

## Survey Results

Advocates and advocacy groups (North and South), shared a survey, to gain information about access to ABA in Nevada. The survey was distributed via emails, Facebook and Nevada PEP's Epost newsletter. The ultimate goal to help provide Legislators and State Decision Makers a perspective from the parent's position.

Some providers also shared. Questions were provided in both English and Spanish.

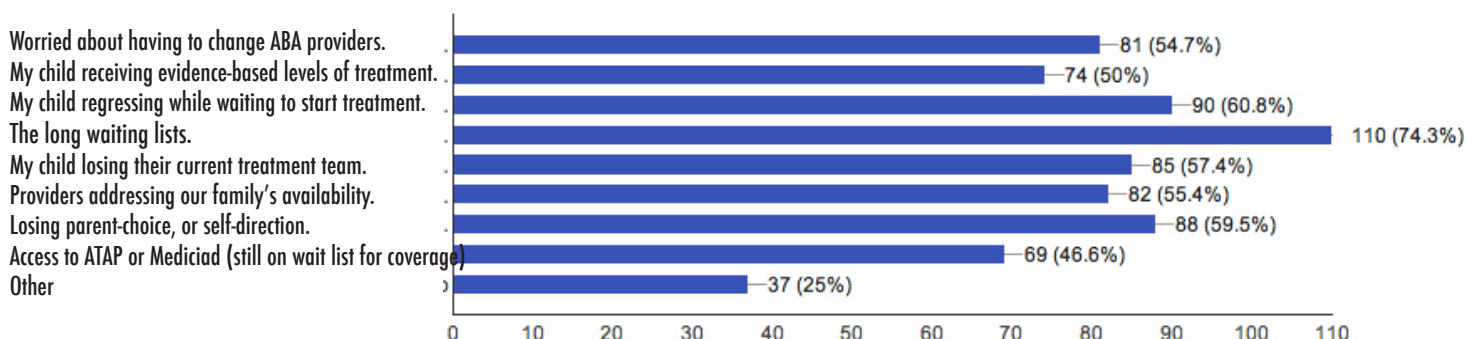
148 surveys were completed in 16 days

- 68.9% of responders' children were receiving some amount of ABA treatment.
- The majority of responders do not feel they have been given enough information to understand ATAP's changes or Medicaid's process.
- More than 90% of responders would like to maintain parent-choice and self-direction including the ability to utilize either parent-hired interventionists or provider-supplied Registered Behavior Technicians. (RBTs).
- Waiting List is a major concern.

All questions and answers have been represented in this overview. Any identifying information has been removed

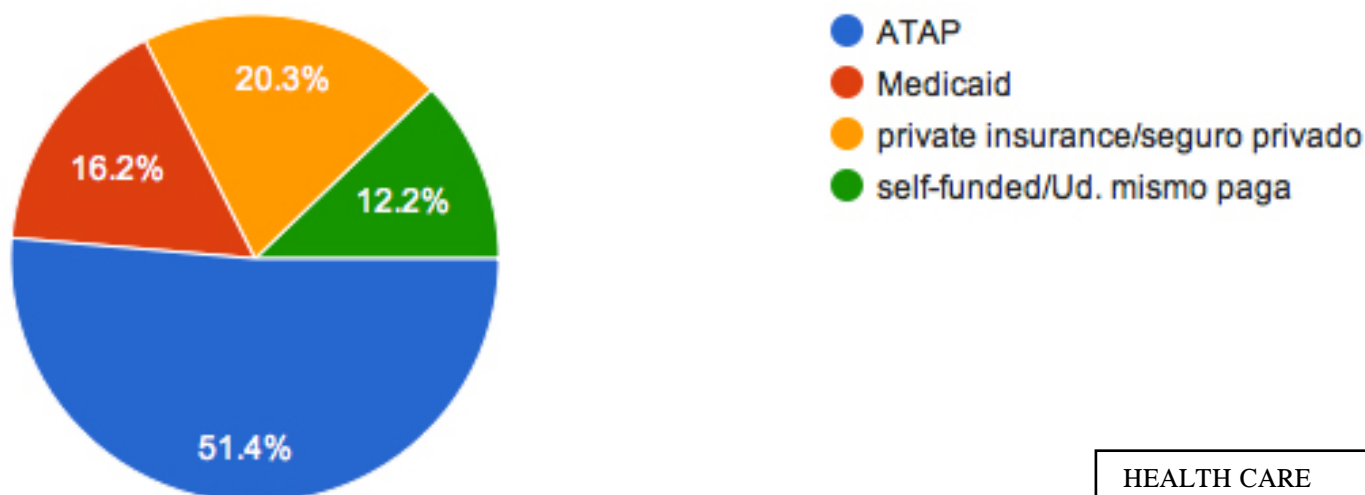
What are your critical concerns about Medicaid or ATAP's current implementation and/or pending changes. Check all that apply.

(148 responses)



Who funds your child's services?

(148 responses)



If you are new to Medicaid services, how many hours a week of ABA treatment are you receiving?  
 (If you are not a Medicaid client please answer "N/A".)  
 (148 responses)

