

Appendix A

Statewide Member & Family Forums 2019

Executive Summary and Facilitation Notes Detail from Each Forum

The information in this appendix is an executive summary of the Statewide Member and Family Forums and the member and family detailed input provided at each of the 51 in-person forums and the 2 statewide online forums facilitated through WebEx. It is important to note that comments reflect the exact wording, as captured, to the extent possible, by forum facilitators that members and families used throughout the project.

Executive Summary

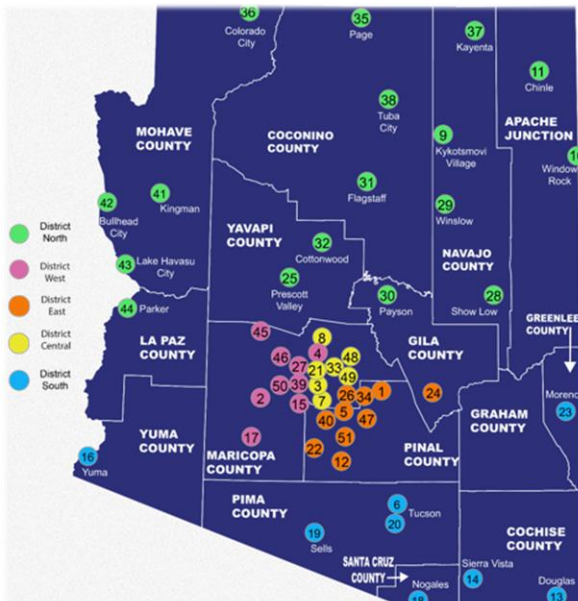
General Purpose:

Engage Arizona's communities to provide Arizona State Agencies with authentic stakeholder feedback to understand the unique needs of Arizona's families and members who require, and use, Long Term Services and Supports (LTSS), also known as Home and Community Based Services (HCBS), through the Division of Developmental Disabilities.

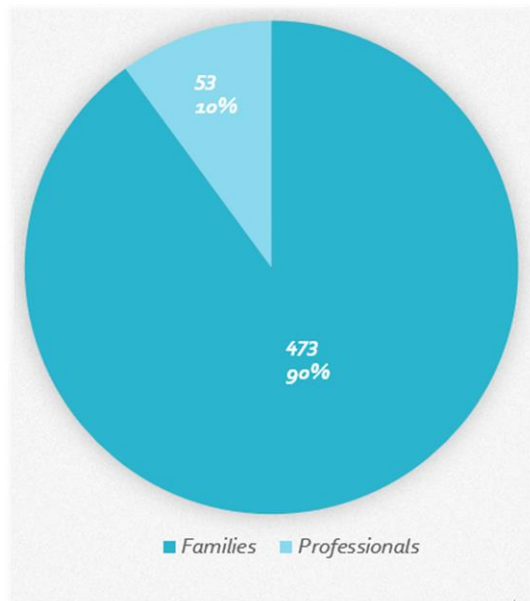
Primary Purpose:

Engage members and families in a discussion, and hear from them, about an alternate model for healthcare delivery in Arizona that has been referred to as 'fully integrated care'.

Forum Locations 51 Forum Sites 2 Statewide via WebEx



Participation 526 total participants 473 Members and Family Members 53 Professionals



Facilitated conversation with members and families to elicit broad feedback on:

1. What is going well?
2. What needs to be improved?
3. Ideas for improvement
4. Thoughts on an alternate service delivery model
5. Thoughts on The Governor's Executive Order Relating to Enhanced Protections for Individuals with Disabilities
6. 'Blue Sky' – What does your ideal world look like?

Key Findings and Common Themes:

What is going well with DDD LTSS? A total of 352 comments were recorded. Members and family members generally shared that they have positive interactions with their Division of Developmental Disabilities (DDD) Support Coordinator and were happy with the array of services available through DDD. Participants also shared that they were satisfied with the quality of their home and community based service providers and that they were happy with their health plan benefits.

What needs to be improved? A total of 517 comments were recorded. Participants cited a high rate of Support Coordinator turnover; Support Coordinator lack of knowledge of available resources for families; and a lack of available, and high quality, service providers (provider shortage) as the top areas that needed improvement.

What are the solutions for improvement? A total of 429 comments were recorded. Participants stated that more training for Support Coordinators was needed along with a rise in salary for Support Coordinators to attract and retain qualified, and high quality, personnel. Participants also reported wanting more information, and transparency, from the Division of Developmental Disabilities.

Thoughts on an alternate service delivery model. A total of 593 comments were recorded. The majority of participants reported general concern (67% of all recorded responses) about the alternate model presented citing: general doubts, loss of their Support Coordinator, general barriers to services and loss of services, loss of advocacy rights, lower quality of life for members and conflict of interest noting that the alternate model presented appeared to be a for-profit business model. Participants also asked many (23%) specific questions about the alternate service delivery model and wanted clarification, or more information, on the model presented for stakeholder feedback. Few participants (4%) expressed conditional support for the alternate service delivery model.

Thoughts and suggestions on The Governor's Executive Order. A total of 308 comments were recorded. Participants overwhelmingly supported the Governor's Executive Order and the provisions therein. Additional recommendations from families were: increase monitoring and oversight, provide training and education for staff and families, increase funding, strengthen background checks, increase advocacy training and reporting requirements, and review hiring practices for people that work with individuals with disabilities.

Blue sky is the ideal vision of the world the members and families live in. 'If you could have anything you want for yourself or your family, what would it be?' A total of 317

comments were recorded. Participants responded with a wide range of unique comments. Many comments had a general theme of inclusion, employment, independent living, and communities working together to support all people.

Raising Special Kids would like to thank the Division of Developmental Disabilities, The Arizona Health Care Cost Containment System, Professionals that work in the field of disability, and most of all the Members and Families who participated in the Statewide Member and Family Forums by sharing their lived experience and providing their honest input.

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Acronym Key:

A key to the acronyms used throughout this document has been created, and comments from the initial practice forum with Raising Special Kids Staff (many who are parents of children who are eligible for Division of Developmental Disabilities, Long Term Services and Supports) is included here.

- AAC – Augmentative and Alternative Communication
- AAPPD – Arizona Association of Providers for People with Disabilities
- ADE – Arizona Department of Education
- ALTCS – Arizona Long Term Care System
- APM – Area Program Manager
- APS – Adult Protective Services
- ASD – Autism Spectrum Disorder
- ASDB – Arizona State School for the Deaf and the Blind
- ATT – Attendant Care
- AzEIP – Arizona Early Intervention Program
- DCS – Department of Child Safety
- DCW – Direct Care Worker
- DES – Department of Economic Security
- DDD – Division of Developmental Disabilities
- DTA – Day Treatment Adults
- DTS – Day Treatment Summer
- DTT – Day Treatment and Training
- DME – Durable Medical Equipment
- DPM - Division Public Meeting
- DX – Diagnosis
- EAP – Employment Assistance Program
- EPD – Elderly and Physically Disabled
- ERE – Employee Related Expenses
- GSE – Group Supported Employment
- HAB – Habilitation
- HCBS – Home and Community Based Services
- HP – Health Plan
- IDLA – Individually Designed Living Arrangement
- IEP – Individualized Education Program
- IOC – Independent Oversight Committee
- ISP – Individual Service Plan
- LRE – Least Restrictive Environment
- LTC – Long Term Care
- LTCF – Long Term Care Facility
- LTSS – Long Term Services and Supports
- MCO -Manage Care Organization
- OT – Occupational Therapy
- PCH – Phoenix Children’s Hospital

- PRC – Program Review Committee
- PT – Physical Therapy
- QVA – Qualified Vendor Agreement
- RES – Respite Care
- RSK – Raising Special Kids
- SC – Support Coordinator
- VR – Vocational Rehabilitation

Practice Forum: Practice RSK Date: March 15, 2019 Attendees: 12

What is going well with DDD LTSS?

