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About the Early Learning Alliance Network

ELAN is a not for profit, 501C-3 organization focused on developing networks that can support children ages 0-8. The Early Learning Alliance Network envisions a community that is empowered with information and resources to engage in and support high quality early learning. This community will exist through transparency, networking, learning, and a commitment to all young children. As a result of our work, systems of learning connect to ensure that all families and children and educators have access to what they need to thrive.

ELAN has three priority areas including transitions to K12 schools, data collection to help all stakeholders, and the empowerment of educators, families, and other stakeholders to better serve young children through their individual contributions. As an organization we are founded on the belief that there are resources in existence to support high quality learning for our children both in and out of formal learning communities; our job is to empower, engage, and ignite access to and understanding of those resources and supports so that all young children have countless opportunities to thrive.

Because our founder is a former special education teacher, our organization is by nature committed to supporting all children. As such, our early intervention priorities for 2019-2020 are provided below.

Early Intervention Fair Pilots. We have planned four pilot Early Intervention Fairs this year. These will take place at preschools which focus on children ages 2.5-5 years of age and will include initial evaluations for the following: Speech, Hearing, Vision, Fine Motor, Gross Motor, and Social-Emotional Skill development. Evaluations will be conducted by trained early intervention specialists.

Hamilton County Systems of Care Early Childhood Initiative. Along with the Hamilton County Systems of Care Coordinator, we are co-facilitating this work that is focused on understanding expulsions and separations. Further, we are part of a cross-disciplinary team that is developing parent/family training and other resources by to address needs in early intervention.

Universal Design Initiative. We are happily supporting eleven local educators as they earn the UDL credential from a nationally recognized organization. UDL is a process by which learning environments, instructional programs and processes are designed with the whole child and all children in mind, so that all children may equitably participate and learn.

Data Collection and Analysis. ELAN is an organization committed to evidence-based policies and decisions. To that end, we will collect and use data to support advocacy, to develop of solutions to better support and communicate with families in need, and to document our ongoing community conversations with specialized providers, families of young children with a range of disabilities, and early childhood educators (ages 2-8).

ELAN Leadership

Dr. Jody Britten has been a classroom teacher, special educator, educational leader, professor, assessment coordinator, author, advocate, consultant, and researcher in education. Jody has been engaged with public and private schools around curriculum, creativity, learning environments, systemic change, student advocacy, and accessibility since a very young age. Jody's most recent work has positioned her as a thought leader in 21st Century skills, digital learning, and developing educational systems that impact student engagement. Jody co-authored several guiding documents on the implementation and assessment of critical non-academic skills throughout Canada and the United States. Having trained school leaders and teachers from preK-20 on six continents, Jody has made courageous contributions to education worldwide. Under the Obama administration she served as one of the chief architects to the Future Ready Schools framework and the Future Ready Schools assessment system that has impacted more than 20 million students and 2 million educators in the United States. She has coauthored the research foundations and classroom strategies for the International Society for Technology in Education 2017 learning standards for students used in over 27 countries. In addition, Jody has continuously supported the Center for Applied Special Technologies and the Universal Design Implementation and Research Network. With a rich history in Positive Behavior Intervention and Supports, Dr. Britten continuous seeks opportunities for all children to thrive. As a community advocate, Jody founded the Early Learning Alliance Network to support children, families, and educators using a framework for community empowerment. Her work in early childhood has supported more than 19,000 young children as she continues innovating to provide supports and resources for young children and their families, educators, and caregivers. Jody's quiet and purposeful advocacy for children and education has enabled her to improve the knowledge and skill of teachers and educational leaders, the skills and awareness of parents, and the lives of children globally. Jody serves as the CEO for ELAN.

ELAN Early Intervention Team

The Early Learning Alliance Network has a dynamic team of professionals. The following provides an overview of the expertise we hold on our team.

Peg Rideout has been a special educator with a focus on early childhood for her entire career. As a professional serving families throughout Hamilton County for over thirty

years, Peg has joined the ELAN team to continue her advocacy. Peg is a certified IN*SOURCE parent support advocate and works directly with our preschools to support families living through the early intervention process.

Amanda Comage-Trower has been an early childhood educator since the age of seventeen. She is an author, advocate, and trainer for model preschool education. She works to directly support young children with Autism and is continually advocating for developmentally appropriate practices in ABA and other specialized supports.

ELAN's Advocacy for Children with Autism

In late Fall 2019, our organization was contacted by parents, families, ABA providers, and early childhood educators/preschool directors about the pending insurance rate reductions for individuals with Autism receiving ABA therapies. Since that time, we have immersed members of our team in understanding the issues, the impact on families, the impact on non-trained early childhood providers, and, most importantly, the impact on children.

What is ABA Therapy?

ABA Therapy is a research-based intervention that supports social, communication, and learning skills through carefully planned positive reinforcement and supports. ABA therapists hold expertise in the constant evaluation and monitoring of behaviors and developing responsive reinforcement that lead to mastery and consistency with desired behaviors, communication patterns, and skills. ABA therapies are designed based on unique needs of individuals.

About this Report

The ELAN team recognized the need to collectively capture the stories from providers and parents with whom we have recently dialoged. To that end, we deployed a seven-question survey to these families and groups in order to identify themes and common "stories of impact" surrounding the ABA therapy reimbursement rate reduction that will come into play December 1, 2019. This report is a summary of survey results. While not exhaustive, the feedback we were able to capture does make it clear that families will be directly impacted by this insurance-company decision.

Analysis

Survey questions were open-ended; these text responses underwent a three-level analysis process. First, an automated theme-based search was completed using JMP text analytics software. Second, responses were hand-coded to and emerging themes

identified. Third, an external party reviewed this work, and helped to select sample statements from the overall data set to include in this report. While we make no conclusions concerning this survey data, these survey results do make evident that the insurance industry's ABA decision will negatively impact children.

Survey Questions

The following are the questions that were asked of parents, providers, and advocates.

