

Public Comment:

1. My name is Shanai Smelosky. I sat in on the phone conference earlier today and didn't get a chance to make a public comment so I thought I would send one in. I am a parent of a child in Elko that's been in the ATAP program for 3 or 4 years now. We've gone through 8 interventionists and 2 providers, fully expiring our options as Lovaas does not accept our insurance. I've personally contacted BCBA's in Reno asking about their interest in traveling to Elko to provide services of which none said it was worth the time and money.

All except one of my 8 interventionists were college students who needed a flexible job to rotate around their school schedules. None of them were studying special education or had an interest in continuing down that path after this employment. Our first interventionist left due to the school district offering her a position with benefits, higher pay, consistent paychecks etc. Around the time we started with our next interventionists, the RBT requirements started and each one after that complained of not having enough time between school and providing therapy to us and other families to complete it. Soon the pay, inconsistent hours, PPL and then Palco issues, pressure of the RBT requirements and stress of working with special needs kids wasn't enough to keep them around. The lack of interventionist options has led to a long delay without therapy for us. The people who are applying aren't looking for a serious job or a career. In Elko you need only your high school diploma to get hired at the mines and make \$30 an hour. I believe if we want higher quality interventionists and ones that last we will need to offer competitive compensation.

Currently my son is not on Medicaid or Katie Beckett. Evidently our insurance will only approve of 5 hours per week for therapy. Five. And because of the co-pays/allotted co-pay assistance from ATAP we will have to do two 2 and half hour sessions. I don't know what kind of progress we are supposed to make with that sort of time. My son is extremely self-injurious and regressing more every day, and while we are once again waiting to find a new interventionist, I find out we are getting a third of the amount of therapy we previously were. I'm not sure how we will find an interventionist now that will be interested in a five-hour-a-week position.

Shanai Smelosky

2. I shared these parent concerns about ATAP with the commission today and was asked to send them in email. I would like them to be added to the agenda as future resolution items if needed.
  1. Timely communication - give warnings about changes well before they occur. Give families and providers time to adjust to changes.
  2. Clear and transparent communication - fact check and clarify info before sending it out to families. Information needs to be spread in an accessible, parent-friendly manner, in consistent and multiple forms.
  3. Consider a parent advocacy team for ATAP - many decisions made do not reflect the needs and preferences of families using ATAP.

4. Plan changes - current plans do not always support scientific findings for recommended treatment hours and intensity based upon individualized needs. Children aging out of the programs and plan types does not always reflect service needs.
5. RBT requirements - these are difficult to reach and maintain with the low hourly wages these providers make. In many areas, these same people would be able to find full time employment with benefits at better wages for much less difficult work; this is a barrier to achieving and maintaining a work force. Why work for \$14/hr with a child who is aggressive towards you, and pay your own way to do so, when you can make the same amount at a grocery store? RBTs are expected to complete unpaid training. RBTs are also expected to pay for some aspects of their credentialing process - background checks, test, and in rural areas travel to take tests. Medicaid/insurance require immediate RBTs, even when there are none available which is a barrier to treatment.
6. Funding - there is not enough funding for ATAP for the families currently using it, let alone the many on waiting lists. We are all aware that this program is underfunded. That is why it is treated like a temporary service until clients age out or stay on too long. There is not even enough funding in a given month on a comprehensive plan to cover 6 hours worth of BCBA visits, cover roughly 20 interventionist hours, and add in anything like occupational therapy or speech therapy. We don't have anything else waiting out there for us to replace ATAP funding with. Our insurance doesn't cover these treatments. Our school districts are ineffective. When providers need to work extra time to meet a client's needs, they are expected to do so for free. When RBTs or interventionists need extra training or time to create materials they are expected to do it for free or take away from treatment hours. Parents are expected to provide educational resources and their own time for treatment hours, with money and availability and skills they may or may not possess. Many providers don't even know how to use assistive technology platforms, which leaves parents to learn how.
7. Provider availability - many providers already have waiting lists. Some providers that would travel to rural areas are no longer able to do so.
8. Medicaid is not always a viable or reliable option for the families that are even able to access it - Medicaid is not faithfully paying the bills submitted for ABA therapies. Most ABA billing to Medicaid is being completed via ATAP, where ATAP pays the provider for services rendered (that Medicaid has given prior auth for) and then ATAP tries to collect money for the services, which isn't always successful. Providers will not want to work with families who use Medicaid because of these issues. Ultimately this steals funding from ATAP that is never replaced by Medicaid.
9. Insurance issues - with both Medicaid and private insurance there are problems even when treatment is supposed to be covered. Treatment hours are insufficient. Family costs for using private insurance are sometimes high even with ATAP assistance. There have been no established guidelines between ATAP, Medicaid, and private insurance about who will pay what when a child has Medicaid or Katie Beckett as secondary insurance. Again, if providers are not being paid they won't want to work; if parents costs are too high and treatment levels too low, then the child will suffer. Someone within or outside of these agencies needs to be assigned to deal with strictly these issues.

3. Susan Anderson, member of the public and parent, commented that her son was diagnosed at 2 ½ and started with Early Intervention at eighteen months. He did not pass the screening for autism. Ms. Anderson used a private therapist who made a full medical diagnosis. She received unlimited hours of therapy for her son through the Lovaas Center. Ms. Anderson's insurance covered up to 25 hours a week of therapy. Two years ago, her insurance stopped paying for therapy and she started a plan with the ATAP.
  
4. Eric Kesler, member of the Workforce Development Subcommittee, commented on his concerns about the changes to the Autism Treatment Assistance Program (ATAP).