- SC improved responsiveness.
- Provider consistency.
- DTA accommodating.
- Home modification - streamline process.
- SC provided accurate resource info.
- Cell phones to SC improved access.
- Website is awesome easy to navigate Spanish resources.

What needs to be improved?

- Assign to DES office nearer to home.
- Inform families of change in SC warm hand off between SC.
- Email communication difficult to open.
- Email communication open on mobile devices.
- Access to therapies authorized but lack of providers.
- Transition information at six and at eighteen.
- Info at DTA who what where.
- More providers families waiting 3-6-9 months for OT, PT, HAB, RES, Feeding, Attendant Care.
- No clear communication to families regarding ATT for children.
- More training understanding at care needs difference between ATT, skilled nursing, toileting.
- SC to reassure family they are here to support not judge (Not specific to Spanish speaking families).
- Fear of DCS inspect.
- Providers trained.

What are the solutions for improvement?

- Other states allowing parents to Respite while waiting for provider.
- Hippo therapy be called covered provided information on how to have it covered.
- Providers provide information if they have access to stables/horses/pools.
- Transition - next steps options what to do next? Warm Handoff.
- YouTube videos on step by step process.
- Specify these are services specific to LTC.
- Warm handoff when SC is changing.
- SC offer best communication style for family.

What are your thoughts on the Alternate Service Delivery Model?

- Sounds like it will make things easier.
- Seamless unless switching health plan.
- In theory we can have one card.
- Concerns that providers will contract with the health plan we choose.

- Concerns about choosing between providers.
- Can there be exceptions with medical director.
- Conflict of interest SC working for the health plan.
- Parents concern the other option is the first step to being the only option.
- Fear of the change.
- Worry about providers not contracting.
- Is DDD going away?
- Will my SC change?
- Will the current model of behavioral health wrap around stay the same?
- Worry that SC would be an employee of the health plan.
- Worry that the health plans providing SC would not have the expertise.
- EPD Case management are with health plans (employees).
- Families should have a choice - not only one option should be offered.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Completely agree with Executive order.
- What is happening now with licensure?
- Check sex offender's registry.
- Self-declaration notarized.
- Expand APS checks and DCS checks.
- Providers shouldn't be allowed to work till cleared.
- Should not last for six years renew more frequently (fingerprints).
- Assume competency awareness.
- Education prevention.

What does your blue sky look like?

- Providers arrive trained with expertise specific to my child.
- Every SC was a parent of a child with a disability.
- Nurse attends school with my child.
- Every SC has compassion and empathy.
- SC last at least three years.
- All in home therapies.
- ALTCS eligibility more streamlined.
- Safe and Happy.
- Day Programs presumed competence.
- Big picture get everyone to the table facts.

Forum: Apache Junction Date: March 18, 2019 Attendees: 1

What is going well with DDD LTSS?

- SC among providers and health plans coordinated communication and problem solving.

What needs to be improved?

- Access to electronic documentation for examples (service plans, IEP, Notes).
- Sharing with health plans (guardianship paperwork).

What are your thoughts on the Alternate Service Delivery Model?

- I don't want to lose my SC.
- I don't want to lose my providers and HCBS.
- Would this change my benefits?
- I don't want to have to change where my child is currently placed.
- If all things stay the same, no problem.
- If my provider does not participate with the health plan, having to change providers is disruptive and impacts success.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- This is Big!
- Do we educate our families to: 1.) Identify 2.) Report concerns 3.) Not be afraid of retaliation.
- What do the families need to feel supported? Feel safe every day.
- If you don't feel safe speak up!

What does your blue sky look like?

- Freedom without barriers.
- My family member is being taken care of.
- I have support for myself.
- Getting a break that is ok!
- Having my family offered/supported the same freedom to have goals.
- The freedom to be me as well as the whole family.

Forum: Buckeye Date: March 19, 2019 Attendees: 2

What is going well with DDD LTSS?

- Current group home (Rusty's Ranch) designed specifically for ASD.
- SC is supportive.
- Communication (responsive) with SC.
- HAB provider (in Buckeye) ISS goes above and beyond to help us understand our son's progress and how to write ISP (HAB) goals.
- It is better than it used to be! (Buckeye).

What needs to be improved?

- Group homes in valley personnel without adequate training related to specific DX.
- Needed Services not always available due to provider shortage has not received PT, Music, OT.
- Confusion around funding Music Therapy in group home settings.
- SC turnover.

What are the solutions for improvement?

- System for setting up group homes to specialize in specific Districts in order to provide more appropriate supports and target training of staff.
- Team based model (AZEIP) for DDD eligible individuals only in times of extended periods of time when providers are unavailable.
- Competitive pay for the providers to allocate shortage (Direct Care Workers).
- More quality providers in my community (Buckeye).

What are your thoughts on the Alternate Service Delivery Model??

- Concern around what SC. What would it look and feel like (not local)?
- DDD SC feels like an advocate for my family. Would the MCO SC do the same? Could be a conflict of interest.
- Comfortable with service delivery model change as long as my providers don't change.
- Not comfortable if our family experiences service disruption.
- Is there a clause for returning to existing model as of Oct 1, 2019?

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Relating to enhanced protection for individuals with disabilities.
- Prevent agency owners from having agency close then open under another dept. and name.
- Training for providers on difficult behaviors (de-escalation).
- Sexual Abuse prevention training.
- Develop standard protocols that adults are never alone with child/member.
- Training on how to recognize signs of abuse for providers and families.

- Mandatory APS checks.
- Increase drop in (unannounced) monitoring (internal audits by supervisory staff).
- Increase oversight.

Forum: Central Phoenix Date: March 20, 2019 Attendees: 7

What is going well with DDD LTSS?

- Certain Support Coordinators (responsive, seemed to care, was a friend).
- Support Coordination (involves child in conversation, encourages member participation).
- SC remembers Birthday's and Christmas.
- Resourceful Support Coordination.
- DDD Customer Service Centers.

What needs to be improved?

- DDD needs more support coordinators (burnout, stress, high case load, turnover, continuity of case).
- Communication needs to be improved SC to member/family (responsiveness).
- Paperwork management and burden.
- Aug Com Authorization.
- State employee salary.
- Better and more providers (HAB, Speech, PT, OT Therapies).
- Waitlist for providers (HCBS).
- SC high case load.
- Training the staff.

What are the solutions for improvement?

- Examine hiring practices training, prerequisites, and experience.
- Salary raise for the state employees.
- Electronic records adopted and access to families as well.
- Protocol for a warm hand off when SC's change or a warning.
- Incentivize good work make it targeted (leadership).
- Improve vendor network pay rate reimbursements increases.
- More workshops with community involvement for education and problem solving.

What are your thoughts on the Alternate Service Delivery Model?

- If it can help alleviate some of the issues we've had tonight it may be something to consider.
- If adopted would members and Families have a choice in models (fully partially integrated).
- This model would work well for families with a high level of involved in the child's care.
- Need Continuity of case management (support coordinators).
- What happens to the existing DD provider's network?
- What happens to SC?

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Training in who is vulnerable: families, employers, employees.
- TV, Online, workshops.
- Awareness training.
- Reporting Responsibilities (abuse) “If you see something say something”.
- Like mental health first aid.
- Training to assume competency.
- Protocols/rules that ensure safety.
- Written safely protocols.
- Can DDD be the leaders in developing protocols (common facilitator) beyond just licensing?
- Mandate APS checks.
- Making sure all facilities are licensed.

What does your blue sky look like?

- Daughter will be well taken care of happy and safe.
- Confidence to be a self-advocate, fall in love, to have a job (employment).
- To have someone who cares that will look out for her (my family member).
- Every one that works with our family is a parent of a child with a disability, shared life experience.
- To have someone who cares that will look out for her (my family member).
- To be safe and to be loved.
- To be able to not worry about my child (living in the world).