1. How do you think the insurance rate reduction for ABA Therapy will impact quality of care for children with Autism?
2. What will be the greatest impact of the insurance rate reduction for ABA Therapy on staff who serve children with Autism?
3. What is your greatest fear about the insurance reimbursement rate reductions?
4. How will the learning environment for children with Autism change as a result of the insurance reimbursement rate reduction?
5. How will the continuity of care be impacted for children with Autism as a result of the insurance reimbursement rate reduction?
6. Anything you would like the state to advocate for to better serve the needs of children with Autism?
7. Any other comments from your vantage point on the impact of the insurance reimbursement rate reduction?

Participation

This survey was deployed only to parents/families and providers with whom ELAN has contact. Participants were invited to share their opinions via a secure link that captured no identifying information (both location and IP address remained anonymous). Participation was completely voluntary with no affirmation of participation, nor reward or benefit for participation.

After a three-day survey completion window there were 28 total respondents including 22 individuals identified as *parents*, 4 individuals identified as *providers*, and 3 individuals identified as *advocates*. Please note that respondents could select more than one role that they play in the life of a child or children with Autism. As such, one participant selected their role as both parent and advocate.

Level 1 Findings: Text Analytics

The following provide an overview of the findings from responses when using the JMP text analytics coding software (version 14). This level of analysis used artificial intelligence to

review the text-based responses and pull the most frequent themes that were submitted for each question.

How do you think the insurance rate reduction for ABA Therapy will impact quality of care for children with Autism?

- Reduce access
- Reduce quality of care
- Impact quality of life
- Reduce trained staff
- Pay reductions for staff that are already underpaid

What will be the greatest impact of the insurance rate reduction for ABA Therapy be on the staff who serve children with Autism?

- Continue to lose staff members
- Not able to provide quality training
- Lower will to serve in this role
- Forcing quality staff to leave the profession

What is your greatest fear about the insurance reimbursement rate reductions?

- Direct impact of family wellbeing
- ABA loss of treatment
- Distract from progress being made
- Deduce care for kids that can't face anymore hardships

How will the learning environment for children with Autism change as a result of the insurance reimbursement rate reduction?

- Less funding leads to less staff, less quality, and less opportunities for kids directly
- Therapists won't be as consistent
- ABA quality will be less

How will the continuity of care be impacted for children with Autism as a result of the insurance reimbursement rate reduction?

- Increased staff turnover
- Change if facilities to lower cost areas
- Out of pocket payers will have access to better care
- Cost of quality will decrease immediately

Anything you would like the state to advocate for to better serve the needs of children with Autism?

- Protect our kids

- Do anything you can to ensure that the lives of our kids are not in the hands of private insurance companies
- Develop some type of family/parent support network this is a hard disability to support and we need advocacy

Level 2 Findings: Qualitative Coding

Open-ended response data was reviewed and coded based on repeated ideas or themes that emerged across respondents related to each question. These themes were then organized into concepts or categories that ultimately resulted in patterns. Those patterns were reported as follows.

Impact of reimbursement rate reduction.

Responses indicate that while the sample is small there is a high likelihood that the insurance rate reduction for ABA Therapy will impact quality of care for some of our most vulnerable children. Data highlighted that the care of individuals with Autism/Autism Spectrum Disorder necessitates high quality staff, personalized intervention, and continuity of therapist and routines. Further data suggested that insurance rate reduction could cause closing of centers, forced employment changes for families, and limitation of care plans that could have a grave long-term impact on the overall capacity for individuals with Autism to see full social inclusion.

Importance of Early Intervention.

The importance of early intervention emerged as theme, often with respondents noting that reduction in services could lead to increase depression, exclusion of the individual and his/her family from the greater community, and increased interactions with law enforcement as parents/families are unable to independently address behavioral issues. It was clear from the data that both providers and families are concerned with large caseloads, quality of staff, quality of staff training, and an overall reduction in services. Especially for our youngest children these impacts have dire long-term effects.

Frustration and Stress Experienced by Families.

The frustration being felt by both providers and families was evident. They are concerned about burn out of staff, closing of centers, case overloads, and more. Further, with families seeing the direct impact of ABA therapy on their children's ability to successfully communicate and acclimate to typical social situations they are fearful of their child's future. The impact of insurance rate reduction is expected to impact our society as a whole, not just individual children or families. Review of responses made it clear that there is already a high degree of stress and concern among parents caring for individuals with Autism.

Expected Staffing Impacts.

Data demonstrated a focus on expected changes in staff numbers, quality of staff, available training to staff, and long-term financial impact of individuals entering the ABA therapist field. Parents and providers are concerned with centers being forced to close (with no long-term financial model available). Data suggests that staff morale could decrease, making an already difficult job of an ABA therapist even more personally draining.

Continuation and Access to Care.

With a clear need to focus on the care of individuals with Autism data suggests that there are unanswered concerns about the how centers will continue without some capacity to project financial health. Responses indicate that quality of staff (including the staffing of individuals with higher degrees) could no longer be possible after rate reductions. Parents seem genuinely concerned about consistency in care and continuity in services. Because it takes time for therapists to develop positive relationships with clients it is imperative that consistent and quality staff be available.

Long-term Impact and Care.

Respondents demonstrated fear for the quality of life of their children. Themes emerged around not only quality of staff but long-term access to care for individuals with Autism. There is fear for the immediate impacts of insurance rate reduction, but further concern that this one action could lead to additional losses in benefits and care. Fears that were shared in responses indicated a long-term view of impacts; parents suggesting that this one action could limit the overall potential of their child to thrive. Parents are concerned that centers will stop accepting certain insurance providers. Providers state that there will be forced reductions in pay, forced increase in case load, and increase staff turnover. There was mention of limits in case load being imposed by other organizations that are not aligned with rate reductions from insurance companies.

Need for Support and Safeguards.

