

Minutes of 12/12/19 Meeting Respite Services for the Delaware Autism Program

This was the third of three scheduled meetings and was held at the Lewes Public Library.

The meeting began at 9:30am. General minutes were taken but were paraphrased in an attempt to capture as many questions and discussions as possible. Those wishing to hear the entire meeting may click [here](#).

I. Purpose: The Department of Education was asked to lead a working group to make recommendations on the future of the respite program operated through Christina School District's Delaware Autism Program. Members will include, but not be limited to, representatives of Autism Delaware, families, respite providers, districts, the Office of Management and Budget, the Controller General's Office, the Department of Health and Social Services, and members of the General Assembly. Meetings are open to the public.

II. Process: Initial meetings will be held in all three counties to begin to gather information. This morning is the third of three meetings. Minutes and items from the first two meetings (12/2/19 and 12/9/19) are posted on DOE's website and on the public meeting calendar. These meetings will provide an opportunity to share ideas moving forward. Participants are asked to bring suggestions for discussion and future consideration. After the first three meetings, other meetings will likely be held to review ideas and make recommendations. The working group will make recommendations on the future of the respite program including, but not limited to, the services offered for families and payment structures for providers.

III. Introductions: Emily Cunningham (DOE), Rick Gregg (CSD), Mike Andrews (CSD), Samantha Kolodi (CSD), Annalisa Ekbladh (Autism DE), Daphne Cartwright (Autism DE), Kim Klein (DOE), MaryNash Wilson (OMB), Sharon DiGirolamo (Seaford SD), Vivian Bush (SC Consortium), Jim Mark (Kent County Community School), and members of the public.

Ms. Cunningham was asked why parents weren't on the working committee and explained that instead of naming individuals to serve on the working group, that the groups listed in #1 were asked to serve (not one particular person) and that we didn't feel it was fair to select a few parents, so instead made it more broad, but would still share information with a broad base of stakeholders.

IV: ISSUES and FACTS: Christina School District Superintendent Rick Gregg was asked to share what we know are the facts and issues/concerns facing DAP's respite program currently. He broke them down into categories and, within each one, added detail.

GROWTH

- Significant growth in number of hours provided and related expense.

EQUITABLE ACCESS

- Services provided on a voluntary basis result in those with highest need potentially denied access.
- Services provided to only families with students enrolled in State approved programs excluding access to families with students served elsewhere.

EQUITABLE COMPENSATION

- Currently requires all providers be compensated as employees of Christina School District (CSD).
- Paraprofessionals with full time employment in CSD quickly exceed 40 hours/ week creating overtime rates, while Paraprofessionals from other Districts are paid straight time until they exceed 40 hours of respite service.
- Teachers are compensated at the Respite hourly rate until they exceed 40 hours of respite service.
- Pay practice aligned with Federal Law.
- Inequities subject of [Auditor of Accounts Overtime Inspection](#).

RESPITE ALLOCATION

- “Lacks capacity to assess degree of respite most beneficial for each family” so allocation is 24 hours per month plus 7 days every calendar year, unless exceptional circumstances. (456 hours/yr.). (Mr. Gregg said that if the 1020 students with autism served through DAP programs received their maximum amount of respite, it would cost \$22.5M/year).
- For families with children attending the Brennen School, this has potential cost range of \$3 – \$9.5 Million.
- Services provided on a voluntary basis result in those with highest need potentially denied access.

FUNDING

- Respite is not an educationally-related service, and is independent of a student IEP.
- Respite payment by Parent/Guardian 5-25% of “total cost” depending upon income as determined by eligibility of Free and Reduced Lunch. [Payments not consistent, nor based on “total cost”]. This is not disclosable – it is an “honor system.”
- Expectation that Respite Provider collect funds.
- No process to operate within a set budget. We can’t provide unlimited services.

EMPLOYEE AND DISTRICT RISKS

- Transporting children
- Caring for children in personal residence
- Taking children on outings
- District risk profile considered higher by Insurance Industry

V. Public Input/discussion

Ms. Bush: Teachers only receive respite rate no matter what because they are exempt.