Forum: Peoria Date: March 23, 2019 Attendees: 3

What is going well with DDD LTSS?

- Offering respite gives families a break.
- Provider provides transportation and consistent respite.
- Client funds working well.
- Responsive SC.
- Thorough data/information given/provided to by SC.
- Appreciates all of the services used Respite, DTT, DTA, ATT uses all available.
- Relationship of consistent providers.

What needs to be improved?

- Turnover in support coordination, why is it a revolving door?
- State standards for hiring SC unprofessional.
- Encrypted correspondence is difficult to use "unfriendly".
- More communication between provider agency and parents.
- DDD e-mails goes to junk sometimes.
- DTT Improve communication with DTA.

What are the solutions for improvement?

- More user friendly secure e-mail.
- Text Options.
- Identify how families best communication.
- Better salary/wage state employees (SC).
- Market study.
- It is ok to retire.
- Give families more specific user-friendly search tool for provider lists.
- Descriptive more advanced searches specialties ex: enhanced ratios.
- Check list for provider characteristics.
- It would be nice if you could provide families with regional resources by their house.

What are your thoughts on the Alternate Service Delivery Model?

- Feels like too much - issues could get bigger.
- What if my providers are not contracted with the health plan?
- I'm worried that I would have to choose between provider's health vs qualified vendors if contracted with different plan.
- Who would do the ISP?
- We've never had it like this in AZ are there other states where it has been implemented? Success stories?
- It would be monumental to roll out.
- Nothing to go off haven't seen it.
- DDD has historical knowledge that the health plans don't have. Scary.
- Full integration feels like too much.

- How are the QVA going to help the members with the continuity of care? How do I look up? Please make that easy for families.
- We don't know what kind of people they hire.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Conduct APS background checks.
- Disappointing that it hasn't been done.
- Are they going back to check past for existing employees.
- What will the roll out look like?
- Method for good cause exception with implementation.
- Process.
- More communication with agencies is better.
- Review fingerprint clearing requirements.

What does your blue sky look like?

- Continued services, recreational, health, happy life.
- He is pretty happy, he is living a good life, he has a job.
- Let them be what he wants to be, what is right for him.
- It is ok to retire.
- Compensate fair worker/provider fairly this is hard work and meaningful.

Forum: Gilbert Date: March 23rd, 2019 Attendees: 3

What is going well with DDD LTSS?

- Respite I can be here today.
- Parents getting paid-adults.
- Diapers over 18.
- Home based therapies PT, OT, Speech, Music.
- Attendant care- can't imagine not having it.
- Still married because of respite.
- LTC Health plan covering the co-pays (remainder).
- Kept our family together.
- Love having a summer program.
- SC saying "I don't know but I will find out for you".
- SC that show empathy.

What needs to be improved?

- PT should continue after 21 and be treated like other services.
- SC too much turnover.
- SC training improved some not as knowledgeable.
- Not as many SC that show empathy.
- Feeling judged by SC and intimidated.
- Not knowing parent can appeal. Teaching appeal rights, denial, discontinue a service, or reduction.
- I feel like DDD isn't on my team.

What are the solutions for improvement?

- After SC are trained they partner with a parent.
- Utilize parent volunteers to share stories - perspective (to give feedback).
- Question to AHCCCS as to why the PT over 21 was limited.
- DDD train/teach families partner with RSK at rights - responsibilities how to problem solve.
- Families need to feel heard.

What are your thoughts on the Alternate Service Delivery Model?

- Hard to understand.
- How will it affect my family?
- Offering an option to opt out if it isn't working for my family.
- Would I still be able to access my choice of doctors?
- Trusting if my best interest are being taken into consideration.
- I have no idea which option would be most beneficial.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- I won't ever put my son in a place for fear of abuse and neglect.

- Because he can't tell me.
- This is why my kids are home schooled because he was hurt in a public school.
- It is awesome. Makes me really like him - Governor Ducey.

What does your blue sky look like?

- Not being on the phone all day with doctors or insurance companies.
- Sleeping all through the night.
- Never hearing again "We all have the same 24hours in a day".
- Feeling understood - not judged, listened to.
- Human kindness.
- Knowing my kids are safe and perhaps tomorrow I won't have to fight.
- To be healthy and pain free.

Forum: Central Tucson Date: March 26th, 2019 Attendees: 9

What is going well with DDD LTSS?

- Consistent schedule/contact with SC.
- Grateful for respite services.
- Supported living services IDLA.
- Employment Support - job coach.
- DDD offers Service member receives thankful for.

What needs to be improved?

- Mental health transportation system.
- Day program that teaches new skills to improve.
- More members to have opportunity to have IDLA options.
- More employment opportunities.
- Better communication of what is available from SC.
- We don't know what we don't know and we may be missing opportunities.
- Blind and Autism more training to work with multiple disabilities.

What are the solutions for improvement?

- Additional training for SC about October model changes.
- Group homes for specific disabilities.
- Additional disability specific training for day program, staff provider agencies, group home staff, respite, HAB.
- Have Southern region coordinate with Maricopa County on how transportation works.
- Responsible person in Tucson needs to visit other day programs in Phoenix to see what is available and raise expectations of the programs offered (no babysitting).
- Provide additional living opportunities outside of the home.
- Sexual awareness training for members.
- Use community agencies to give additional training ASDB Autism Society.
- More summer program options.
- Life skills training for member, laundry, shopping, cooking.
- Additional training outside of home living independently including staff.
- Would like to see SC more supportive and more knowledge. SC doesn't know what is going on. SC hopefully will know about these changes.
- Phoenix has a transportation system. Tucson could use the same.

What are your thoughts on the Alternate Service Delivery Model??

- Might be easier because 1 agency does everything.
- Members are individuals with unique needs.
- Insurance companies are about making money.
- Savings in money on coordination should go toward improving member services.

- Seamless transition for families that are happy with their current health plan provider to HP. Anyway to encourage new provider to contract with health plan. Qualified vendors have same budget as they have with DDD. Health plan may have new better ideas, challenge consumers. How might grievances be handled?
- If my child is a square and will not fit in a round hole our kids are individuals with unique needs, will they be treated as individuals? Insurance companies have rules such as in network.
- Home modification Aug Com will be more difficult where will they fall, what incentive will the healthcare plan have to provide? Will it be even more difficulty to get these services?
- Recommend outside agencies handle grievances.
- Would insurance company own or contract with group homes etc.
- Where do AAC devices and home modifications fall?
- What incentives will the health plan have to give AAC's etc.?
- Will it be even more difficult to get above services?
- What requirements will be put in place to make sure there are adequate provider or for services?
- Are there other states that do something similar that AZ could talk to? Talk to them.
- Survey parents who receive DDD/ALTCS until age 6 then move to EPD positive/negative what changed? What do you like/dislike?
- Huge ball of wax to handle.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Agency employees reviews sensitivity training about work with someone with a disability.
- Better screening for employee's different type than given now.
- Agency Directors get more training on how to interview, hire the right people and train them.
- Personality test for potential employees.
- Fast food places pay more than provider agencies.
- Provider agencies need more funding.
- Enough funds to keep people safe.
- More monitoring/oversight of the facilities - follow through and consequences when they do not follow the rules.
- Possibilities of losing providers because too much oversight.
- More external monitoring weekends and nights included.
- 6 year fingerprints clearance is too long anything can happen within that time.

What does your blue sky look like?

- Parents never die.
- Parents never get depressed.
- Parents get a vacation.

- Long term facility geared for specific disabilities.
- All individuals are valued.
- All individuals live in the community.
- All individuals will be healed by God.
- All the way we need to provide fabulous services.
- All professionals working with individual with disability will be happy in job, get paid well, and educated.
- More training for doctors about disabilities.
- All High School students receive training on life skills and be fully functioning adults.
- Don't have to worry about budgets - unlimited money.