Parents, providers, and advocates aren't sure what the state can do to actually halt the insurance reimbursement rate reductions. However, they do know that continuity of, quality of, and access to care is growing increasingly dependent on insurance provider decisions. Autism is a complex, individualized, and long-term challenge for families and children. Survey responses demonstrated that parents feel unable to meaningfully advocate for their child; i.e., parents believe that their individual voices have little to no change of changing the decisions of large insurance companies.

Level 3 Findings: Selected Responses

ELAN worked with an external party to select typical and high impact responses for each survey question. Each of the responses was coded for impact (0, typical to 5, high impact). The follow provides the high impact responses.

- Where does it end? These services are important to my son. I'd assume that the insurance officials making these decisions have no special needs children. At what point does the insurance company begin re-diagnosing children in an effort to reduce or eliminate their costs?
- For young children I think it has a huge impact, we only have a small window to address major needs of kids before they get into the K12 system and if that care isn't 100% effective and driven by quality assessment it could really hurt our children long term.
- It will depend on what happens to his Center. If they stay in business, I am sure there will be an impact on the quality of care my son receives simply because the business structure will need to change. If he is thrown into the public-school system, his entire world will be turned upside down and he will regress and have to start over with an entirely new learning environment.
- There is only one thing important to the future or the world, OUR CHILDREN! Delaying or hindering, my child's fight to concur/cope with autism will do long term damage to him and all the others like him. One symptom, my 4 year old son has is a significant speech delay, which causes him to not participate/engage /play with his peers. This self-isolation then causes depression/anger, which further delays his social skills leading to furthering delays in his speech all in a constant loop.
- The number of tears, sleepless nights and stress this has placed on the families that have children and or adults seeking this scientifically proven medical intervention for their loved one is immeasurable. Studies have shown that parents of children with special needs show similar stress levels to soldiers returning from war with PTSD. I know parents who have sought mental health support due to the additional stress this rate reduction has caused. Why are some of Indiana's most vulnerable kids and their families under attack with so little support? Please help. Hear our cries. Hear our breaking hearts. Please help.
- The quality of care is diminished and has impact on my son who has complex needs. As a result of the initial rate cut in-home visits from a BCBA stopped. I no longer have the support I need to generalize my son's progress to all of the community settings our family needs to access. There are in home behavioral programs I cannot do any more. The center staff are less available to speak with me about my son's programs and progress. He is no longer able to attend important community settings with his therapist. My son's treatment and progress are compromised.

- This will drastically reduce the quality of care. A high-quality center provides ongoing professional development for behavior technicians. Behavior technicians are paid about the same or lower than some fast food restaurants. This leads to a high turnover rate in a difficult career. Without proper training behavior technicians are not as effective. Many centers cannot afford a training specialist. Also, every BCBA, board certified behavior analyst, will likely now have the maximum number of clients allowed by law. I cannot emphasize enough how this will drastically take away from the BCBAs time to properly observe and create the best plan of action moving forward for each child and/or adult with autism. Many centers used to be able to hire expert consultants for extremely tough situations and the budget will no longer allow for the experts to be consultants. This field of medicine is still considered to be very young and the expert pool is very limited. Most centers rely on expert advice often. Without their help children's quality of life will suffer. It is very probable that centers will leave Indiana. Thus, the already long wait lists for a spot at a quality center will become even longer. Scientific research shows the importance of early intervention and children are missing all or part of that window because of waitlists at high quality centers.
- A rate reduction will lead quality staff to possible other higher paying positions. long. The staff have a right to make a living wage. Quality people being underpaid drives frustration and unnecessary anxiety, not necessarily allowing them to focus on my child. Alternatively, you may not be able to hire and retain quality staff, again impacting the care my child receives. He will not be in ABA forever, just a couple years. However, without quality care while there that couple years may turn into a couple more years, ultimately costing insurance more money in the long run.
- Less funding means less spending overall. For us this would mean less opportunities for community inclusion. Some centers may need to relocate to less expensive and accommodating locations.
- Because of insurance rate reduction, ABA therapists, technicians and employees will be paid less, many will not continue their carrier and will might leave jobs for another carrier. Some ABA therapy centers might close. Due to lack of providers Autistic kids will not be able to continue therapy and will go on a long waiting list.
- It's not as if the insurance company is going to take a hit in profitability. Every time an insurance company says they're doing something to better the client experience and lower costs, all they're saying is that they're looking to increase their profitability. I agree that we need to look at reimbursement rates for providers, there are some providers who charge an insane amount; look at the cars they drive. When a provider drives a Bentley, has a Range Rover in the garage and another Bentley at their winter home in Florida they're making too much money. However, ABA therapy doesn't fall into that category, ABA providers are a high touch, heavy staff involved provider which has a unique presence in the

healthcare delivery market and these factors need to be taken into consideration whenever any kind of reimbursement reduction is taken into consideration.

Closing

ELAN's community conversations with providers, parents, and advocates for children with Autism have demonstrated frustration and deep levels of concern. ELAN put this survey together to capture discrete input from those stakeholders. While the sample size is too small to be conclusive, it does clearly demonstrate that parents and providers are in need of support, advocacy, transparency, and some predictability in the care of their children.

Given the continually increasing population of those diagnosed with Autism/Autism Spectrum Disorder and the initial responses ELAN has collected, it may be in the best interest of our greater community to have some safety net provided by the state. Without it, these families will continue to be powerless, without the collective voice to advocate for the care that their children need in order to thrive.

Appendix A: ELAN's initial letter to state leaders

We are a not for profit organization serving the children, families, and educators of Hamilton County, Indiana. County-wide we have an estimated 24,000 children under the age of five. An estimated 450+ children in our county have been identified with Autism. Since, 2017 our organization has very carefully monitored the capacity of our great community to provide services and supports to these children and their families.

If we as a community want to see all children thrive long-term, access to effective support for young children with Autism is critical. As national research pinpoints, early intervention is an absolutely necessity for individuals who are faced with the challenges that Autism presents. It has been a pleasure to witness Indiana be a leader in Autism therapy.

However, the leadership our state has been presenting will soon be invisible.