Barbara Powell: Where does the budget come from and what is it? Tuition coming from districts – is CHSD funding part of the program? Mr. Gregg: it is billed to tuition; apparent there were questions. Tuition tax is supposed to be for educational services only. \$750,000 requested from the state for the statewide program. DAP is just run by CSD. Provision for budget line – built into cost of services. Billed to districts. Two years ago it was \$200K. Ms. Klein – billed to kids in residential service – that’s part of the issue, they weren’t paying their fair share. Those that had students in residential may not have been paying for respite. Ms. Klein also clarified that CSD did submit a request but not for this funding cycle. OGOV and OMB stepped in – CSD is providing expenditure information as a one-time fix. We are talking about next fiscal year; their request was too late this year.

Ms. Bush: What do the numbers look like on a monthly basis? Mr. Andrews: CSD uses the most. Probably CHSD and BSD next. Mr. Mark – is there a report? How do we know who is getting services? Mr. Andrews: We work with their respite facilitators. Ms. Ekbladh: I know you talked about how families are using it; how many hours and that is important for future planning. Mr. Andrews: holidays and time off of school are the busiest time, followed by weekends.

Ms. Bush: the bulk of the cost comes from CSD employees? Mr. Andrews: I can see what you are saying – a report would be helpful.

Bush: how does day/group respite during the day? FLSA rules apply.

Ms. Powell: recommendation – take payroll mechanism out of CSD and choose a different option (3rd party non-profit – would there be fees?). Different entity to take on payroll?

Ms. Bush – applaud CSD for doing this for so long. It is a huge liability risk; this is a long time coming.

Ms. DiGirolamo: for Seaford, increasing access would be great, as we don’t have any respite providers. This could spread access. What about students with autism that are not in DAP? Wouldn’t other disabilities appreciate respite?

Mr. Mark: create another line item – no cross over. State agency or outsourcing.

Mr. Gregg: what about relationships with students? It is a recommendation, though.

Ms. Ekbladh: this works for families because they know the providers and can support them. Ms. Bush: With DDDS, you can use anyone. Ms. Ekbladh: Autism Delaware had a pilot a few years back with DDDS to try to train respite providers (especially those with complex needs) and it wasn’t successful because we couldn’t find enough people to train to the level they would need.

Dawn Ramirez: Risk is huge; financials are a mess. Providers (even if outsourced) could be school district employees – would have to apply to be providers in another way. Districts wouldn’t have to worry about time.

Mr. Mark: the pool of people that want to help won't change. The argument of outsourcing isn't an issue – you will still have the same pool in the cue. We need to ensure it is accessible. Bottom up, not top down to provide good care for our kids.

Ms. Bush: it could diminish the pool a little but could open it up. My liability doesn't fall under my homeowners now but it will if I contract.

Mr. Andrews: opens up provider pool because people now must be employees of DAP. Ms. Bush: the people that use family friends could apply to work with that student. Or family.

Cunningham: we had a college student in the Dover session ask if we have reached out to colleges – or even high schools – to increase the pool of providers. Ms. Powell: as a parent, I'd like to see the pool expanded. I understand the benefit, but it is limited. When it works, the program is great. Open pool with qualifications. Don't need to be a special ed/para/teacher.

Mr. Gregg: following up on your question of how CSD decided on the \$750k was based on past expenditures, the current program design and proposed capacity to serve. [Mr. Gregg texted CSD CFO Bob Silber, who was unable to attend the meeting. Mr. Gregg left the meeting for another commitment around 10:15am].

Dawn: still working under same OT rules? Yes.

Ms. Powell: 3rd party – budget is a separate piece. I think there could be a lot of transparency. Where does it come from; better process. Usage, reporting. Look at number of hours and parameters. Cut back number of hours – I'd rather have less hours; one hour a week is better than no hours a week. If we are at risk of losing the program, I'd rather have fewer hours. There needs to be a formal process of oversight to the DAP program. Transparent reporting. Ms. Cunningham: we heard this concern in the New Castle County meeting and DOE/OMB/CSD have agreed to make sure a better reporting system is in place.

