Governor’s Committee on Disability Issues and Employment (GCDE)

Community Outreach Subcommittee meeting

January 10, 2023

4:00-5:00pm

Minutes

1: Welcome to the Community Outreach meeting – Marsha took a few minutes to check in with everyone while folks were still joining. People were reminded that the email about today’s meeting and attachments (agenda) were sent out in advance. The meeting was called to order.

2: Roll Call – Present were: Emily Heike, Ryan Bondroff, ASL interpreter Aaron Medlock, Marsha Cutting, Patti Dailey-Shives, Amy Cloud, Andy Song, Warren Weissman, Damiana Harper, and Daniel Ledgett. Absent were: Matt Nash, Elizabeth Gordon, Nathan Hoston, and Associate Member Lucy Barefoot.

3: Housekeeping rules – suggestions for housekeeping rules were requested, and it was stated that folks should please state their names prior to speaking, and hearing no others the group moved onto the next agenda item.

4: Brainstorming about the future of the committee – Marsha confirmed that everyone had a chance to review the email from Ryan sent prior to today’s meeting regarding her thoughts about how the subcommittee currently operates, and how we may consider changing that going forward. No one stated otherwise. Folks expressed their appreciation and gratitude to Marsha for bringing this forward, and agreed that even though some folks are relatively new to the committee, they felt it was a bit odd that we bring the disability community together to discuss their concerns one night but then seemingly do not include them the next morning in the solution-building. People felt it was important to be able to include disability representation in the conversation, and put a face to the issues, rather than just presenting them to leadership. We have to practice what we are preaching with regards to Nothing About Us Without Us in the legislature, in other words. Folks agreed that we can thoughtfully address this and look at it in terms of what has been brought up. Those new to the committee expressed that they did not necessarily understand what GCDE did before joining, but have learned a lot, including about the partners and allies involved in this work, both locally and relating to certain issues that they were not previously aware of or involved in. They equated it to pulling a thread and now being left with a ball of yarn. Folks agreed that we should not be speaking for those we serve or represent, but rather, create the venue and a channel for that message of lived experience, as those folks are the best ambassadors of their needs and message. It isn’t always clear how we can help facilitate it, but that does seem to be the issue at hand.

It was noted that a lot of those on our committee are people with disabilities, sometimes speaking of our own experiences, not just in service roles. The reminder was noted that sometimes folks are speaking for themselves, too. It was stated that the majority of our committee is required to be people with disabilities. People with disabilities seem to be present at the Town Hall meetings, but not at the LAP meetings necessarily. In Port Orchard, we made a point of inviting the local county ACAC members, but that may not have been the practice in years past (or even a possibility, depending on if the location we were visiting had an ACAC). Marsha thanked everyone for their agreement, and wanted to ensure there were no concerns. Amy wanted to mention that we should be thoughtful about making this change, and don't mean any disrespect towards what has been done before, as we are standing on the shoulders of that work. It was agreed that while historical knowledge is great, it doesn't necessarily mean that it's how we need to continue doing things, and that there is a lot of value in new approaches. We need to make sure we have the voices of people with disabilities throughout the whole outreach process. And though many of us on the committee identify as having disabilities, or family members with disabilities, or work with people with disabilities – we are there more to facilitate the discussion than to provide input or influence decisions (unless participating as a community member). This has happened in the past with ACAC's before as well, in Shelton, and in Walla Walla. We do try to partner with them where possible, but it isn't always feasible if there isn't one established.

Marsha realized that the three questions were likely more than we could cover in the meeting today, and reminded folks that we do have a 3-hour meeting scheduled in February, but wanted to at least overview and look at the questions, so that we can be thinking about them and answer them more fully in February. Looking at them again, Marsha realized that she may not have necessarily put them in the correct order, since we asked what the needs of folks with disabilities across the state are, and then what questions we might need to ask to answer or learn more about that. She believes that every Outreach has likely highlighted the issues of housing, transportation, and employment, but that one thing that hasn't been addressed thus far is the crisis of in-home care providers for those living with spinal injuries, or intellectual or developmental disabilities, for example. She shared the story of one individual she knows who is in their early 20's and has been living at home for their whole life, as they need 1:1 care full time, which is currently being provided by their mother and grandmother – but the grandmother is 85 and it's getting to be too much for her, and they are really having difficulty finding someone else to provide care, in part due to the lack of pay differential for providers who are providing more complex care at odd shifts (as opposed to those with less intensive care and regular shifts).