Forum: South Phoenix Date: March 27th, 2019 Attendees: 1

What is going well with DDD LTSS?

- Quick determination of DDD eligibility.
- DDD Coordinator keeps appointments.
- Coordinator comes prepared to appointments.
- DDD Staff is friendly.
- DDD Staff is language appropriate.
- Aug com evaluation was thorough.
- Process for environmental modification was easy.
- Ramp was easy.

What needs to be improved?

- Lack of PT, OT, and Speech services in community.
- If DDD does not have a sufficient network, families may have to consider class action lawsuits.
- Lower turnover of DDD coordinators.
- SC have a lack of knowledge of community resources (Ryan House, RSK).
- Improve communication between provider's agency and DDD SC (outside of 90 day meeting).
- Families unaware that they can call special meetings outside of 90 day review.
- Transparency in denial authorization and re-appeal process for DME equipment.
- Transparency in the process to obtain an Aug Com device.
- Filling of DDD request.

What are the solutions for improvement?

- Reaching out to new graduates and schools of graduates to recruit new PT Speech and OT therapists.
- Offer internships PT, Speech and OT undergrads.
- Raise pay rate for DDD coordinators and study impact of increased wages.
- More training of outside community resources for DDD coordinators and a cheat sheet.
- Better communication and collaboration between provider's agency and DDD coordinator prior to 90 days.
- DDD in form when meeting with family that they can request meeting outside of the 90 days. (A check initial box).
- Add check box.
- Transparency in DME process.
- Cheat sheets for SC.

What are your thoughts on the Alternate Service Delivery Model?

- Concerns about navigating a system that large.
- Would want more information about how the system would operate.

- Large system navigation looks scary. Potential for failure because navigating the system is already difficult.
- Concerns about lack of transparency when decisions would be left up to the health plan.
- Health plans have a large membership that they have to serve ex: 300,000 vs. DDD 33,000.
- Very much opposed to this option.
- Unclear who point person would be.
- Difficulty trying to get info from the health plan they could not be transparent about items very fearful about potential placement.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- With all coordination of all the department we should have less incidents.
- Appreciated that families are part of the work group.
- Stakeholders from other states that have experience with protecting vulnerable population need to be in work groups.
- AAPPD needs to be involved in work groups.

What does your blue sky look like?

- Like to see family members be able to receive compensation for care for their children under 18.
- Ability to choose respite and skilled nursing services dually.
- DDD would provide vehicle modification.

Forum: Anthem Date: March 28, 2019 Attendees: 14

What is going well with DDD LTSS?

- SC not judge.
- SC Awesome.
- SC good at listing and anticipated needs.
- Availability of many services.
- Health care is awesome.
- Homebased services are good.
- Able to get service providers that are good.
- Covering copays.
- Respect parent choices.
- SC consistency.
- SC try to meet family needs.
- Getting hours transferred from vendor not a problem.

What needs to be improved?

- Group home not well trained on mental health and positive behavior.
- Vendor call process is difficult, really confusing, especially when coordinating OT, PT, Speech.
- Becoming a vendor is difficult.
- Family should have choice/option to work with DDD instead of vendor services.
- Lack of physical education and recreational exercise.
- Difficult getting hours released from agency (services).
- Lack of service providers in area.
- SC not good at follow through.
- Difficulty finding HAB, Respite, and AAC provider.
- Low wages for direct care providers.

What are the solutions for improvement?

- Better recruitment to hire providers.
- Collaborate with Universities, etc. to encourage graduates to work as HAB, OT, Respite, Adaptive PE, nursing, social work, etc.
- Direct service system.
- Social group run by RSK to ensure safety and privacy to families and members.
- Parents get trained and do HAB for their own children.
- Positive Behavior and mental health training in group homes for staff (competency based training).
- Transparency what vendors are paying their staff and decrease the gap
- DDD train all direct workers.
- Internships that allow students to be direct workers.
- Hire OT, PT, Respite, so that they are employees of the state/DDD.
- Family network swap for respite.
- Recruit teachers as provider.

What are your thoughts on the Alternate Service Delivery Model?

- It is not fair state employees cannot lobby for kids.
- Health care has ultimate choice not the best choice.
- Health care does not understand long term care.
- Healthcare plan that reviews notes on speech progress - what are their qualifications.
- Are these health care for profit?
- The more services our members receive the less profit they get. Health care is in it to make money.
- Respite is not a health service so does not make sense.
- Prior experience in another state (Oklahoma) had a similar system and child always got denied.
- Concern health care rely on families giving up on trying to get services and then it's an expense for the parents.
- We would become anonymous.
- Heck no.
- It is a bad idea.
- It is always about money.
- Would lose our SC from DDD.
- Families need SC because parenting our children is a hard job.
- Need help from SC. Someone who understand disabilities.
- Tired of Special Needs kids always on bottom of the priority. The brunt of budget cuts.
- Rural kids would fall through the cracks.
- Respite is not healthcare.
- This is putting our children in a hole.
- Potential for inconsistency of care maintain continuity of care and the healthcare ability to access for long term care.
- Who in the HP will be making decision for long term care?

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Direct care members should never be alone with a member.
- Cameras.
- Training to recognize signs of abuse.
- Training members on strategies when things aren't going right / Give them the tools to report, and adaptive training.
- Provide laws that recorder can be used and are permissible for members.
- Background check to rule out the use of child pornography.
- Culture of bullying needs to change.
- Initiate to hire disability member to work with disabled.
- Even with nonverbal children can teach them some way to fight back.

What does your blue sky look like?

- Everyone look like Camphill movement (A community model that has a transition from home to community to work).
- Change education from 22 to 26 (high school).
- Change requirement on School District to not graduate without proficiency prior to 26.
- Provide support, additional transitional services from preschool- school – life – work - life skills.
- Employ services for members in State and Government positions.
- Programs for Parents support.
- Parenting class.
- Be nice to my child.
- I want an Annie Sullivan for my daughter.
- More training engagement for parents and individuals connect and support each other.
- Guardianship not be expensive.

Forum: Window Rock Date: March 30, 2019 Attendees: 4

What is going well with DDD LTSS?

- Direct nursing home support is going well.
- Help with transportation to appointments and other activities.
- Nutrition support and information.
- Environmental modifications.

What needs to be improved?

- Educating families to know how to get medical equipment.
- PT, OT, Speech to provide service in home.
- Get therapy provider to the area.

What are the solutions for improvement?

- Providing more information to families.
- Mass media, flyer distribution, using USPS.
- Telehealth provided services.

What are your thoughts on the Alternate Service Delivery Model?

- May lose the support coordination and trust.
- Health plan may give services families don't need.
- Alternate service delivery model might speed up process.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- This order will give families reassurance.
- Extensive background important, \$20 vs \$67 depending on contact with children.
- Navajo/tribal background checks (include background from all entities).
- No exceptions to background on fingerprints.
- Be transparent with sex offender registries.
- Require sex offender registration on tribal lands, no exceptions.
- Sentencing for crimes against vulnerable children and adults should be consistent on and off tribal land.
- Make unannounced visits when parents are paid providers.
- Educate public on where to report (appropriate agencies).

What does your blue sky look like?

- Having a home vehicle and a job.
- Well-disciplined kids.
- Loving what I do.
- Good outcomes/teaching for our kids.
- A growing positive community that supports each other.
- Discontinue competing with each other and partner together.

Forum: Chinle Date: March 30, 2019 Attendees: 2

What is going well with DDD LTSS?

- Good resource for therapy.
- Good feedback and info from SC.
- Making the best of the few resource available (4 providers with Attendant care).
- Positive rapport with DDD and families.
- Linkage to community resources.
- DDD staff are active listeners accommodating and understanding of family dynamics.
- DDD SC recommended options.
- DDD hold providers accountable.

What needs to be improved?