### 50 Medicaid recipients responded

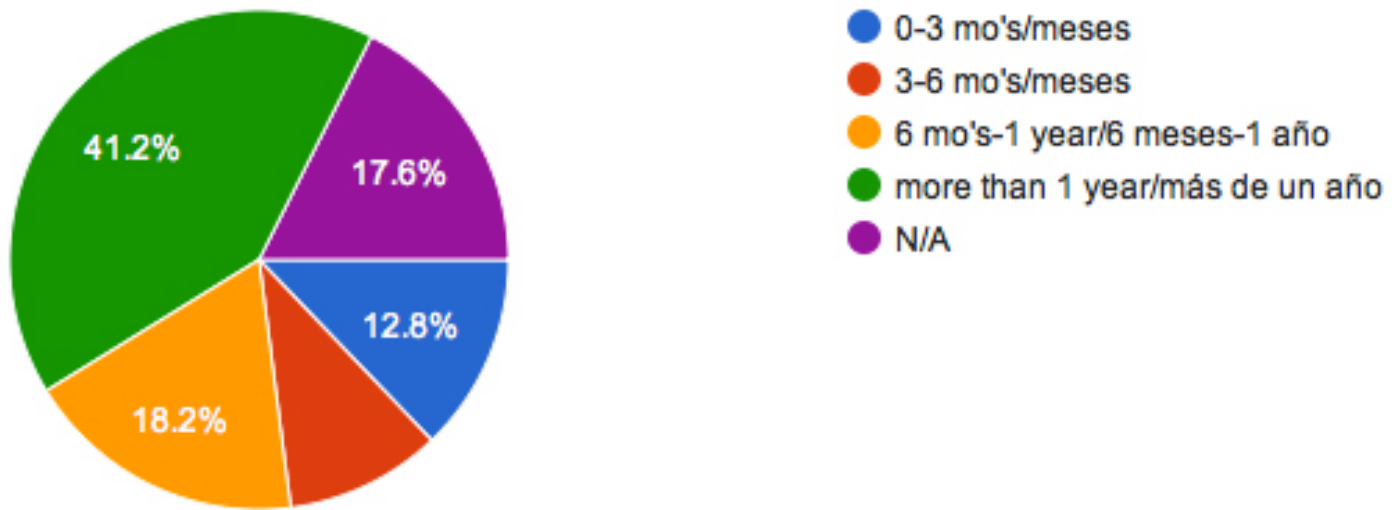
24 parents indicated <i>(this number includes those with narrative listed below)</i>	0 hours a week
One parent indicated	1 hour a week
One parent indicated	2 hours a week
Four parents indicated	8 hours a week
Three parents indicated	10 hours a week
One parent indicated	12 hours a week
Six parents indicated	15 hours a week
One parent indicated	18 hours a week
One parent indicated	20 hours a week
Two parents indicated	25 hours a week



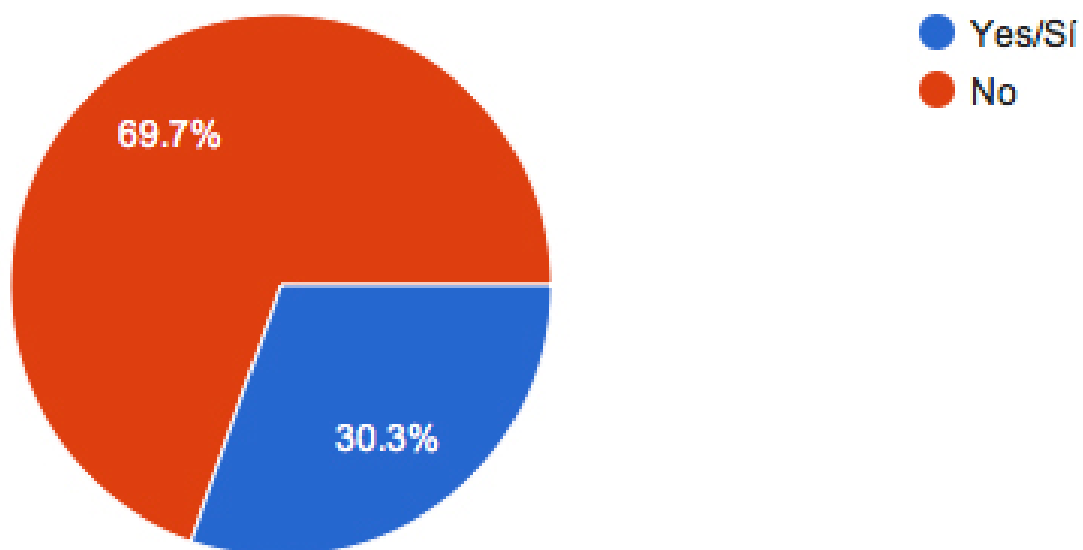
### Additional Comments Received

- No ABA in my area
- Haven't received anything yet! There's not enough providers and therapists for all the kids
- We haven't started services yet
- Still waiting for services
- We do have Medicaid but cannot find a provider
- We are on a long waiting lists, not knowing when we will be called to start
- Hours not yet determined
- On waiting list
- I don't yet have services for my son
- I do not think we will get any provider with medicaiad services so no ABA for our children
- Tengo service de medicai pero estroy en lista de espera
- Haven't worked that out yet as ATAP can't seem to keep case managers in Northern Nevada so there's no one to help with the transition
- Right now we are not able to get ABA our primary insurance does not cover ABA but with Mediciad you must use a provider that goes through your primary insurance and medicaiad. There is only one and we are on a waiting list.
- My kids have Mediciad. But my currently receiving 8 hours from ATAP
- por aseguadora
- I don't know
- Haven't started through Mediciad - I need different insurance.

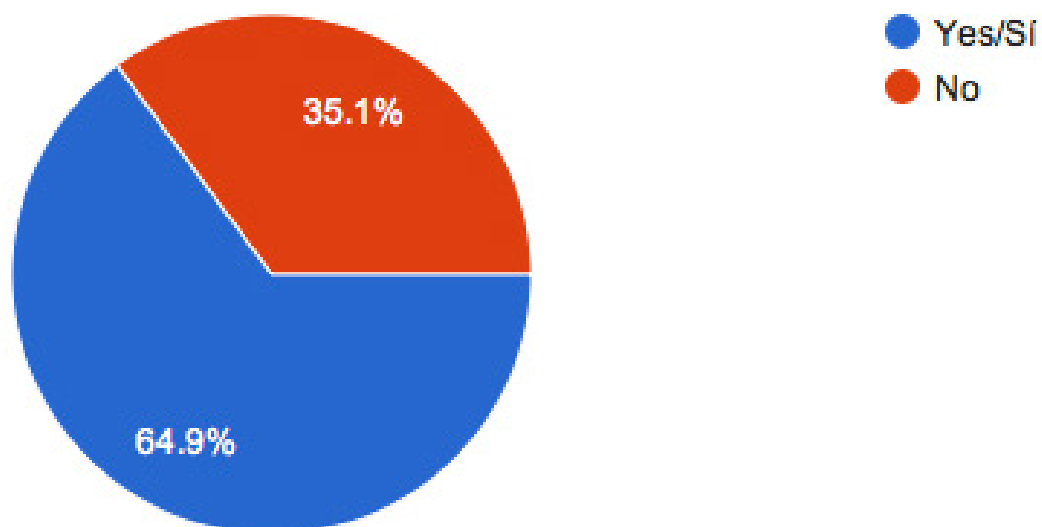
How many months after receiving a diagnosis of Autism did your child start receiving ABA treatment (at least 15 hours a week)?  
(148 responses)