Marsha also brought up Andy's point of the psychiatric boarding of young people in emergency rooms. There has also been a Washington Post article released about this recently. These are people who had been living and home, and for one reason or another, whether related to the pandemic or not – their condition has been exacerbated and they start acting out or being aggressive. Of course, this puts a strain on their families, who often times end up leaving them at the emergency room so that they can get on a list for placement in a facility that can meet their needs. However, these facilities are few and far between, and beds at them are even more so. This means that they can be left in the ER's for a year, 2 years, sometimes more. So, this is another crisis, and in some cases, they don't have any place to go. Andy was asked if he would like to comment on this topic.

Andy thanked Marsha for bringing this up and said he could talk a bit about it. One of the main issues with this is lack of any kind of adolescent or child services for kids who are on the autism spectrum, or who have intellectual or developmental disabilities or delays, and are not often included in the discussion when it comes to legislative work or the thoughts around the process of access to care and services for Washington and nationwide. Seattle Children's is the only hospital that will serve children who have that autism or IDD diagnosis. When discussing access to care, this leaves out a large chunk of families, for example those in other locations such as the Eastern, Central, or more rural areas. So we might consider a dialogue around what outreach and education to that population could look like, including community members and families, but also any other stakeholders involved with the care and support needs. Law enforcement is another one that often comes up. Currently, only the Renton Police

Department has any sort of training on autism and IDD incorporated into their program in WA, and even that is only an hour-long overview. So, it's an issue when this population, who often times has a limited ability to communicate, and law enforcement sees them behaving in ways that could be construed as atypical or aggressive, they have no training for how to handle that and don't realize that sometimes that is the only way that these kids have learned to communicate. The same thing happens with fire departments. Sometimes, in rural areas, they are the only ones available to respond. One recent case that comes to mind is that of a family who the fire department responded to their call about their child with an intellectual disability running into traffic and not having those safety or awareness skills. The police didn't know how to respond either, so essentially they ended up sedating the child who was perceived to be aggressive, and intubating and airlifting him to Seattle Children's and he woke up a couple days later with no idea what was going on.

It all comes down to a lack of community education, and that there is a lot of steps to accessing care, and the overwhelmed families don't know how to navigate these systems. So, the question is, how do we serve this population? That is something that has been left behind in a lot of our efforts.

Marsha noted that Andy has accepted the position of Vice Chair of the committee. She believes one thing that we'll have to keep in mind when addressing this issue are the various different parties involved, such as the Developmental Disabilities Administration, and others. We'd likely need to partner or work in cooperation with them on this issue.

Andy shared that he has noticed that it falls under multiple jurisdictions in terms of who has ownership or involvement or leadership in different areas. Where he sees us fitting into this puzzle is doing more community education and pulling communities together, since there are so many groups and people involved, that it can get sort of blurred. You don't always know who has authority over what, so that may be something that GCDE can help facilitate or streamline that conversation, because of lot of things can get lost. This was added as an agenda item for the 3-hour meeting.

A question was posed about the number of children at Seattle Children's who had been left in the ER in this type of situation that we've been discussing. Andy shared that he actually has date from hospitals nationwide on this, since there are so few that serve those with ASD and IDD, and they meet every other month. For WA, it's a little over 30 children across the state who have been left in that way and don't have the systems setup to be supportive to their needs. Of those, there are a handful who he would classify as actual abandonment, who have just been dropped of in the ER, the parents leave, and in a couple of high-needs cases the parents can't even be reached or known who they belong to. Seattle Children's is boarding probably half of those 30, and the others are spread amongst other emergency departments across the state, such as Mary Bridge, Swedish, Providence, and Sacred Heart in Spokane. Those hospitals don't know what to do because they don't have programs or services designed for those families or that patient population, because Seattle Children's is the only one setup to do that. The others are just sitting the ER's or urgent care rooms and are not receiving any care other than being bathed and fed.

Marsha shared that in the recent Washington Post article, the parents were told that if they took their child home, then they would drop to the bottom of the list as far as getting a bed in a designated treatment facility, so they were essentially told to just leave the child there if they wanted any hope of getting a bed at a facility.