- Provide better education for families.
- DDD needs to provide a conference on disability awareness.
- Education for tribal council.
- St. Michaels and DDD parent consultations.
- More providers needed for therapies.
- More DTA providers on reservation wide.
- Explain difference between ALTCS DDD & State DDD.
- Getting providers to attend ISP annual meetings.

What are the solutions for improvement?

- Transparent provider rating.
- Family surveys for quality of DDD and Providers.
- More training for setting goals for adult life.
- Getting providers to attend annual meetings.
- Educate providers on DDD rules regulation and policies etc.
- DDD follow through investigate complains seriously.
- Follow ISP DDD needs to monitor.
- DDD needs a public rating system.

What are your thoughts on the Alternate Service Delivery Model?

- Hope to keep current therapy (Oct 2019 changes).
- Will traditional therapy be covered? (Oct 2019 changes).
- Seems that it will work better (Oct 2019 changes).
- New Plan experienced from Farmington NM where this idea better.
- Would like to have assistance from DDD.
- Need effective CM's with new plan.

Forum: Douglas Date: April 1, 2019 Attendees: 2

What is going well with DDD LTSS?

- Targeted Service Coordinator at home with reassurance that everything is going well with her son.
- Physician is in agreement with the above.

What are your thoughts on the Alternate Service Delivery Model?

- Does DDD supervise services in both options?
- Other option would offer more direct support by being closer to health plan.
- Keeping support coordinator under DDD for some families would be beneficial.
- Family appreciate the help from DDD.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Agree with Governor's orders to come together to protect individuals with disabilities.
- Verify background checks for new employees.
- Possible "personality" checks for new employees.
- Verifying clearance cards are valid and up to date.

What does your blue sky look like?

- Parent feel everything is going well for now.

Forum: Sierra Vista Date: April 3, 2019 Attendees: 1

What is going well with DDD LTSS?

- Using sister for respite.

What needs to be improved?

- Minimal training for respite providers.
- Lack of communication regarding billing and authorization. (Pre-approved time cards).
- Lag time in signing for services and in knowing the available units. We ran out and services had already been rendered.
- Never knew you had to bill your own insurance first.
- Multidisciplinary services at the hospital between private insurance and long term care, because providers were in 2 different networks.
- SC Turnover- multiple support coordinators is tiring.
- QVA unprofessionalism e.g., Therapist sharing her drink with son without permission, Gave son gum without permission.
- NO BCBA in Sierra Vista.
- Under 3 years old have more options.
- A lot of things are missing from my DDD File, e.g., the pediatrician diagnosis, I am nervous about where these things are going.
- Transition-SC are talking poorly about previous SC.
- Therapy facilities should not be reaching back out once service is discontinued.
- Lack of communication between hospital and mercy care.

What are the solutions for improvement?

- Build a better network of providers.
- Build a traveling network to address lack/gaps in service providers.
- Provide DDD get together quarterly or two times a year around the state with child care.
- How do parents submit feedback?
- When I question policies it goes up the chain (it's never gone above an APM), but it is a learning opportunity for staff, who are doing things the way they've always done.
- Vendors should be bringing timesheet to house.
- Transparency in Provider billing.
- How cancelations are addressed in billing.

What are your thoughts on the Alternate Service Delivery Model?

- SC being under the health plan scares me.
- The scale of how few members are LTC compared to health plan's acute care population scares me. We would get lost in the system.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- I am glad precautionary steps, unfortunately it had to come to this.
- It helps prevent and protect or futures.

What does your blue sky look like?

- Inclusive world.
- Having quality providers that are available to you.

Forum: Laveen Date: April 4, 2019 Attendees: 3

What is going well with DDD LTSS?

- We finally have a good coordinator.
- Good therapist.
- SC is sensitive to my child's needs.
- It is great when providers has a child disabilities themselves so they understand the demands.
- SC is gender sensitive.
- Appreciate the creation of outreach administrator that connect parents to the administrative staff ex: Leah Gibbs.

What needs to be improved?

- Augmentative Communication device process needs a loner library while the device in repair.
- Coordinator needs to speak language the family understands.
- Ask family which gender that is preferred for coordinator/therapist acknowledge that a 16 year old girl needs assist while not going against her privacy.
- Therapist provider needs to have the ability to work with age appropriate consumers.
- High turnover in therapy providers.
- Quality of service provider's dependency on zip code of members home. Services and providers faster or slower (different quality).
- Support Coordinator consistently assessing consumer needs no matter where family lives.
- Why are the therapy sessions set up for so little time three 45 minute sessions a week that take three hours to get to and from.
- Certification needs to transfer between provider agencies.
- It took two years to get an Aug Com device and no one taught us how to use it.
- Some SC are so young it seems they are only workings to get the credit hours or experience.

What are the solutions for improvement?

- Create a comprehensive parental orientation for everything related to special needs.
- Sensitivity training for DDD staff.
- Center for excellence to access different disciplines to support special needs at one center.
- Community needs park adopted for special needs kids and adults.
- I'd like to have a lot of meetings like this where we get to speak directly to administrators.
- Need Aug com loaner program for when repairs are needed.
- SC need to have consistent assessment skills.
- Transportation to disability related events.

- Special Needs crisis line for parents that are overwhelmed.
- Bridge the gap with police to help them understand people with disabilities.
- Comprehensive parent orientation.
- One stop shop a variety of providers in one location.
- Sibling training.

What are your thoughts on the Alternate Service Delivery Model?

- The health plans may or may not have my child's best interest at heart.
- Terrible idea.
- Insurance company will spend the least amount of money possible to care for my child.
- Health plan answer to stockholders not the voters.
- With this option we are on our own with Oct 2019 model we have some assistance from Support Coordination.
- The job is for the insurance company to make money so they will determine what is best for my child based on what makes their company the highest profit.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- With the same rule, everyone is on the same page.
- I think it is a good idea.
- I didn't realize having a child with a disability made me an instant politician.
- We are terrified of the whole group home possibility our child will be with us forever.

What does your blue sky look like?

- Everything harmonious.
- Problems would be taken care of quickly with a single call.
- Crisis line for Special needs parents.
- Parents can be paid to take care of their children.
- Stress free.

Forum: Yuma Date: April 9, 2019 Attendees: 38

What is going well with DDD LTSS?

- DDD Case Manager & Provider agency very supportive of his needs
- Finds employment and enjoys it!
- PT services are consistent and working well.
- Building rapport with DDD SC same coordinator over time
- Amazing SC.
- DDD Case worker has been part of our journey since my son was born and she has offered what has been available.
- The services I have for my son is what he needs at the moment
- SC offers according to my son's needs.
- Thanks to DDD we have respite, attendant care and habilitation which we are extremely thankful for.
- Provider Abrio working really hard with son.
- Community network is working well does not see the need for change
- Care from providers is working well.
- Communication.
- DDD SC very knowledgeable caring and loving- love for working with their members.
- Program flexible to the needs of its members.
- DDD supports son with IEP provides support, HCBS, and transition and intervention between home and school.

What needs to be improved?

- Therapy availability is not good.
- Therapist were never consistent because there were no therapist available.
- Lack of therapist (Speech x3, OT x2) selective of the ages of the members PT.
- Delay for AZIP services (2 months) gap in services.
- Case management overload - too high of ratio of members to case manager.
- Courtesy and communication ALTCS & DDD need to coordinate and communicate together.
- Family not understanding the expectation of what needs to happen "what is the next step".
- Lack of transparency and communication in the process.
- Was told there were no therapist available.
- Having to find own therapists.
- Limited age (only young children) get therapy.
- Parents must advocate to receive services.
- Vendor call process for therapies not working.
- Transparency in how we hold DDD case managers accountable?
- Accountability of DDD manager/Supervisor/Supervision and services being rendered.
- We need money for more coordinators and paying providers.