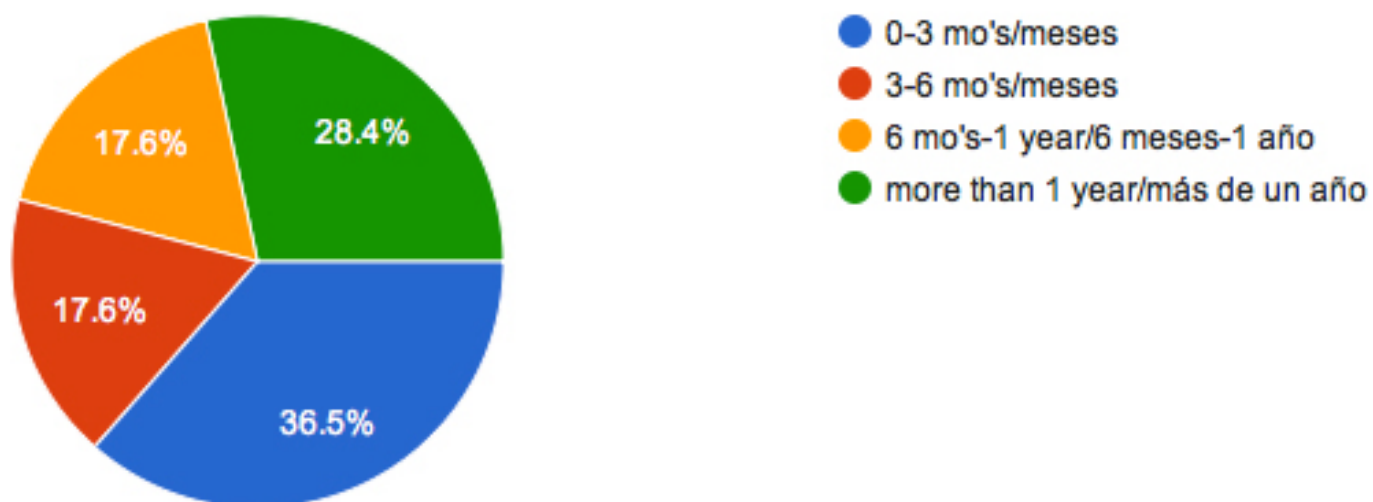
Have you been given enough information to help you understand and participate in the process about the current implementation of Medicaid for ABA coverage and ATAP's pending changes?  
(145 responses)



Have you been put on a wait list for ABA services?  
(148 responses)

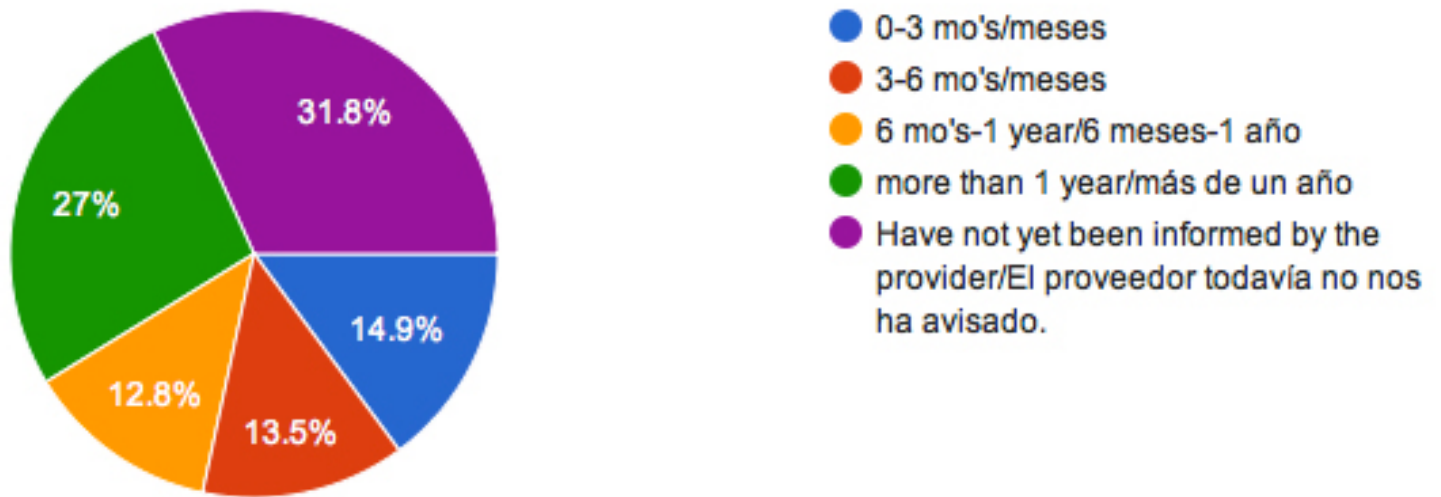


Do you expect to get services within?  
(148 responses)



