: Establish an out-of-state caseload with Case Resource Managers (CRMs) whose role is to help youth at out-of-state placements return home. Youth who are sent to out-of-state placements should automatically be assigned an out-of-state CRM. This CRM should actively

search for and organize services in Washington by collaborating with the youth’s family to ensure that they have everything they need when they return home to be successful.

Recommendation 10: Reallocate the \$13 million a year spent on out-of-state placements for youth with developmental disabilities to services in Washington.

Problem: Washington school districts are spending \$13 million a year on out-of-state placements for youth with disabilities.^{xxxiv} Instead of ensuring that youth with developmental disabilities’ needs are met in state, money is being spent on expensive out-of-state placements that separate youth and families.

Solution: Reallocate the \$13 million a year spent on out-of-state placements to provide services in Washington so that youth with developmental disabilities are not separated from their families, can receive services in their homes and communities, and end out-of-state placements.

Conclusion

By not helping disabled youth and their families access the resources they ask for, Washington’s social service system has created conditions that do not allow youth to thrive in their homes and communities. Offering services that youth and their families need, like trauma-informed peer mentorship and expanded personal-caregiving, would help prevent out-of-home and out-of-state placements so families can stay together. Ensuring that youth can access comprehensive community services is a start towards allowing disabled people to live rich, full lives that are founded on their rights to self-determination, dignity, and humanity.

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^{xxxiv} Criscione, Wilson. “Why Washington Is Shipping More Disabled Students out of State, Splitting up Families and Costing Taxpayers Millions.” *InvestigateWest*. February 22, 2022. Accessed July 28, 2022. <https://www.invw.org/2022/02/22/why-washington-is-shipping-more-disabled-students-out-of-state-splitting-up-families-and-costing-taxpayers-millions/>.