Since July 2019 we have also been carefully monitoring the impact of changing reimbursement rates have on families of young children with Autism and providers that support Autism therapy. These changes have been focused on the insurance provided by one of the largest health insurance providers in our state. It is estimated that the state has allowed one insurance provider to own more than 60% of the market share of health insurance for its citizens. In 2012 this insurance provider reimbursement for Autism therapy at a rate of \$50/hr. The last 4-5 years have seen that reimbursement rate go to \$60/hr. By December 1st of this year, that rate will plummet to \$49/hr.

The hourly rate has to cover provider insurance, facilities, materials, and cost of trained therapists. Costs that have risen over the past decade, not decreased.

Centers in our network will lose up to \$580,000 per year, which is not an insignificant amount. In our county alone, if centers providing support to young children receiving Autism therapy are left with the \$49/hr reimbursement rate we can plan on a 1.75 million-dollar financial hit. As a result of the declining hourly pay, capacity to train and support staff, and cover costs for therapy our **youngest, most vulnerable children are staged to suffer.**

While Medicaid waivers may provide support for these families, there is currently an estimated 8-10 month delay in waiver processing. The financial implications over insurance provider choices cannot be ignored. If we choose to dismiss the cost of and need for early intervention, the long-term financial impacts on our state will be unquestionable. Current research suggests that by displacing early intervention supports for a child we are setting our constituents up to cover care/remediation at a cost of \$1,082,000 per child for ages 3 through adult hood. In our county alone, that cost would (even if the financial impact is just 1/3 of that estimated) be over 150 million additional dollars in support.

I am aware that there may be limits in terms of the outreach and support you, as an elected official, can provide. I am however asking that you (1) familiarize yourself with the impact that the insurance provider's reduction in reimbursement rates is having on our most vulnerable children, and (2) help our organization to identify other avenues of support.

I have no doubt that if nothing changes in the approach of insurance companies, we as a community that places a priority on the longitudinal care of all children, **will see our children and their families suffer.**

After talking with centers, providers, trainers, and families from around the state the following are examples of impacts already experienced.

- An estimated 20 trained professionals have left Autism support centers due to drops in pay.
- The hourly rate of certified behavior support specialists typically working with young children with Autism is under the rate which is paid to work in the fast food industry; *if we can't pay high quality staff, we will not have high quality staff.*
- One child had a reduction in reimbursed costs moving their 38+ hours of support to under 20 hours of support each week. Leaving parents to locate other care opportunities and ultimately having an impact on the ability of care givers to stay and thrive in our state.

We can do better for our children and our community. I look forward to hearing from you and contributing to any conversations that furthers our capacity to support these important citizens. **They deserve our advocacy and are entitled to our support.**

Appendix B: ELAN's updated letter to state leaders

As background, we are a not for profit organization that serves preschools in Hamilton County, Indiana. Over the past few weeks it has come to our attention that insurance provider reimbursements for Autism therapy are causing a bit of a stir among parents and Autism therapy and support providers. To be short, when reimbursement rates are getting cut and care is no longer available parents of young children are seeking alternative (not best-case scenario care) for their young children with Autism - which is why this issue has come to our attention. When I have preschool directors with no readiness to support these kiddos (some of which are non-verbal, among other struggles) being faced with provided care we have to find a better way.

Below are additional bullet points from conversations we have had with parents, foster parents, providers, therapists, and others over the past week.

- Instability in staffing is already hitting because of pay rate reduction expectations for December 1 (Autism support centers are expecting a 10% reduction in pay, and this will lead to 12:1 ratio of kids to therapists reducing reduction of care and increasing focus on billable hours).
- Even with concurrent billing our Autism providers that serve just 150 individuals with Autism will face a near \$400,000 deficit in 2019.
- It is expected that at least 40% of all center cliental will be directly impacted by reduction rates.
- Currently, even though these support centers have to administer medication they can't afford to hire a nurse.
- Liability coverage continues to increase while reimbursement rates decrease, create a continuous circle of chaos.
- While the Rand study is often cited as demonstrating that Indiana is among the most expensive - that study does not clearly articulate that Indiana has been a leader in supporting individuals with Autism. Our state is ahead of the game in mandates and we have an opportunity to continue to be a leader in care (and not a case in why positive movement in mandates fail). See https://www.rand.org/pubs/research_reports/RR1334.html for full Rand study.
- Currently, while most businesses have a 5-10% profit, at its **healthiest** our Autism centers only make a 3% profit (typical years is 1.75%)
- While one insurance provider provides insurance for just a portion of all families and individuals receiving care, there is great concern that other insurance companies will follow their lead.

Appendix C: Individual Responses

For your convenience we have included all responses data below. Note that while responses are numbered by question the numbering sequence does not mean that number 1 is respondent 1 across all questions.

How do you think the insurance rate reduction for ABA Therapy will impact quality of care for children with Autism? (Open-Ended Response are provided.)

1. This reduction by [REDACTED] (largest in the state) will put pressure on all other payors to reduce their rates.
2. It is already difficult to find ABA providers let alone a quality provider.
3. Providers will be pre-occupied with insurance billing and budgeting - a reduction in the quality of services is a likely outcome as bandwidth gets shifted from service delivery to administrative minutia in order to safeguard against additional rug being pulled out from Providers.
4. Majorly. I see this side of the reduction. Kids are losing quality learning and teaching because of this.
5. Reduce resources and the availability of quality therapists.
6. Serious negative impact on access to treatment
7. The fee schedule reduction is going to have a more adverse effect on ABA therapy providers than other providers as they are a more highly skilled labor driven provider. When insurance companies cut their reimbursement and cite cost savings all they're doing is hurting the patients, as undoubtedly the providers will have to cut back on staffing and will be unable to continue providing the 1 on 1 attention these children need. The children receiving ABA therapy are completely dependent on their providers to help them understand how their behavior does or does not fit in to the environment they are in and provides coping and behavior modification therapies to help them better understand not only their behaviors impact to themselves but to those around them. Without therapy these children will be more vulnerable to bullying because they're "different" and that's not a position they should be put in.
8. Organizations that provide this much needed therapy (ABA) will go out of business and we won't be able to get these services for our children (or won't be able to provide quality services w/o enough staff and resources).
9. Continued reduction will decrease the level of care provided for those on the spectrum. Decrease in funding equates to decrease in pay which equates to decrease in caliber of providers which equates to increase incidence of adults on the spectrum requiring long term supports. The potential for greater interactions of special needs consumers with law enforcement and so on.