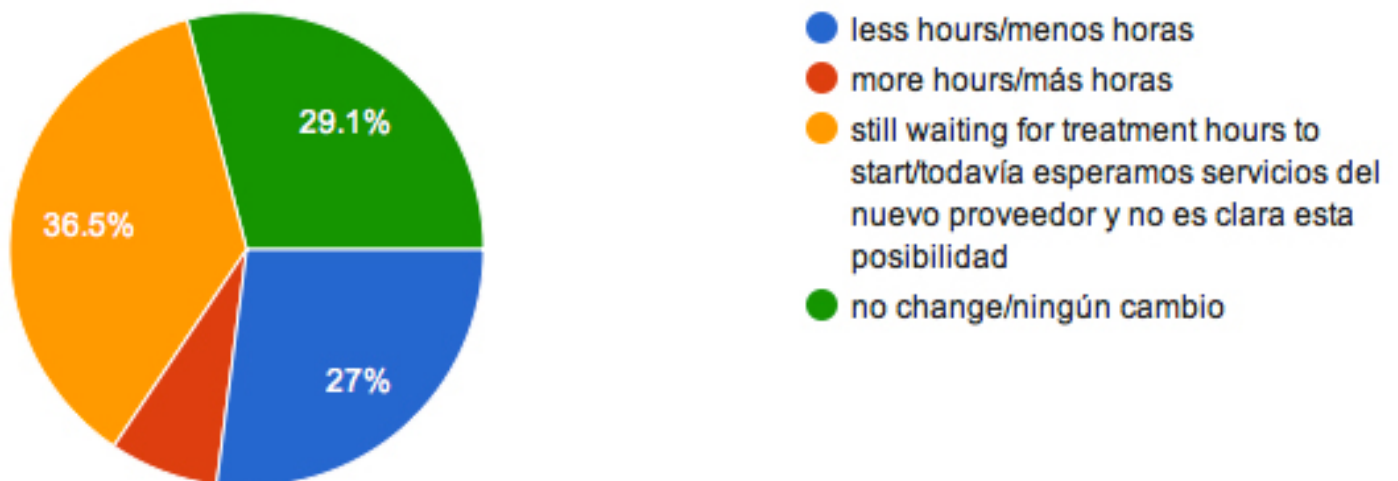
If you answered “yes” to being on a wait list, how long have you been told you will wait for services?

(148 responses)

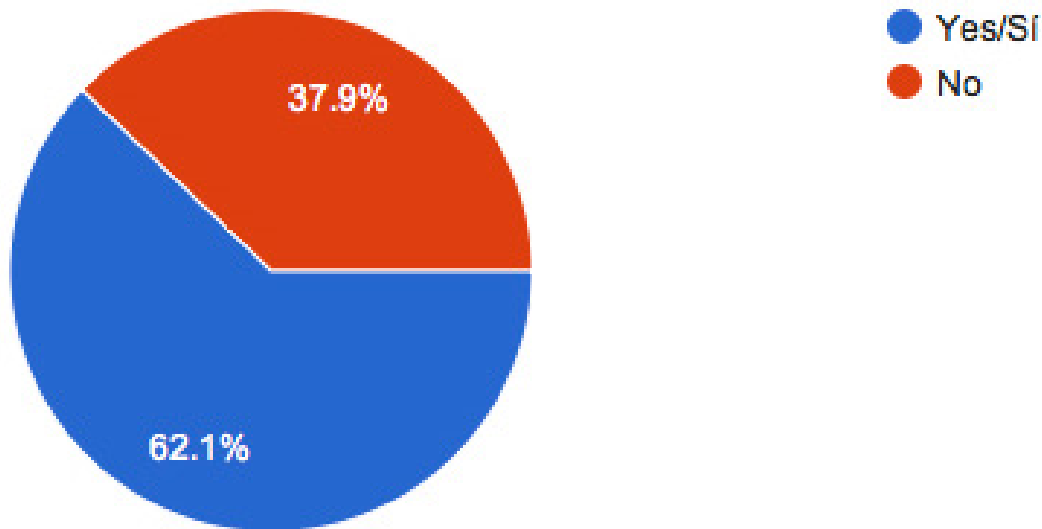


If you begin services with a different ABA provider is your child still receiving the same level of weekly ABA treatment hours as they were receiving before?

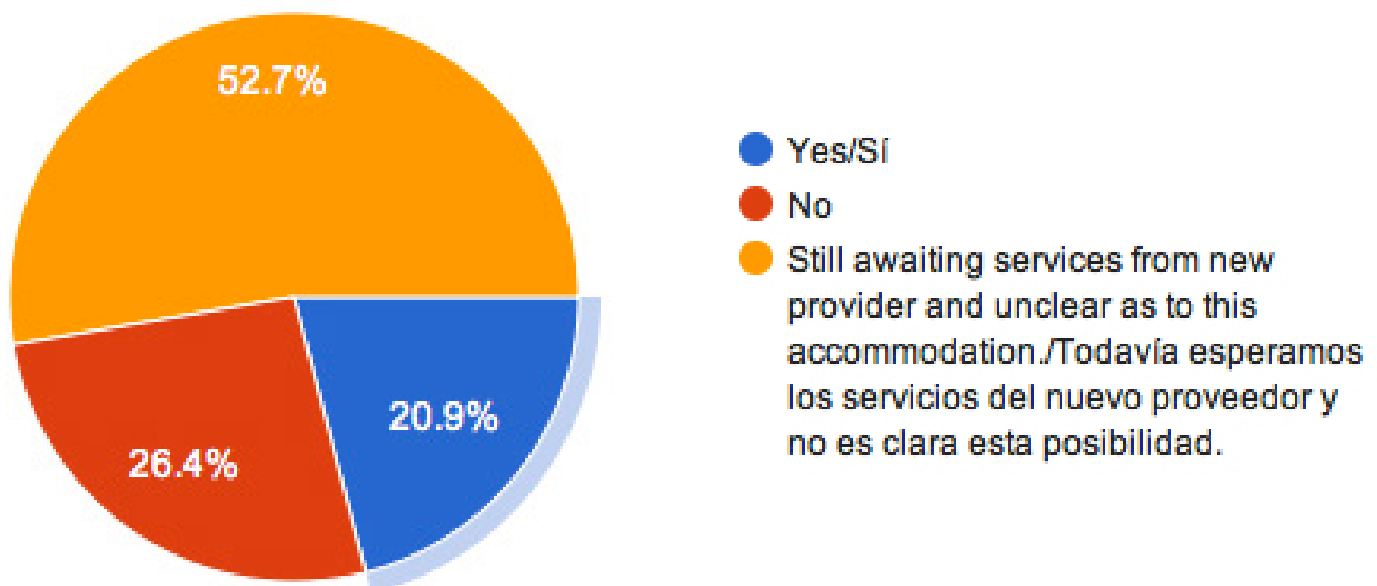
(148 responses)