- Rates paid for providers.
- Home health nurses lacking in Yuma.

What are the solutions for improvement?

- Diligent on contacting our representatives.
- Increase rates to market.
- Habilitation figuring out what goals to set up for members by parents.
- And need for quality training for support coordinators and providers.
- Goals are removed too soon.
- Lack of continuity with established goals.
- DDD videos English/Spanish webinars.
- Be persistent with denials.
- Provide parents with an agenda before the next meeting.
- Evaluate ISP doc see if it is the most effective.
- Meeting with family with DDD Coordination and providers before ISP meeting
- Describe members abilities for ALTCS evaluations (not yes/no answers).
- Not have members present for evaluation.
- Pull employment services back to DDD.
- Habitation insist on better goals. Continue to have scheduled family forums in rural areas and get notifications.

What are your thoughts on the Alternate Service Delivery Model?

- Why change the system if it is working?
- Many years have been used to make families network work for them DDD.
- Insurance oversight.
- States who rolled out proposed model have had many problems.
- Concern with health plan not individualizing. One size not fit all.
- Concern oversight of DDD without addressing existing concerns.
- Insurance company might not give appropriate e services because they don't know my son as well as the DDD Coordinator does.
- Present model is more personable than one being proposed.
- Who would decide what services and hours will be provided.
- Like current model: DDD provides alternatives system. Questions medical model to do the same.
- Would like to have options on the models.
- Not enough information to make a decision - too much control from proposed model.
- Why get rid of what is working?
- Concern of networks in rural communities.
- Dealing with insurance companies which change needs constantly.
- Insurance companies respond to boards.
- Old model have voice to call state rep.
- Monitor quality care.
- Willing to try new model might have better service.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Families have shared their thoughts!

What does your blue sky look like?

- Participate in service he desperately needs.
- Services provided when he needs them.
- Full funding to provide services.
- Continuity of care if parent is no longer available.
- Having a plan in place and knowing what is going to happen.
- Having a place with more independent living with support.
- Immediate response when crisis comes up and capable of handling situations.
- Community of highly trained supports for individuals with special needs.
- Coordination of services and care between systems (health, school, HCBS, crisis team, etc.).

Forum: Nogales Date: April 12, 2019 Attendees: 8

What is going well with DDD LTSS?

- Treatment of family and members by DDD coordinator.
- Speech therapy is going well at U of A Department head is outstanding.
- Occupational therapy is going well.
- Vendor calls are going well.

What needs to be improved?

- Lack of follow through - appointments by coordinator (home & educational).
- Days or weeks before call back is had by DDD.
- SC need training on more topics (504, IEP).
- Lack of professionalism had by DDD professionals with SC and managers.
- Lack of community support by DDD.
- Lack of DDD involvement in school education/transitional plan.
- More DDD summer programs in the area.
- Alternative providers options when services are pending.
- Lack of therapy providers in the area of PT, speech, OT.
- DDD needs to see each child and family uniquely treat them as such.
- Each member needs to be seen as an individual.
- SC do not show up at the IEP and they do not say anything during the meetings.

What are the solutions for improvement?

- 4-6 times annually forum with DDD families.
- Communicate with families when there is a change in administration.
- Have more DDD summer programs for members.
- More money for direct care providers.

What are your thoughts on the Alternate Service Delivery Model?

- Option is workable.
- Health plan would have experts.
- Concerns as to the consistency of care and care coordination.
- Would transportation be provided by this option?

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Improve things and expectations or care worker.
- More money for direct care providers.
- Children with disabilities needs to be integrated more in their school career.
- Stop sheltering children with disabilities and prepare them for the real world.
- School therapist and other educational professional are trained to keep child in self-contained regardless of LRE and parent's wishes.

What does your blue sky look like?

- Daycare and preschool would welcome my child and be able to work with him.
- For parents to past their children.
- College education preparedness.
- Need person not disability.
- Program to educate schools on children's needs.
- No bullying.
- For all families to be happy and loved.
- To have a local buffet of agencies to meet your child's needs.
- No fighting at home to meet your child's needs.

Forum: South Tucson Date: April 13, 2019 Attendees: 11

What is going well with DDD LTSS?

- Day Programs is excellence: Achieve, Beacon Group, Southern AZ Family Services.
- Group Home is going well x2.
- Consistency in day program staff.
- Employment services x2.
- Speech therapy in home after work hours.
- Respite care.
- Split time between day programs.
- Medical services/medical x2.
- Homebased therapies.
- Sun Van transportation to work/day programs.
- Support coordinator.

What needs to be improved?

- Lack of retention of SC.
- System to transition from one SC to another.
- SC to specialize in one of 4 disabilities and or age.
- More thorough training for SC.
- Lack of follow through of SC.
- Vendor call process is broken.
- Broader applicant pool for SC.
- Reduce caseload.
- Faster response (solution based) with answers.
- SC to communicate directly to child without guardianship.
- More empathy to understand parents and members situation.
- Emergency respite out of home on demand.
- More information on transitional housing for SC.
- More options for transitional housing.
- More coordination between DDD/BH.
- District south needs updated network list of providers.

What are the solutions for improvement?

- Better training for SC.
- Smaller case load.
- Hire qualified candidates.
- Increase funding for SC.
- Flexible hours for SC.
- Increase funding for providers.
- Core transparency for members knowing about customer service opt.
- Check in more times with parent possibly monthly.
- Ask member how often they want check in

What are your thoughts on the Alternate Service Delivery Model?

- Participants don't have enough knowledge to give thoughts.
- Case manager would have to know about every program.
- Health plan is huge our members may be overlooked.
- Fix SC issues and keep the current system.
- Aware of other states who have moved to this option it was a mess.
- Cost savings translated to better services available.
- Representation of parents on committee for the group who decide if to do this option.
- Assurance that relationship with providers is maintained under managed care organization.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Good idea.
- Direct care workers need more support, training and supervision.
- Families need more support and training.
- Difficult for families to advocate.
- Transparency and partnership with families and providers.
- Family needs to prove that there is a problem.
- Family afraid to talk for fear of retaliation.
- Employees need to be empowered to speak up.
- Follow through and better communication among staff members.
- Documentation shown to families.

What does your blue sky look like?

- All members need are met.
- Less rhetoric that does match outcomes.
- Care givers that really care and are great communicators.
- Transparency.
- Everyone has their own bathroom.
- Individualize for member's needs.
- Member living in his place and caregivers come to him.
- Interview and pick caregivers for member.
- No power struggle.
- Collaboration (team).
- Transportation arrives on time and is available.
- Actively engaged throughout day.
- Caregivers appreciate their jobs.
- Value caregivers monetary and other things.

Forum: Sunnyslope Date: April 15, 2019 Attendees: 15

What is going well with DDD LTSS?

- Consistent services for my son's HAB, Respite, OT, and Speech.
- Good array of services.
- Medicaid money turn into enhance daughters life.
- Great SC.
- Current DDD leadership good guide.

What needs to be improved?

- PRC getting approved, needs to be consistency, can be difficult to get approval.
- Staff training.
- PRC consistency statewide.
- Difficulty accessing services due to lack of staff training.
- DDD coordination with health plan not good.
- Problem in particular with West.
- SC case overload, Ration for ISC is over 100 cases, concerned quality suffers, rolling out the new planning document takes time.
- SC more pay.
- DDD needs to automate (electronic).
- Fill SC vacancies.
- Lack of therapy providers Surprise, Sun City, and El Mirage.
- AzEIP transitioning is really messy. AZIP and long-term care. Who pays for what? Clarity and how to access.
- Quality of caregiver's reflection of pay.
- Rates paid by DDD not good.
- Extended hours 24 hours customer service.
- Getting my daughter behavior plan approved was a nightmare. The plan was approved last year and was not approved the following year. PRC stated all services needs to stop until plan was approved (including DTA).
- Regarding AzEIP the team based therapy model is the breakdown.