10. Reduced pay for providers = reduce pay for employees = reduced quality of therapy, bigger caseloads and a slower acquisition rate of skills in the treatment plans.
11. The rate reduction will apply unnecessary strain onto providers being able to recruit, adequately compensate, and retain high quality staff. It will also impact provider's ability to provide layered oversight and training that is not compensated by third party payment, but mandated by the BACB, which is the board that regulates certification of those providing ABA services. Overall, it will negatively impact quality by requiring providers to do more with less.
12. The rate reduction will reduce the quality of ABA therapy that my child currently receives.
13. There is only one thing important to the future or the world, OUR CHILDREN! A rate reduction will hinder my child's fight to cope with autism and will result in long term damage to him and all the others like him. The sooner they learn to cope the sooner they can lead a more normal life, which is what you and everyone deserves.
14. The best therapists won't stay in the field.
15. Will have less good quality resources available for children making it less likely they can achieve goals to be as high functioning as possible
16. The quality of care is diminished and has impact on my son who has complex needs. As a result of the initial rate cut in-home visits from a BCBA stopped. I no longer have the support I need to generalize my son's progress to all of the community settings our family needs to access. There are in home behavioral programs I cannot do any more. The center staff are less available to speak with me about my son's programs and progress. He is no longer able to attend important community settings with his therapist. My son's treatment and progress are compromised.
17. Less dollars going to the ABA centers will cause them to be forced to reduce services and wages therefore negatively impacting the services they are attempting to provide. Some centers may be forced to close all together.
18. It is only a matter of time before rate reductions will negatively impact the moral of staff, which will have a direct impact on the quality of care for my child.
19. I think a lot of kids with autism won't be able to have access to ABA
20. It will decrease the pays for ABA therapists, many might leave the jobs, parents with autistic child will try to find a job with alternate insurance, will affect the quality and quantity of service to autistic kids, effect the families of providers and autistic kids.
21. Providers will not be able to pay highly qualified staff to work directly with the children. Also, larger caseloads for the supervisors will reduce quality of programs and clinical oversight.

22. Significantly impacts the level of service – specifically increased turnover in therapist, reduced care
23. Rate cuts mean we have a reduced ability to pay for treatment therefore limiting, and in the extreme curtailing the possibility of giving the patient important treatments
24. Rate reductions are likely to lead to less providers willing/able to provide evidence-based ABA services for children with Autism. Less providers will be able to contract with ██████; consequently, individuals and families with ██████ plans will suffer.
25. It will impact my child tremendously. I am worried about the care he will get due to the rate reduction.
26. Less reimbursement threatens the stability of my son's care, can lead to staffing cuts or increased workloads for the techs. Neither is ideal.
27. This will drastically reduce the quality of care. A high-quality center provides ongoing professional development for behavior technicians. Behavior technicians are paid about the same or lower than some fast food restaurants. This leads to a high turnover rate in a difficult career. Without proper training behavior technicians are not as effective. Many centers cannot afford a training specialist. Also, every BCBA, board certified behavior analyst, will likely now have the maximum number of clients allowed by law. I cannot emphasize enough how this will drastically take away from the BCBA's time to properly observe and create the best plan of action moving forward for each child and/or adult with autism. Many centers used to be able to hire expert consultants for extremely tough situations and the budget will no longer allow for the experts to be consultants. This field of medicine is still considered to be very young and the expert pool is very limited. Most centers rely on expert advice often. Without their help children's quality of life will suffer. It is very probable that centers will leave Indiana. Thus, the already long wait lists for a spot at a quality center will become even longer. Scientific research shows the importance of early intervention and children are missing all or part of that window because of waitlists at high quality centers.
28. For young children I think it has a huge impact, we only have a small window to address major needs of kids before they get into the K12 system and if that care isn't 100% effective and driven by quality assessment it could really hurt our children long term.

What will be the greatest impact of the insurance rate reduction for ABA Therapy be on the staff who serve children with Autism? (Open-Ended Response)

1. I imagine that there will be less providers so less jobs in this field.
2. I expect a higher turnover rate which will lead to less experienced and possibly lower quality of services

3. Staff will be less focused on their clients' outcomes and goals as more focus shifts towards the insurance rigmarole in order to ensure payment for services rendered.
4. Quantity of work due to money loss
5. The rate reduction means a reduction in staff pay, in order to keep the facility operational. These staff members are college graduates, many holding a masters degree. They can't afford to be paid less than what they deserve and have worked so hard for.
6. Therapists are already paid very little. Many leave the field to pursue better pay. This will only make the availability of these providers sparser.
7. Decreased staffing abilities. Decreased training. Decreased quality
8. The greatest impact on staff will be the forced reduction in pay, which could cause many high-quality staff members to look for employment outside of the industry; causing the industry and many wonderful children to lose out on great therapists. Staff cutbacks will increase caseloads and stress on those who remain and will lead to diminished care for the children in ABA therapy programs.
9. Staff will ultimately be paid less than they deserve for this demanding job. Burn out rates are high. Without proper incentive, staff turnover will be high. It will also be difficult to recruit qualified staff
10. Reductions in the workforce.
11. Pay and quality of the job
12. Please see response above. Providing quality ABA services costs money. The cost of providing those services have only risen over the years and yet reimbursement rates have remained unchanged. Reimbursement rates directly correlate with a provider's pay rates and ability to cover overhead costs of providing ABA service.
13. Rate cuts mean more pressure on staff to expand caseloads, thereby impacting potentially the quality of care despite their best efforts. It also means it could negatively affect the staff morale, further impacting quality via attrition or lower morale.
14. Some staff members will leave the ABA therapy industry and get a job somewhere else.
15. A rate reduction will lead quality staff to possible other higher paying positions. long. The staff have a right to make a living wage. Quality people being underpaid drives frustration and unnecessary anxiety, not necessarily allowing them to focus on my child. Alternatively, you may not be able to hire and retain quality staff, again impacting the care my child receives. He will not be in ABA forever, just a couple years. However, without quality care while there that couple years may turn into a couple more years, ultimately costing insurance more money in the long run.
16. Many of them will have to leave the field. I've already seen it at my center.
17. More burnout, good people leaving, less quality care