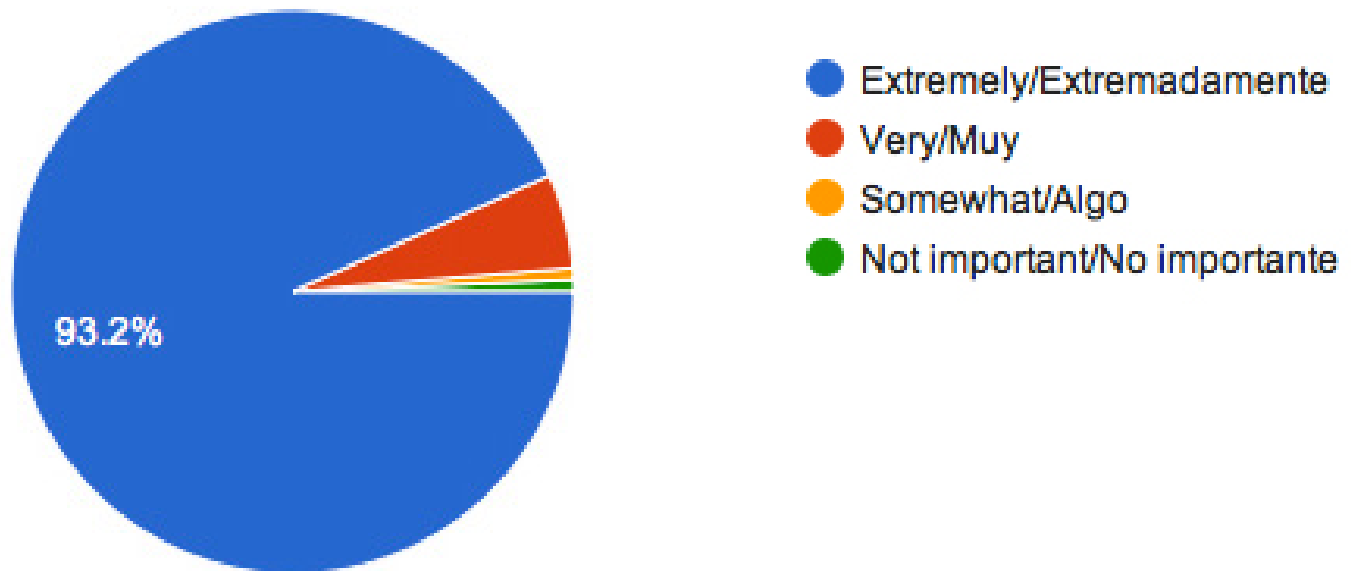
If you have recently had to transfer to a different ABA provider, do you have concerns about the new treatment team and how your child's needs will be address?  
(132 responses)



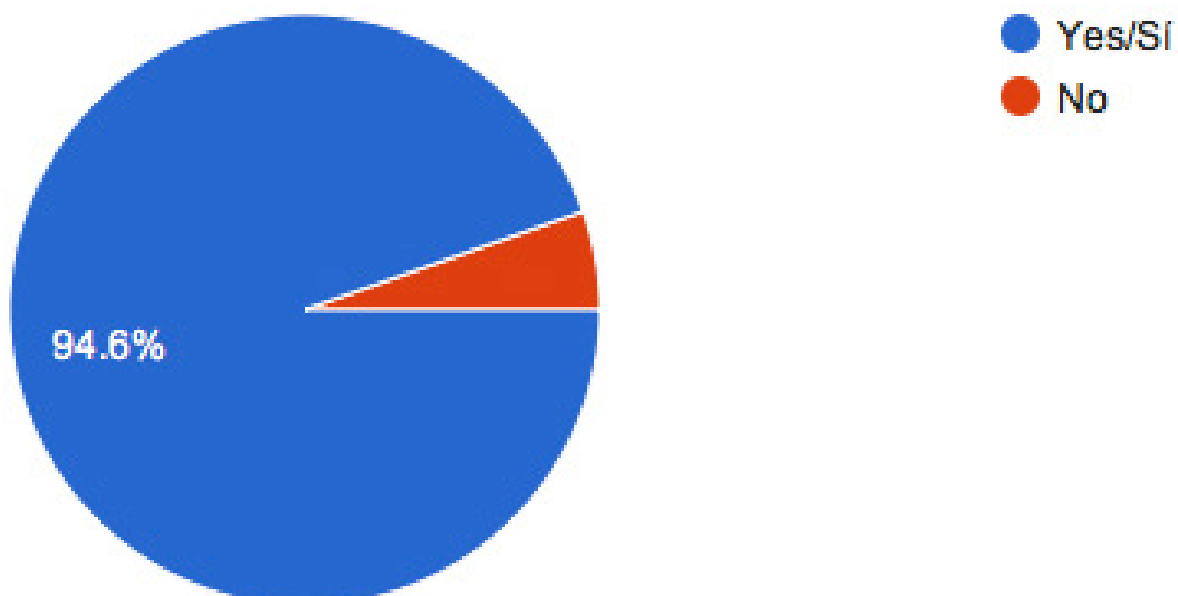
Has your child's new provider been able to accomodate your family's availability to deliver treatment?  
(148 responses)