Andy said that this is a complicated topic that he has provided training on. What happens is that when the family identifies that out of home services are necessary, and that's the next steps that they want to pursue, there are three different options. The first is called residential treatment centers. This is paid by insurance, whether private or Medicaid, and it is out of home services where the child will go to a facility to be served. However, in the case of residential treatment centers, the primary reason has to be medical – meaning that, say, the child has a seizure disorder or uses a feeding tube or has any other medical concern. That is the primary reason for the escalation and severity of their related behaviors, where they can't be served at home. The second path is called an educational residential center, meaning that if a child has extreme behaviors and are unable to be served in a school setting, and the primary goal is education – then the school will pay for an out of state long term educational residential center. And the third one is in-state where it's paid for by the Developmental Disabilities Administration, and it's called out-of-home services waiver or supported living programs. And these are essentially group homes where the state will either pay for a contracted agency that runs group homes, or a state-run group home. What they run into is when a family tries to get on lists for these services, when you use specific terms of keywords, it's essentially a game of semantics. If you say that the child has no medical needs, then residential treatment is automatically ruled out. If you say that the child needs education, then the school will pay out, and if you say that the child needs out-of-home services but can't engage in school then supported living is no longer an option, so families are in this spot where no matter what they say, if their child is a complex case and has multiple needs, then all the of the agencies essentially fight each other in this cycle of who is responsible. There is one child currently at Seattle Children's who has been there for 500 days, had 2 birthdays there, where this is what they are running into. It's the funding source that they are fighting amongst each other, saying no, this isn't medical or yes it is. Or one group is saying that it is educational, and it can get to just be a big mess. The terminology can be confusing because it is residential treatment, residential education, or residential supported living. And families are trying to navigate these systems on their own, while caring for their child with complex needs, so it is difficult for them and easy to get lost in the system.

Another thing is that there is a barrier because there are no in-home applied behavioral analysis or any other type of therapy with in-home supports. That's where there's a wait list, and it's very long. So, when families or organizations say that they are waiting to be put on those lists, that's likely what they are referring to. And they aren't necessarily a chronological list, meaning that if you were 10th in line, you would get the 10th bed that opened up. They are more so pools of applicants. So, say, if a child is on the wait list for a residential treatment center. There might be another child who applies to the same place a month later, and gets in sooner, because the residential treatment center (or either of the other two options actually), whenever there's a bed available – they look at the entire pool of referrals and take the child who would be the best fit for the existing population that they currently have. So, when it comes to the discussion of waitlists, it's hard, because we can never know when an appropriate bed is going to open up where the child is going to match with the existing groups of children that the agency is currently serving. There's a group on Facebook called the Severe Autism Moms Group of WA, made up of self-advocates. And they're the ones that are telling other families that, okay, if you can't get services – then leave your child at the hospital. So that is where the conversation started to happen about leaving your child at the hospital to get services. But as evidenced by this discussion, that doesn't necessarily make it any faster, and if anything may make it harder because the longer the child is in a hospital – the more the facilities are coming back and saying, if they're not well enough to go home, and there at the hospital – then they're too much for us to handle. So it's a tough spot for parents to be in.

A pause was taken for questions. Amy shared she used to work at a different agency and is aware of this concern. She is wondering if we might consider leveraging the voices of other groups who may have similar concerns, albeit for different reasons in our outreach. For example, when it comes to the ER, if a bed is being taken up by a child who does not have any access to services elsewhere (at home or a facility), then that mean's there's one less bed available for someone else who may have an emergent situation going on that brought them to the ER for another reason. So, in other words, there may also be other stakeholder groups out there who feel strongly about making sure the right resources are available at the right time for the right people, as well. And while it may not be a natural or obvious partnership, they could be out there, for groups who would be willing to come forward and say that they feel strongly about this too (even if for a different reason). But if we could get together and share all of this information that's just been expressed about what works and what doesn't work, and how sometimes intent can differ from outcome and all those sorts of things, just looking for those opportunities to partner together with other stakeholder groups in our outreach who we may not necessarily otherwise thought of or reached out to in the past but could be on the same page.

It was also suggested that we consider what other states are doing with their waivers. This could also relate to the topic Marsha suggested earlier of in-home care and also aging populations and people with disabilities. That may be another way to continue the conversation, in terms of in WA, another barrier is that you cannot double dip with regards to receiving services – in other words, if insurance is paying for a service, state waivers cannot also pay for the same service or assistance. But in talking with other groups such as those in CA, their health care authority found a way to work around being able to only bill Medicaid services, but also uses that same federal funding to help increase access to services. The same goes with OR. So, the question is there a place for us to start bringing that conversation forward, too and get some more information because there are also Medicaid rates to consider. There are services available, but a lot of individuals with disabilities that need services rely on Medicaid, and the rates make it difficult. There is a lot of work going on already in talking about reimbursement rates. So, outreach may also be able to partner on that, not necessarily legislatively, but even just promoting and connecting with the community around the importance of this topic. For example, with a private practice, if you were to bill Medicaid for a therapy service (or any other service). Maybe you could get a maximum of $40/hour. Billing private insurance, you may be able to get $150/hour for the same service. So, it makes it difficult for providers when offering services, because to take on exclusively patients on Medicaid only means a much lower rate of pay that really isn't sustainable (which is decreased further after paying taxes, fees, licensing etc.)