18. They will not have the training and ongoing support they need to help my son reach his treatment goals.
19. They will most likely lose their jobs.
20. Decreased pay
21. Lower pay rates, less job perks and less training in an industry with higher stress and higher turnover.
22. Compensation, many may be forced to look elsewhere for employment or subsidize
23. Rate reductions for [REDACTED] members for ABA services will lead to staff layoffs, more rapid turnover, lower compensation for ABA providers. Consequently, individuals with autism will be less able to access high-quality, evidence-based ABA services.
24. They will get a pay reduction. Which means they will leave to find a better paying job.
25. It is already so hard to find help that we travel over 40 minutes each way to attend therapy. This could lead to a closure of facilities.
26. Cut wages and elimination of promotional opportunities will force them from the industry leaving to no one qualified to work with our children.
27. There is a chance that staff income and training received will both be reduced. It is projected that staff turn-over rates will increase.
28. We have already seen quality staff leaving centers because they just can't afford to make so little.

What is your greatest fear about the insurance reimbursement rate reductions? (Open-Ended Response)

1. Families impacted by Autism has sharply increased and [REDACTED] is trying to reduce their cost at the expensive of children. Early intervention is key and my son is example of how important this therapy is to a child and family.
2. I am concerned that my child will receive lower quality of care and eventually could be dropped from care due to lower pay from the insurance
3. Where does it end? These services are important to my son. I'd assume that the insurance officials making these decisions have no special needs children. At what point does the insurance company begin re-diagnosing children in an effort to reduce or eliminate their costs?
4. That ABA will go away in full and these kids need the therapy.
5. That facilities will close because they cannot restructure their overhead quickly enough and cannot predict how many [REDACTED] clients they will have.
6. That the progress we are seeing will be halted if he cannot obtain quality therapy
7. That my child will suffer!

8. Short staffed, so quality of care suffers. Staff unable to keep my child moving towards the goals set forth to improve communication and quality of life for my child
9. Quality
10. ABA fading away and the children with ASD being underserved
11. The quality of care will decrease due to pushing providers to do more with less and staff turnover will increase in a field that turnover due to working in an emotionally, physically and mentally demanding field is already high. This will ultimately negatively impact consumers of the service and science of behavior analysis.
12. I am afraid that my child will regress in all progress that they made.
13. Losing quality staff which causes my son to require ABA for many more years than than is necessary. It delays his ability to develop those social skills effectively causing much longer terms problems.
14. I'm terrified my center will drop [REDACTED] clients.
15. My child won't be able to get quality care he needs and therefore won't reach his full potential in life (being self-sufficient, etc.)
16. The impact on my son's progress and on my family's welfare.
17. That our ABA center will close or will stop accepting clients who have their insurance through [REDACTED].
18. My greatest fear is that my child's center will close, or that my child's number of therapy hours will decrease. That in turn will mean that my child will be forced into the public-school system, of which he is NOT ready for. He is non-verbal and will suffer in a non-structured (specific to his needs/learning style) environment such as that.
19. Lack of care for kids with autism
20. The quality and quantity of therapy for our autistic child will be ruined.
21. That all funders will reduce rates and that my small company will have to close.
22. Impact of therapy and available resources for my child
23. Already stated. Inability to offer therapy.
24. Families of individuals with autism will have less access to high-quality ABA services. ABA is the most evidence-based intervention studied for treatment of autism. Likely to lead to protracted, costly litigation that won't serve [REDACTED] insured or children with autism.
25. The people that will work with my son.
26. That other insurance providers will follow suit, further endangering my son's therapy.
27. My greatest fear is that my child and many other children will not live their lives to their highest potential.
28. That this will be a rock that starts rolling down hill and gains speed, in our county we might as well not have centers if they can't afford to be open.

How will the learning environment for children with Autism change as a result of the insurance reimbursement rate reduction? (Open-Ended Response)

1. Again, it will divert the focus of Providers away from their clients and towards insurance processes.
2. Greatly.
3. The quality of the therapy won't be as good due to not having as much time or want!
4. Decreased providers
5. It will mean less individual attention to alter specific problem behaviors.
6. The very thing children need from ABA therapy will be the thing they might not get because the funds aren't there to cover it.
7. Fewer resources to maneuver the learning challenges that our children face. (staff and supplies)
8. Potential decrease in clinical practices
9. They will go to schools with educators who do not specialize or have knowledge on treating children with ASD.
10. Please see previous responses. Nothing good will come from a rate reduction.
11. The ABA will have to change their one to one therapy model.
12. Less focused care. At that age, they don't understand how to apply group setting learning to themselves. Focused care helps my child change his behavior much quicker helping him to move on to standard public education.
13. Children will not get the individualized services they need to make ABA effective.
14. More babysitting less learning and advancing
15. It is already affecting staff retention. High rates of staff turnover have a negative impact on continuity of treatment and treatment integrity.
16. My family is already seeing the impact.
17. ABA centers will be forced to cut corners, even more than they are already forced to do, to stay in business.
18. It will depend on what happens to his Center. If they stay in business, I am sure there will be an impact on the quality of care my son receives simply because the business structure will need to change. If he is thrown into the public-school system, his entire world will be turned upside down and he will regress and have to start over with an entirely new learning environment.
19. I think centers will most likely compromise on the quality of care they provide, staff morale will go down too.
20. Decreased number of therapists, decreased time of therapy, low morale of therapist because of job reduction will affect the quality of therapy in learning environment, decreased 1-1 therapy. Learning environment will be ruined.