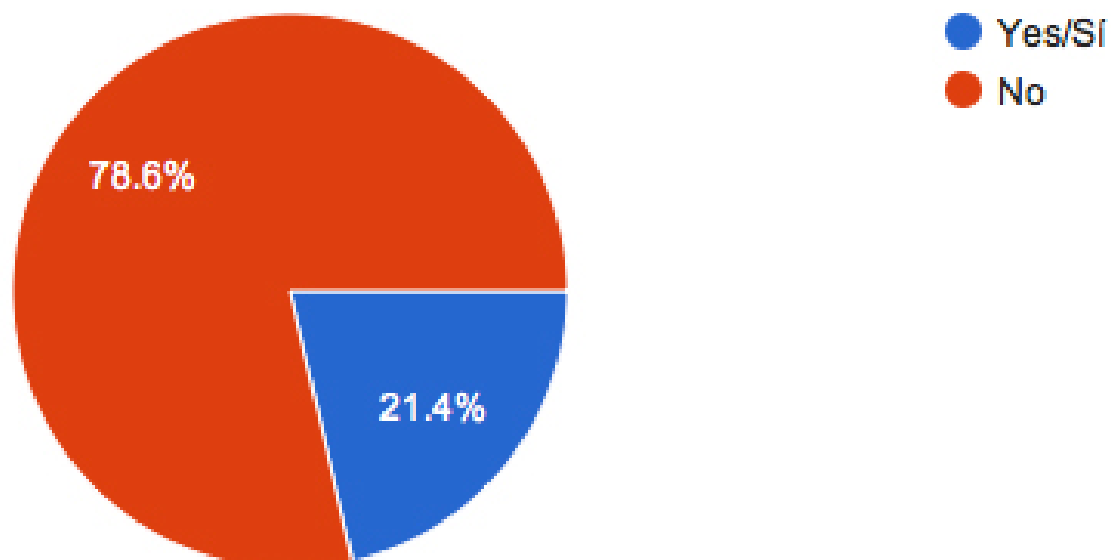
How important is it to you as a parent to be allowed to continue to have parent choice and self-direction with your child's treatment?  
(148 responses)



Is it important for parents to maintain the option to use either parent-hired interventionists or provider-supplied Registered Behavior Technicians?  
(148 responses)



If you have selected or been told you have to select a new provider, were you given enough provider choices to feel confident your child's treatment needs will be met?  
(131 responses)





Please include any other information that you feel is relevant regarding your access to ABA services. (optional)  
(72 responses)

Autism is a growing epidemic and will continue to grow. Without a selection of proven therapy teams to implement treatment improvement is at best limited or nonexistent. This diagnosis tends to tear families apart leaving a single parent to deal with these lifelong battles alone. Early detection is critical to develop of skills due to the early growth spurts of the brain that manifest early in childhood in all children. Without immediate or expedient funding for these therapies these families will not have as high a functioning individual as was possible. We pay out of pocket and this expense would cripple most families leaving other children and adults bearing the emotional, mental, and financial strain of keeping such a intensive program going for years. For all families on the spectrum this is a life long ordeal and not a single one of us can predict if our kids will be socially accepted and capable of self sufficiency, but the families receiving these therapies will tell you the majority of the time that these programs are invaluable and overseeing them should not only be every parents right but duty!

Hasta el día de hoy se ha pagado el ABA de mi hijo con los fondos de DRC. Me preocupa la calidad de profesionalismo de los proveedores. Tenemos muchas opciones , pero sin experiencia y los que la tienen espacio.

I had to call several places to find any that accept Medicaid. I finally found one and was given about a 20 page document to fill out and was told I would be put on the wait list. I haven't completed it yet, but I intend to this week.

It took longer than expected for my son to get services because of the changes that happened with ATAP. He should be starting in May.

I am very concerned about a lapse in services. My son is low functioning (no verbal language) and the loss of ABC for even a week is too much.

we are a established client/patient through our ABA Therapy provider. our child has been doing this with the Same provider and same interventionists for 2 years!!! the transition and changes will be extremely hard for our child and the stress to our family will be more. not being able to choose our interventionist and provider is like taking away our freedom on who enters our home and deal with our child's strengths and weaknesses. the rate they are introducing is unacceptable and there is no way we can get the quality of care if the push through this rate because no providers will be able to provide good services for that rate. you have to listen to the parents who walk the walk. the therapy should be consistent and continuous this is the only chance our children have for them to have a quality of life in the future. do not fail them! we need ATAP, we need our insurance to cover ABA Therapy and we need Medicaid to increase their rates and be fair to the providers!! so we won't have to delay our treatments and provide services for kids who needs treatment as early as possible not 6 months of waiting let alone 2 years! the delay in treatment or Therapy will just be hard for the child and the family.. pls listen

The new provider needs to pay attention to the current programs my child is receiving, trying to know his needs.

ABA providers are currently very low in numbers. My son has to be pulled from school daily to attend ABA in the early afternoon since the facility has no available spots later in the day. The facility also has to change his therapists frequently due to high turn over and availability. There should be a state funded program/school for autism with ABA as a curriculum instead of a hourly based service.

Disappointed that there is Certification needed for Medicaid as secondary for ABA services. On the Medicaid side it seems there are administrative barriers to coverage that result in denials either due to proper understanding of paperwork needed and red tape.

We were on a waiting list for with a company on our insurance for 2 years. We did have a program with the school district but they discounted the ABA home program. We had to contact the health commissioner and work out a deal with our health insurance company. Right now I run my own program for my son, with a bcba and my health insurance is paying me back for most of it.

Live I rural area and limited by access to therapy

The survey wouldn't let me skip questions regarding wait list thoughts so I had to pick an answer . those 2 questions do not apply to my family I am aware changes are coming but not sure his it will affect my son he is funded they June with Atap no information has been given to me on how to deal with the changes

we are on a wait list for transitioning from ATAP to Medicaid. Our plan with ATAP expires 4/30. There are not enough RBT's. We are on a wait list with new provider. We are currently funded for 25 hours a week. One interventionist has left us. We are down to one with 14 hours a week. Nobody wants to work with us with the uncertainty of is it only going to be for a month or what. Meanwhile, my son is not receiving his funded 25 hours weekly and we are in a holding pattern. I am seeing regression already!!!!!! This has all been a nightmare. Medicaid should get the kids started who were on the wait list first and then transition kids off ATAP into Medicaid providers. There is such a rush to find new people that I am concerned with the quality of people that will be coming into my home daily and do I have a say as to who will be good to work with my son. If I do not like the person, I have to go back on another long wait list. This should have all been planned out without taking the 'wait and see' attitude. But being a busy mom, I like that I wouldn't have to deal with hours and pay and finding someone myself. Feel free to contact me to discuss further.