What are the solutions for improvement?

- Division can voice opinion on how to improve specifically rates and pay to legislature.
- Behavioral health clinician need to be added to PRC committee members.
- Direct Service Providers to allow career ladder or tuition reimbursement.
- DDD to pay to at full benchmark ERE.
- Legislature to fully fund DDD.
- Teach SC habilitation curriculum.
- Training SC covered benefits community based services.
- DDD partner with RSK to train families with rights and know the services, when guardianship or status changes.
- Providers to bill to attend ISP.

- Community forums put on web to access for all families to get info.
- All DDD information writing at 11th grade level add more pictures, videos for any correspondence from DDD.
- Advance letters to providers so they can help families understand when they bring their letters in.
- Agencies use to pay 23% above minimum wage now they pay minimum wage and slash middle management.

What are your thoughts on the Alternate Service Delivery Model?

- DDD has ability to be flexible.
- It seems like it would be more streamlined.
- Why do we need DDD for oversight?
- Healthcare does not understand long term services.
- Healthcare does not understand developmental disabilities.
- Don't like using traditional MCO.
- For profit cannot effect change.
- Now have access to advocate through legislature not so with MCO.
- Would be hesitant to go to this system, red flags.
- Insurance does not understand lifelong services. The services EPD ALTCS that are acute care provide are for end of life service, they cut cost, they don't look at ways to help someone get a life.
- Many people get upset dealing with an MCO, they don't get the care that they need. I would be hesitant to put my brother in a residence managed by a traditional MCO.
- I don't know how to escalate issues to someone in Mercy Care.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- If you include predators in these meeting you get their perspective.
- Concerned with methodology they are taking on Executive Order.
- Concerned its getting too big, the number of meeting, and the number of stakeholder. I don't know if it will make a difference.
- Psychological testing.
- More funds for training and testing would help keep members safe.
- This is because the providers cannot pay their people well. The caliber of people in the daily care of my brother suffers. If there were more funds to raise the pay and education the staff, that would help. I've encounter some wonderful workers making minimum wage and they have to work harder to take care for their families. The Safety of my brother is important and staff needs to be trained.
- More people involved can cause it to get worse.
- There will always be people that have a lapse in judgement by a provider, it will happen again.
- The key is rehabilitation.

What does your blue sky look like?

- Give people what they need when they need it.
- Cheeseburger and a winning lottery ticket.
- Non access people to get access services.
- Wish people would stop looking a services like entitlements.
- Seamless coordination of services.
- Add support for peers and family.
- Reduced caseloads for SC.
- Career ladder for anybody.
- That my daughter has a life to live. Services that will not coddle her, but help her to learn and gown to be the woman she needs to be.
- Daughter to have life that she wants.
- Daughter to be happy.

Forum: Morenci Date: April 17, 2019 Attendees: 2

What is going well with DDD LTSS?

- Consistency of coordinator.
- Coordinator is easy to get a hold of and very responsive.
- Group supported job opportunities, and all with job coach and paid minimum wage.

What needs to be improved?

- More providers needed in the area respite, all HB therapies.
- Come July, 45 members will be without therapies in Graham & Greenlee.
- Need at least one other DTA program and enough members for the program to be viable.
- Community has an age gap (30-60) years of age without long term membership – we need more senior programs and young adult programs.
- Need services closer to Duncan.

What are the solutions for improvement?

- Pay direct care workers more so that the Morenci mine does not steal them.
- Conduct an analysis to see how many members would be available for DTA.
- Convince a vendor to open a DTA here.
- Providers need to be paid travel "windshield time".

What are your thoughts on the Alternate Service Delivery Model?

- Families are dependent on their relationship with their cases managers with DDD.
- Concerned about the loss of personal and professional relationship with my SC.
- DDD coordinator is part of the community and we do not know if this relationship would continue under the health plan.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- We need more education and better understanding on what to report as mandated reports to APS/DCS.
- They need to share the project plans with the community.

What does your blue sky look like?

- Have providers available for the hours that are needed.
- Having more choices of programs and activities available for members.
- No judgment for people with disabilities.
- More involvement from families more engagement.
- Schools to have a better understanding of children with disabilities.

Forum: Globe Date: April 18, 2019 Attendees: 2

What is going well with DDD LTSS?

- Providers (Speech & PT) are they are professional and represent DDD well.
- Good communication from speech and PT.
- We are using Aug Com / Ipad and it is working well.
- Therapist leave the family with a home program.
- Providers are on time and flexible.
- Like the provided required training content.

What needs to be improved?

- Turnover in Support Coordination.
- Having SC that are outside the area. We had experience having someone from the area it was a plus.
- Listing needs to be provided on certified training for providers available in area.

What are the solutions for improvement?

- Get a list where direct care giver and providers can go for certified training in their area.
- Fill unfilled SC positions.
- More involvement from providers and caregivers to understand how DDD System works.

What are your thoughts on the Alternate Service Delivery Model?

- Concerned about losing continuity of care.
- Are we putting DDD into a big business model, when it should be more connected to the community?
- I do not like the idea of a broader insurance company doing LTSS.
- There is better ways to address DDD issues rather than this option.
- It would work better if it was community based.
- Navigating a large insurance company can be difficult.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Training specific on sexual abuse for direct care providers and families. The training needs to expand and be current.
- Were the Director of DDD and DES involved when Ducey signed the Executive Order?
- Glad it is being addressed and that this doesn't fade away from memory.
- The more intensive background checks the better.

What does your blue sky look like?

- Knowing what the future is going to look like for parent and grandparents.
- Full confident on how I need to change to support my grandchild.

- Golden key would open the night doors.
- DDD would be just as important as other agencies (law enforcement, transportation).
- Everyone would have the same position to help the special needs community
- The main dept. head of the Department of Education would have a brain in their head.

Forum: Prescott Valley Date: April 23, 2019 Attendees: 45

What is going well with DDD LTSS?

- SC coming to my home and getting to know the member and family.
- Same SC for a while.
- I want to meet my SC face to face.
- Like having someone to contact, who gets back to me.
- Day Treatment Adults knows my family and are part of our town.
- I feel lucky to be part of Day Treatment Adults.
- Appreciate SC having more training.
- SC turn over seems to be less.
- I like Respite Provider.
- SC is returning calls promptly and the communication is good.
- I feel lucky, friends moved to Nebraska and they have had to wait a long time to receive services.
- DDD and ALTCS are advocates for the family.
- Group of passionate professionals with DDD take Medicaid money and use it for meaningful services.
- We have awesome providers in our community.
- I like how my daughter can work when she can.
- DDD for the past 40 years gets better every decade.
- Everyone works together DDD and day program.
- If it isn't broke don't fix it.

What needs to be improved?

- Vendor calls is a big problem.
- Since minimum wage went up, the level of funding for providers is thin.
- Due to drop in funds there is higher turnover in direct care staff.
- Lack of coordination between DDD/LTSS/Behavioral Health needs to improve (Talk with DDD behavioral health liaison).
- Care taker wage where it is, may not get passionate quality care takers.
- Behavioral Health lost copies of my guardianship papers.
- Members need stable people in their lives.
- Concerned with depersonalization in behavioral health.
- My son was in group home, with the low wages, higher cost of living, and high turnover, it's not good (my son had behavior issues).
- Unable to find therapist PT/OT/Speech qualified to complete evaluation.
- Vendor list not adequate for special health care needs.
- We experience high violations with providers.
- There are therapies available for young children 3 to 4 years old, but not for older members.
- Local universities are not training enough therapists, NAU takes only 40 seats for OT a year.
- Vendor application process is difficult.