21. Less funding means less spending overall. For us this would mean less opportunities for community inclusion. Some centers may need to relocate to less expensive and accommodating locations.
22. Increasing diagnosis, decrease in funding available through insurance...will create large gap in development of children with autism
23. Rate cuts also mean staff (technical and non tech) have to do greater loads which, apart from reducing effectiveness on regular basis, also takes away the focus from innovation by the providers on the learning front and limits with is possible for the patients, providers and ultimately insurers
24. Less resources available to provide high-quality ABA services. Learning environments will suffer.
25. I am worried the therapist will not enjoy what they are doing due to the pay decrease.
26. Less reimbursement can lead to less therapy hours, lower quality care as techs try to balance larger work-loads.
27. The learning environment will not offer as many opportunities, such as vital trips into the community to ensure the transfer of skills learned to various situations. The latest most research-based materials may also not be available.
28. Oh goodness, so much - we won't have consistency in therapist and that is a big issue for our youngest children. They will have more kids to serve with less pay and fewer supports.

How will the continuity of care be impacted for children with Autism as a result of the insurance reimbursement rate reduction? (Open-Ended Response)

1. It is simple - there will be less providers when we actually need more providers. Many more children when they become adults will need to be institutionalized because of the lack of early intervention and this cost will be shifted to the state and families all because [REDACTED] bottom line benefited at the expense of the children, families and state.
2. Likely this will result in new staff which will need training and then slow down the child's progress
3. I'd anticipate Provider staff being subject to higher rates of turnover due to reduced salaries, payment delays, and burnout related to imposed insurance processes that divert their attention away from their core therapy functions.
4. It will be impacted greatly. Their insurance is everything and when they don't have as much what are they and their families supposed to do now??
5. Same as above.
6. High staff turnover affects the continuity of care greatly. When a new RBT is introduced to my child, it often takes several weeks before they are paired well enough with my child to get anywhere with her learning goals.

7. Spread supervising clinicians across larger caseloads resulting in decreased oversight
8. Please see previous responses. Nothing good will come from a rate reduction.
9. Unfortunately, some ABA therapy centers may closed and their clients may not be able to be serviced.
10. More staff turnover. It takes time for children to bond with the staff directly overseeing his treatment. He has to trust them. More staff turnover will cause him to remain in ABA even longer, which is going to cost insurance companies more in the longer run.
11. Because of the insecurity of reimbursement last summer, my son's ABA therapist left our center for another career.
12. My son had made so much progress with her and he regressed significantly after she left. He is still benefiting from ABA, but probably lost several months of progress due to her leaving.
13. Changes in personnel which are difficult on child and tends to set them back
14. It is already negatively affected. Even though the first badly implemented cut was postponed it had a negative impact that is hard to undo
15. Turnover in the industry is already very high, this will only become more exasperated by these cuts. Our kids need consistency to be successful, these cuts will make that even more difficult.
16. Those that are currently providing services to my son will be impacted, their pay will be decreased, their moral will go down, and they will start looking for other means of employment.
17. Rebuilding an ABA foundation with lesser funds is not the answer.
18. Kids will have access to the right care.
19. Because of insurance rate reduction, ABA therapists, technicians and employees will be paid less, many will not continue their carrier and will might leave jobs for another carrier. Some ABA therapy centers might close. Due to lack of providers Autistic kids will not be able to continue therapy and will go on a long waiting list.
20. Most of these activities are a "cost of doing business" and therefore not reimbursable.
21. When rates are adequate providers are more likely to engage in these activities because it leads to better programming for the client. Now anything "non-reimbursable" will not be provided.
22. In the worst-case therapy has to stop if we cannot afford to pay the increases out of pocket
23. Having more frequent turnover (due to lower compensation to providers) will result in less generalization and mastery of ABA skills.
24. It was impact them negatively.
25. Staff turnover, layoffs, potential closures of facilities
26. This will have a life-long impact.

27. Children that receive high quality early intervention have a better chance at reaching their full potential as a future adult citizen. If we ignore these children now, we may be paying more to help them in the future.
28. We just won't have the consistency.

Anything you would like the state to advocate for to better serve the needs of children with Autism? (Open-Ended Response)

1. If the DOI and the state did their job ██████████ would not represent 60%+ of the Indiana insurance market. The DOI chooses not to get involved with rate discussions between payors and providers (which I agree with in principle) but with ██████████ being so large and having a monopolistic hold on Indiana the DOI MUST get involved and make sure these rates are fair.
2. Providers do not have a choice not to serve 60+% of the market.
3. How about some EMPATHY?
4. These children deserve the best quality therapy just like everyone else. I don't see insurance cutting rehabilitations or therapy for mental health along with health care. This children and adults are just as important as any other person.
5. The state legislature required these devices be incorporated into group healthcare coverage. Don't effectively skirt those requirements by providing ridiculous reimbursement rates that don't equal the actual cost of care.
6. It would be nice to have funding from state and federal agencies to help offset the reimbursement reduction. Additionally, it would be helpful for the ABA providers to negotiate with carriers and remove the "no balance billing" clause from their contracts. We simply cannot have an ABA provider go out of business because insurance so severely cut their reimbursement and prohibited them from balance billing the member.
7. More needs to be done to ensure that the amt of hours of ABA therapy are adequate for the child's needs. The insurance company seems to quote "research doesn't specify how many hours of ABA are recommended". This gives them the power to arbitrarily cut much needed therapy hours on their own timeline, without regard to the individual child's needs.
8. ABA programs that work collaboratively and inside of public schools
9. Children with autism and other developmental disabilities are amongst the most vulnerable of populations and are deserving of high-quality care and services. The quality of services received directly correlate to short term and long-term outcomes for these individuals and will impact their ability to live as independently as possible in the future. Without quality services, these individuals, for whom the data reflecting adult employment and continued reliance on insurance and public funds is already bleak, will undoubtedly face even bleaker circumstances given

rate reductions. It is inhumane to make decisions that will negatively impact quality of services for these individuals.