We have had are son diagnosed 8 months ago and still have not been able to get him ABA that he desperately needs. my childs care is self + insurance funded. not medicare/atap. hence the blank answers. the funding issue should maybe allow multiple answers.

Direction need a direction.

Need more providers because they can't even tell us how long it might be before we receive Aba therapy for my son

I feel there should be a choice for the families not accessing Medicaid and not covered by insurance who qualify for services. The choice should be up to the family whether to have all RBT's working with their child or not. I feel very comfortable with hiring and training tutors to fit the needs of my child and ABA program. It would save resources for the state and help alleviate the stress on the ABA providers to find/hire and train enough RBT's to handle all the case loads. Which in turn will provide more families to receive and/or continue to receive services.

I wish there was a place where you can get all your options listed for you then playing guess work with what services are available

My son has been waiting for 3 years now! He has regressed and even regressing in school! We can't even take him to the store any more or out anywhere due to his behavior! It's gotten really bad

To me is really important that the ABA therapy takes place at home and that my child can continue to receive services after he is 10 years old.

If he loses his therapy he will need to be put in a nursing home.

We have been with Loovas since day one and we have seen tremendous Positive changes in our Son over the years. I Hate to lose their services because what we'll happen is my Son well regress BIG time by bringing in some different ABA services from a different company. All that we worked for all these years we'll be forever changed!..

These "nonprofit" companies are supposed to care about the children and all they care about is profit and money. They dont care about the fact that they are disrupting thousands of lives and taking away the stability of consistent tutors and programs that are working. They are forcing us to change everything because of greed. I have had the same consultant for 4 years and she loves my child.. He went from complete non verbal to reading and slowly starting to speak. He is able to finally at 8 tell me he is hurt and where..

This program works but is so expensive it is cost prohibitive. When you make above poverty level there are few funding options. It needs to be covered by all insurances in all states not just a chosen few. It is hard to watch other states require insurances to pay while you pay out of pocket.

For the past 2 months, I have been calling the lists of providers given to me by our ATAP coordinator, many are not even answering their phones, some put us on long waiting lists, and others, who are available to work with my son, says they were not even given the opportunity to be Medicaid providers. Am frustrated, and scared for my son as his behaviors are getting worse, and he is regressing. Am also concerned of losing my right as a parent to choose a provider and participate in what is the most crucial treatment for my son. I know him best and what is right for him as I have worked diligently with all his providers and interventionists. I sought out for his diagnosis when I noticed something was wrong in his development, cheered his assessments and evaluations, left my career to make sure that am there for him and all his therapies, participated in all family, parental and community awareness and trainings. Interviewed, hired and supervised his therapy team. Am concerned that he will fall into the crack of “managed care” and regress. Also, my son has an interventionist that has been working with him for the past 3yrs--that he loves and respects. I worry what losing her will do to him--as autistic children does not take changes or transitions very well. I am worried for my Son!

My son has worked so hard and shouldn't be forced to transition at this stage of his therapy. At 9 years old he cannot afford to risk a set back or gap in his services, this will literally be traumatizing for him. Children with established provider relationships longer than 2 years should be grandfathered along until they are done if the family feels that is the best choice for that child. Especially older children like my son who only has a couple years left in his program. NEW children should start with the preferred providers. When we started our journey 7 years ago there were horrible wait lists in this state and this ATAP to Medicaid move has frankly undone all the amazing progress over the years and put our families right back where we started. For all the good intentions I believe were behind this move it's actually doing more harm than good for the children whose programs are already in progress. My son doesn't deserve to be collateral damage, he's worked too hard to make the progress that he has over the years. He is not a number he's a little boy, please leave him be, let him finish out his therapy with the people he loves and trusts because otherwise we're done. We are not moving to a Medicaid provider, no one will get to bill them on his behalf and make money off of his case #... we will find another way to privately fund his therapy. On a side note, this mom also happens to be an RBT and even though there is a shortage of interventionists I cannot actually work doing it because of the low wages. RBT's are the front lines, we get kicked, hit, head butted, spit on, scratched, hair pulled, things thrown at us, yelled at and all while staying very calm and positive and focused. We put in hours of physically and emotionally demanding work and we deserve to be compensated appropriately for it.

there are not enough interventionists - we are very worried about this change, we are also going to have funding reduced at the same time - its just really bad for us and i am having sleepless nights about all of these changes all at once and not enough time for us to be able to adjust

Hours needs to be larger

My main concern is my son regressing especially after all the hard work Lovaas has put in with him. He has become quite attached to his interventionists and I believe switching providers is detrimental to the progress he has made. I also don't believe it is very ethical that I was given notice that the month of April will be my son's last month with Lovaas four days before the month is ending. I was told my son will be receiving services from a provider I have never heard of and know nothing about. Not happy with new provider.

Que Cada vez que mi hijo reciba una terapia sea diferente tutor.

Es importante el ABA para ayudar a nuestros hijos con su vida diaria

Has been suggested, not likely to obtain services for “older” children, age 14

My son waited for 3 years to get ATAP funding. He finally got it, but I had to fight for everything! I only wanted him to go to FIT Learning as he needed their specific support and we had done all the other ones privately. He got apx. 10 weeks of services and then our funding stopped. This was due to my insurance changing. He was doing awesome and we could not afford to keep him there at almost \$2/month. My "insurance coverage" at the time has ONE provider in all of Northern Nevada and they were joke. It was devastating. Simply put- if your kid is too high functioning and you make any amount of money- you are essentially screwed! My child has been forced to move school placements 3 times in his first 5 years of school, been physically and emotionally bullied and his autism has impacted almost every area of his (and our) lives. But, he is "too high functioning" for KB Medicaid and we make too much money and/ or have insurance to qualify for services. Too much money is apx. \$60k/yr and trying to get services through health insurance is a joke! I lost my job last year, a major part of it being from trying to meet his needs. I have essentially given up hope on any external services and now do my best to meet his needs myself. Sadly, I know you have read too many similar stories to ours. More than anything- services should not be income based and SO HARD to access when you child is young. For high functioning ASD, many times EI isn't even a factor bc they don't get diagnosed till school- our son was 7 years old when we finally got a diagnosis. He went through FIVE preschools! I'm exhausted and just done trying to expect any state or government help. To be honest and with all due respect, even this survey seems like a waste of time. Good luck trying to meet the needs of so many kids with so many layers of governmental barriers and no providers willing to work within the system. My ONLY hope is the educational choice money coming through- if it's implemented the way it reads, I can actually get my son what he needs...as long as I homeschool him!