Ms. Ekbladh: high support needs are not able to access this program; it needs to be equal. Levels of support. How families use it? Not fair. How do we authorize when some families aren't able to access?

Ms. Ramirez – every one of our providers also work 37.5 hours a week. When people need services, it is our only time off. We need a break too.

Ms. Powell: rate of pay, sliding scale? Difference based on the level of kids. Ms. Bush: DDDS has (used to have) a level based on level of need (ICAP).

Ms. Kolodi: overnight requests are higher. But 3-5 families a year don't receive services. Usually not the complexity; the issue is the times or hours requested.

Ms. Ramirez: not every employee is a respite provider. It is voluntary. People don't volunteer because of times – may work other jobs, kids, pets, after-school, life. Depends on whose home; comfort level. Finding a good fit is tough. Pay rate – I make \$15/hour when CSD is making \$35.

Ms. Kolodi: Teachers v. paras in CSD is a pay equity, too.

Ms. Bush: It isn't just respite that is an issue for a family with a child with the most severe needs.

Ms. Klein – you must pay taxes. That will be an issue anywhere.

Sam – there could be an inequity in pay – the paras get to make more in OT. Can you limit them to only 40 hours? Andrews: then limits the pool again.

Suggestion: what about capping hours or eliminating holidays or Sundays? Response: that doesn't seem to be fair.

Ms. Powell: DAP separate entity as a non-profit? Ms. Cunningham: DAP offers much more than respite. Ms. Powell: Funding needs to be reviewed if there are no kids in residential.

Ms. Bush: What if the parent were to pay whole price but operated under DAP? If parent paid out-of-pocket? Can't come through states payroll. Wouldn't preclude you from FLSA. There would have to be a third party entity that pays. Would have to be a non-state entity.

Ms. Klein: What if a parent gets DDDS allocation; concern over provider getting paid? Concerns over parents using provider names – also be looked at. If denied DDDS, where do you stand?

Mr. Ramirez: With DDDS payment there is a reimbursement. Same with Easter Seals. Lots of ways. A similar structure might work.

There was a conversation about the \$15/hour qualification, contracting and subcontracting. Ms. Klein: All state employees are still responsible for paying tax liability through 1099 or your paycheck.

Ms. Ekbladh: we should talk to DDDS – part of adult waiver – individuals providing respite are required to register with a 3rd party vendor (background checks). Hasn't moved to child system, but they have to be registered, etc. so that might be an option.

Ms. Powell: There seem to be three options - 1

1. Stay with state
2. 3rd party vendor
3. Parents get funding (like with DDDS) to find own providers (but must be vetting, overtime similar to adults). We should talk with DDDS.

Ms. Ramirez: combine DAP respite with DDDS and have a new state program? Ms. Klein: we have to work with state payroll – still a state employee receiving a state paycheck. We just need to understand the rules. Kim mentioned the audit ([we can link to it](#)). We know there was an audit, we know CSD responded.

Ms. Ekbladh: Title 14 says that any district may provide respite services; it doesn't preclude any district in the state from providing this service, but has been an agreement with CSD up to now. Some districts haven't been involved in DAP because they don't want to provide respite. Seems like Title 14 would need to be amended.

Parent: What about splitting into each county? Ms. Cunningham: that has come up before.

Ms. Bush: What is the plan for moving forward? I feel a little disadvantaged. I can take information back to my stakeholders – too many question to be able to answer. I think we need people making decisions to come to meetings [we were discussing next steps].

Grandparents: Has anyone looked into other states? Ms. Ekbladh: As far as we know, no other state has this, but they may have different waiver programs. Important to remember this is not educationally related. Other states run similarly to DDDS.

Ms. Powell: well maybe we aren't doing it the right way – look at what other states are doing.

Ms. Powell: what is the timeline? Please lay it out. Be clear on avenues for input. Ms. Cunningham: we are the facilitators and are open to ideas for sharing, but we need ideas on how to do that.

Parent: can we create a state agency just for autism? Deal with all of the issues for autism only. We need support in this state. More specialized services – or a sub agency that would have access to funds and services.

Meeting ended at 11:00am.