10. Please support providers of ABA therapy. They are doing amazing work.
11. If anything, you should get involved in improving the care for our future, our children, not reducing and removing that care.
12. ABA therapy is amazing. My son began services just before turning 4 in June 2019. At the time he wasn't talking and could not be taken in public due to running away from caregivers. After just 4 months in ABA, he can have short conversations and we can actually take him to museums. ABA has changed our lives. I don't know what I would do without it.
13. My son and family cannot deliver the productivity gain [REDACTED] are demanding
14. Insurance reimbursement rates cannot be cut any further, in fact, they should be reimbursing at higher rates. Our kids deserve a chance, these cuts will make that nearly impossible for children like my son.
15. Until there is a cure for autism, there will need to be supports in place for people with autism.
16. These children will grow to be adults and live in a society that does not know how to fully handle their differences. ABA gives these children a fighting chance at some kind of positive future.
17. The public-school system is already hurting; they cannot be expected to care for children with autism on top of the general population when we know there is an alternative that gives them the supports they need.
18. There should be no insurance rate reduction for ABA
19. I would like to see schools consult with or employ BCBAs. Early intervention in school would far better serve a lot of children and in the long run be cheaper than placement in ABA centers.
20. I think eventually we will see full ABA classrooms in public schools and the upfront costs will far outweigh the continued intensive care for older children and young adults.
21. More visibility into the increasing diagnosis.
22. The Autistic population needs to be recognized as a talent pool that needs to be nurtured like any other in this state.
23. Ensure that every Indiana child with autism has access to high-quality ABA therapy on par with those required for any other medical or surgical condition.
24. Provide the best quality of care for our children.
25. ABA is the ONLY evidence-based treatment for autism. It has been shown effective and it WORKS, my son has made amazing progress in 7 months.
26. ABA therapy in an ABA therapy center is the least restricted environment for many children with autism. Public schools and the IDOE are trying to say that is not the case. I beg of you to study and learn about ABA and how this medical intervention is NOT offered in schools.

27. Families of children who need ABA are being denied a free and appropriate education by our public school systems.
28. Can we do anything to safe-guard our kids? This is a quality of life issue for our community.

Any other comments from your vantage point on the impact of the insurance reimbursement rate reduction? (Open-Ended Response, not required response)

1. The ONLY recourse is for legislators to get involved because of the predatory practices by [REDACTED]. i.e. if [REDACTED] was only 10% of the Indiana Insurance market this would not be an issue.
2. 'The true measure of any society can be found in how it treats its most vulnerable members' -Mahatma Gandhi
3. When [REDACTED] knows they are renegotiating rates with a provider that is being actively used by a client, they should also have the responsibility of putting the client on notice of here is a disputed with that provider. Typically, [REDACTED] doesn't do this.
4. It's not as if the insurance company is going to take a hit in profitability. Every time an insurance company says they're doing something to better the client experience and lower costs, all they're saying is that they're looking to increase their profitability. I agree that we need to look at reimbursement rates for providers, there are some providers who charge an insane amount; look at the cars they drive. When a provider drives a Bentley, has a Range Rover in the garage and another Bentley at their winter home in Florida they're making too much money. However, ABA therapy doesn't fall into that category, ABA providers are a high touch, heavy staff involved provider which has a unique presence in the healthcare delivery market and these factors need to be taken in to consideration whenever any kind of reimbursement reduction is taken in to consideration.
5. I have nothing more add.
6. ABA therapy has been the game changer in our lives. Our child has made a lot of progress at his ABA center.
7. There is only one thing important to the future or the world, OUR CHILDREN! Delaying or hindering, my child's fight to concur/cope with autism will do long term damage to him and all the others like him. One symptom, my 4 year-old son has is a significant speech delay, which causes him to not participate/engage /play with his peers. This self-isolation then causes depression/anger, which further delays his social skills leading to furthering delays in his speech all in a constant loop.
8. While ABA therapy is expensive, it WORKS. I used to worry my son would never be able to hold a job and care for himself as an adult. But with ABA, he is now learning to talk and control his behavior. I don't think he will be a burden on the state as an adult only because of early intervention ABA as a child.

9. Look for your productivity gains elsewhere. Families of kids with autism are weary of [REDACTED]'s tactics
10. Reducing reimbursement rates for autism services is morally wrong and makes no sense as insurance companies post record profits year over year and increase premiums year in and year out.
11. [REDACTED] is the leading insurer in the state of Indiana. Other insurance companies are paying attention, watching to see what happens with this rate reduction...they have to be. If [REDACTED] is successful at allowing this rate reduction to take place, the other insurers will follow suit. It is a recipe for disaster and one that must be stopped. If at all possible, the largest employers in Indiana that offer [REDACTED] insurance must be involved in this fight. The biggest one being Eli Lilly and Company. Apex Benefits is another company to reach out to, as they provide employee benefits strategies to companies all across Indiana.
12. It would not affect a person but masses. Insurance rate reduction should be avoided.
13. ABA therapy is scrutinized and denied to many by insurance companies because of the cost and high hours required to make meaningful progress. Insurance companies are trying to force our field to compromise service for the benefit of saving money, when what we do is the only scientifically proven effective therapy for ASD and the progress of the clients we serve shows that!
14. I am extremely worried as a parent.
15. ABA therapy centers won't even see your child without insurance, please don't do this.
16. The number of tears, sleepless nights and stress this has placed on the families that have children and or adults seeking this scientifically proven medical intervention for their loved one is immeasurable. Studies have shown that parents of children with special needs show similar stress levels to soldiers returning from war with PTSD. I know parents who have sought mental health support due to the additional stress this rate reduction has caused. Why are some of Indiana's most vulnerable kids and their families under attack with so little support? Please help. Hear our cries. Hear our breaking hearts. Please help.

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