My daughter had a court order for SLA with a BSP but no one could ever write a plan. My daughter was a WIN case too!!! Her therapist was denied payment. even though Dr. Haas and Jane Gruener referred us. I finally left NV in October 2015 Also the goveners health advocate was involved.

ABA is an incredible oportunity to my soon to improve, please approve an increase on the rates.

Our 3 year old son was enrolled in the public school system early childhood intervention. As his mother, I felt that he was not being given an appropriate education and was not being engaged enough. I removed him, enrolled him in parent hired ABA therapy which we fund solely on our own. We are looking to connect with speech and more behavioral therapy that we can afford.

our out of pocket cost is increasing due to small reimbursement ever since CCSD dropped us from ABA services. We are currently waiting to hear from medicaid, it is taking a long time.

Que sean buenos y calificados servicios, buenos y calificados proveedores y se efectue el programa adecuado para mi hijo

Many provider do not offer services for kid 10 years and older

I feel what is happening will have a detrimental affect on my child's progress. She is just starting to make progress again and I am afraid due to these changes she will lapse again. With that ATAP is a wonderful program but they are tying my hands in this and I am stuck

don't take away our ATAP and funding for ABA services my child has been doing this for 2 years and I dnt want to lose all her skills and behavior therapies that we worked for. I wanna be able to choose my provider and my interventionists. because it's my freedom to shoes the right therapist for my daughter.

pienso que los que recibimos servicio con aseguradora necesitamos alguien el la oficina que este de tiempo completo para que asi mejor sean manejados nuestros casos.

Need more trained providers

I feel that the move is ridiculous. My daughter has done amazing being funded through ATAP over the last 2 years. I am angry that I cannot continue with the same provider. I feel like I have no choices. No other provider is providing services they same way.

The new student choice program where \$5,000 is available for children who were in public school for 120 days should be available to kids with autism who receive ABA

Even if ATAP hired private contractors is board certified, they do not have professional long term research based knowledge to handled these kids. what I learned so far is, they are having controlled by somebody and and they under estimated importance of kids life and goal. Also they are money oriented too. Plus they are not act like not professional and not flexible. Because of all these changes I'm afraid that we are forced to settle for what they can offer and not able to provide what our children actually need and deserve.

The timeline is not reasonable

my child will regress with the waiting period and having to adjust to new interventionists as well as new consultant and different programming - this will be very bad for my child.

Most of the questions did not apply to my son, we have private insurance, no other options were offered to answer questions correctly.

perder la cantidad de horas que mi hijo actualmente tiene

After making the decision to change sevicees from the lovaas center to a better ABA opportunity for my child I find that the individuals from lovaas (BCBA/ behavioral consultant) are handling the tradition in a very unprofessional and unacceptable manner. When my son and myself were their clients I would get responses from his consultant within a reasonable amount of time. I understand these individuals are hurt from my decision to have my son be apart of a better opportunity but not responding to any emails as well as text messages when this is beneficial to my son's future is out of line and unacceptable. I will not tolerate any immaturity and/or unprofessional actions toward myself and my child. Leaving the lovaas center was my choice to benefit my child, and I stand behind my decision. After nurmerous attempts reaching out to the lovaas center for a transition meeting date I have still have not received any response from Lovaas center. If I have to report them to a higher business needing them to investigate my issues I will!

It is a requirement to basically use or lose your funding but these providers are new and unable to accommodate.

My husbands company did not include ABA services in health insurance plan so my son has never had ABA services I waited so long to receive services, now that i have them and we are making progress with my Child now i have to change provider and my son theraphy that has helped him so much. I am so disappointed with this system instead of helping the families you make it works.

Please don't allow that we have to be force to change providers. Consistency is very important with kids like my daughter. We are very happy with Lovaas Center.

I feel the sudden change in service providers does not allow for smooth and fluid transition. Many companies at this time feel more like opportunist then genuine providers. I have already built a rapport with the service provider that I currently have and I do not want to change yet again to a new provider. While I agree with the idea of now having RBT's available for families who need an interventionist, I also feel like it is too soon to transition in the amount of time allotted.

In a panic to retain services for my daughter, I tried transferring to ABA Institute, only to be told during our transition meeting that he did not have tutors to provide services in my area.

As ,of now the provider has submitted our paper work 3 times to Medicaid. Medicaid has denied 2 times .we are waiting on the third attempt.

Not enough providers, been on wait list at Touro forever. Now waiting to hear back re referral to other provider. Son still has NEVER received any ABA whatsoever.

I was not aware that Nevada now has ABA Services available.

Our daughter has shown much progression since she has been with the Lovaas Center and the team we vetted. Any disruption or delay of her treatment will result in her regressing.

don't know how to find it for my 13 year old son

Non

Nevada needs to step up and join the rest of the country in paying RBT therapists. We are always at the bottom when it comes to children.

I was never directly contacted by ATAP to be told that I would have to find another provider until I asked my ATAP consultant who confirmed this. None of the providers that are on the list will be able to accommodate the hours that we currently do with services provided through the Lovaas Center. Many of the service providers on the list do not provide the quality of service we have received. The couple of providers I feel capable would provide quality service have over a year's wait time and would not be able to accommodate our schedule. PARENT CHOSEN TECHNICIANS IS A MUST--the chemistry between client and technician is not one that can be 'assigned'. This situation has been just another situation where I feel like we have been made to be victims. And why? A great program was carved over many years. Why can't we simply grow the system that is in place. It's exceptional and cost-effective!