Andy was thanked for his comments in sharing all of this with us. We need to understand the complexity of these issues.

5: (If time permits) Compile list of existing organizations of people with disabilities – Marsha shared that we likely wouldn't have time to answer this question today, but hoped by raising that we could plan to do some work on it in between this meting and the next. We have looked at this in the past, but don't know that it is a very comprehensive list. Previously, we asked folks for information about which organizations they were involved with locally. Now, we'd like information on organizations you're aware of. If you could send those to Marsha before the February meeting, we will compile the information and send it back out, in case looking at it triggers any other thoughts to keep building the list.

Marsha shared that she would like folks to really think about organizations of people with disabilities that they're aware of, and send her as many of those names with identifying information as possible, because she'd like to go into the meeting on February 17 with as much of that work done as possible, so we are not using up our time in the meeting on that activity.

The final question Marsha had was how the outreach subcommittee can empower people with disabilities to articulate our needs and advance ways to meet them. Might it make sense to work with the AC subcommittee in their efforts to encourage the development of more county ACAC's, since only 14 of WA counties have such a committee at present?

Marsha believed we'd likely need to spend quite a bit of time discussing this at the February meeting, but wanted to get people's initial thoughts. Amy wondered if it might also make sense to link up more intentionally with GCDE's legislative workgroup in that arena, even if only as a good venue for sorting through priorities of a number of different groups and partner organizations with whom we already have pre-existing relationships.

Another item that might be a small piece of a big puzzle is to try to conduct strategic outreach and education around specific topics areas, such as those Andy was mentioning earlier.

Warren agreed that there may certainly be ways for the outreach and AC subcommittees to work together, but shared that there are many and varied reasons that there are currently only 14 county ACAC's in WA, partly due to differing situations in different locations. It's difficult to generalize and say that there's necessarily a specific way for the two different subcommittee groups to work together. He also shared that based upon Marsha's original question shared at the start of this meeting, it is currently unclear where the subcommittee is going, or what the structure will be. So, he believes that question may need to be answered first, before it can be decided whether there is a productive way for the two subcommittees to work together. In past Outreaches, we have certainly brought up the topic of County ACAC's and promoted them to local leaders.

Warren was thanked for his helpful comments. Marsha shared that she would like the committee as a whole to decide the direction of where we're going and how. She believes it will likely involve connecting with other disability organizations, but does not want to say too much now, because she wants the committee to consider the question.

6: Next Action Steps – Marsha was asked by Ryan to recap next action steps at the end of the meeting.

Marsha shared that the needs we've established for the disability community so far are housing, transportation, employment, plus in-home care and lack of facilities for adolescents with high needs (access to services). Otherwise, in terms of ways the disability community is currently already organized, that's where Marsha would like to see us do some serious work between now and February 17, so that we can have the information going into that meeting with as complete a list of existing disability organizations as possible (including names and contact information, with the realization that this changes all the time). This would be statewide, and could include organizations related to various differing disabilities, such as spinal cord injury, blindness, and independent living.

Ryan also mentioned that he is almost done with the Port Orchard report. It currently has 23 pages, and will probably have a few more added. He will share it with Emily for formatting purposes, and then to Elizabeth, who will be able to share it with CO leadership and the subcommittee. Hopefully we can discuss it on February 17. Marsha thanked everyone for their involvement in that event. She is particularly excited about the transportation piece, and thinks that something may actually be able to come out of it, due to the focused discussion. She is not sure so much about the access to services group, but we'll see what happens. Nonetheless, she is grateful for everyone involved.

7: Consider possible change of meeting time – Emily mentioned that she saw this item on the agenda but didn't think we'd have time today to discuss it, so suggested perhaps we could just send out an email about it, and Ryan said that he would take care of it.

8: Next Meeting will be on Friday, Feb. 17, from 2-5 p.m. - Ryan wanted to clarify whether we would have 2 meetings in February. The regularly scheduled monthly meeting is on February 14, and February 17 is the longer planning meeting, is that correct?

Marsha was not sure that it really makes sense to have two meetings in the same week, since she didn't know what would necessarily be accomplished in the 1-hour meeting earlier in the week, before the longer one later on.

It was decided to go ahead and cancel the shorter meeting on February 14, and just keep the longer meeting on February 17 (time clarified – from 2-5pm). No concerns with this plan were heard.

People were thanked for their time and attendance today. It was a great first meeting of the year and folks are looking forward to the rest of it. Everyone was asked to take care and bid farewell.