- PCH took a year for a referral and contract with specialized feeding and speech.
- Rates are too low for therapists.
- There is a lack of therapy for my 3 year old son. We want them to work harder they are not aggressive enough.
- Kids with ASD need early aggressive services.
- Used to have music therapy we don't anymore.
- Timeliness of payment to providers for therapy.
- There are Insufficient medical and dental when member needs sedation for oral surgery.
- Wages need to be improved for care givers.
- I have 2 nonverbal kids that cannot get therapy because agencies are not trained on their devices.
- Cost of living vs cost of rate, state should consider and pay different rates based on location
- Timeliness of paying venders Compounded by TPL.

What are the solutions for improvement?

- Bring providers from Flagstaff and Phoenix weekly. They can contract to use office space of Doctors that are already contracted with).
- Reach out and contract with providers that are already local.
- Stop medical Doctors who won't take members who have TPL because they won't bill private and AHCCCS.
- When insurance co split off provide families with additional information.
- More training to families on Medicare advantage programs.
- Fully fund DDD Benchmark rates & Families should contact legislature.
- Families support the provider's agencies.
- Support creating family groups with your provider agencies.
- Encourage universities to expand therapy education.
- Thank you Governor Ducey for honoring out of state certification for therapy.
- Have AZ local students studying therapies needed get priority or % off degree.
- Encourage internships for students in therapy professions.
- Create a program to reduce student loan debt for people working with DDD Population.
- Develop better marketing to create interest in PT/OT/Speech.
- Direct Care workers were paid above minimum wage and now they are paid minimum wage.

What are your thoughts on the Alternate Service Delivery Model?

- Absolutely not.
- Healthcare will be making decision instead, it will be for profit.
- We will lose our 1 on 1.
- Our kids will become statistics.
- We will lose individuality and individual needs.
- We will lose choice.

- It is for profit.
- It will get in the way of family member's quality of life.
- It will take away the personal part of having a SC that knows our child.
- DDD Advocates for my daughter.
- Oversight role of DDD is different and not an advocate.
- Payment through health plan, there is a problem for providers to be paid (if there is missed sessions we will have no make ups).
- DDD advocated for my child.
- Health plan does not understand or recognize long term care needs. They see service needs as acute care only.
- DDD are experts at support Coordination for the DDD population.
- My son likes to participate in his meetings, we have been known to have 3 hour meetings and people plan extra time for him because of that DDD flexible with working with our members.
- Members get respect and dignity.
- DDD knows us with a Health care plan we would just be a case number.
- This feels like our rights are being lost.
- MCO would be managing DDD member rights instead of raising the quality of their life.
- Insurance gets all the power.
- Alternative model is not defined, it could be anything.
- Insurance is for profit.
- Feels like socialism.
- Feels like institutions.
- Would rather have SC not customer service.
- Don't want to lose my SC.
- Who takes care of advocacy after parents are gone?
- I would be calling numbers and having to push for options, rather than deal with SC who will easily get back to me.
- Families and Children deserve better.
- DDD has other remedies other than contractual. You could call your senator or your governor and they will fight for you.
- If not broke don't fix it.
- Long Term services may not be approved, and that would lead to parents not being able to work (financial hardship).
- Insurance will not care about daughter work day programs.
- Spent 40 years perfecting the system, none of us had complaints about our SC if we went to the alternate model we would lose the excellence system of checks and balances.
- Don't start over and use our kids as Guinee pigs.
- The motive of the "for profit" insurance company is different, their motive is to make profit for their shareholders. DDD motive is to spend every penny on services.
- I don't want to call a health plan customer service for a large plan and get 5 different people in 5 different calls.

- 40 years of perfecting the system, don't mess with the current system we don't have any complaints.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- List of people that are doing things they should not be doing, that list should be shared by different agencies.
- Thank you.
- Concerned when we open a quality of care concern form the family does not know the outcome.
- Services, when not in your own home, is a huge leap of faith for families.
- Collaborating with stakeholders is huge SC are our member's advocates.
- Fully fund any solutions.

What does your blue sky look like?

- Things to stay as they are x2.
- Want my son to be this happy all the time.
- Providers compensated well.
- If all services were available.
- Older families that have paved the way, talk to and engage younger families.

Forum: Mesa Date: April 24, 2019 Attendees: 34

What is going well with DDD LTSS?

- Respite Habilitation is a necessity and luxury to get a break, forever grateful.
- SC are Responsive, not significant turnover, there is continuity.
- SC is interested, responsive and returns calls.
- Accountability structure services, partnership, respite, ATT, and HAB from engaged parents.
- Trusted provider, grateful for SC that were intuitive, sincere care workers that feel called to the work, good people.
- SC gives information to families of what resources are out there (tailored to your needs).
- Offered the right to refuse, choose, dispute and/or disagree.
- Services provided are going well.

What needs to be improved?

- SC lack of communication. Changing appointments at last minutes, paperwork not explained during transition, rushed hurried not offered time to read and digest information.
- SC lack of knowledge.
- Lack of communication upon change in SC and new SC not familiar with member info.
- Provider shortage and DCW direct care worker shortage.
- SC turnover, I feel case load is too high.
- Prepare families for the long ISP meetings that are required for planning documents.
- Provider not able to provide backup provider in emergency.
- 2 hours of PT for 2 years without no one to provide second hour of PT.
- Hours are approved, but lack of providers OT PT Speech, Music.
- Psych evaluation, IQ evaluation, and Adult eligibility for individuals with DS (New Arizona) difficulties with determination eligibility.
- Concerns with environmental home modifications and when DDD funds modification terms of modification.
- Provider rates increased.
- Turnover of staff, experience of staff with dual diagnosis, medically complex, DCW.
- Communication of staff, client moved to new office without notifying the member.
- Behavioral Health provider lack of network capacity.
- SC not providing Spanish interpretation, appointments are getting delayed, pushed copies of service plans not in native language.
- SC act annoyed when asked for more services.
- Finding providers.
- Adult services DTA.
- Would like to keep the same SC instead of changing every 90 days.

- DCW wages need to increase.
- Finding Behavioral Health providers is very difficult.
- SC do not read the file to know when the family needs an interpreter.
- Employment hours cut to member who work, due to the increase in minimum wage.

What are the solutions for improvement?

- Smaller caseloads for SC.
- Prepare families with how long the meetings will last.
- General wages for all disciplines competitive.
- Wages should be higher for SC and direct care workers.
- Central registry training providers should not have to train and re train DCW.
- DDD to provide funding or conduct the mandatory training themselves.
- DDD provide the mandatory DCW training.
- Existing training registry underutilized, could be expanded.
- Standardization certificate training.
- Recruiting qualified providers out of state.
- Including parents in attending DCW training, including prevention and support.
- How to share Information regarding: DCW to other agencies (concerns: termination, theft, abuse).
- Less 90 day meetings, meet 2 times a year.
- Fully funded the state DDD rate rebase.
- Be transparent with families about changes.
- We do not do a good job of tracking poor performance or incidents of abuse with staff providers, agency we have no way to track, unless abuse is substantiated.

What are your thoughts on the Alternate Service Delivery Model?

- I prefer to stay with DDD state agency a not for profit.
- What if my provider isn't contracted with the MCO that gets awarded?
- Continuity of care - scary having to move my brother. They don't have to contract with my agency. He doesn't experience change well :-).
- Contracts with AHCCCS is this already a done deal? Are we just exercising an input forum for nothing? Check the box.... Are we just checking a box?
- I believe that my voice as a tax payer is very import. If this alternate model happens my voice it less impactful. I don't want to lose that.
- Shopping for a low cost care by the health plan is not okay.
- Is this a political move that the state is trying to save money?
- Not in favor of for profit HAB, Respite, ATT, LTSS.
- What does oversight mean? What are my oversight options? What are our appeals options?
- I'm concerned if my appeal grievances are not motivated by state dollars then my concerns have limited affect.
- What would that oversight look like? Up to the MCO.
- If it's not broken don't fit it!

- I'm concerned, if it was a health plan they would just be following the money.
- Stuck with contractual obligations, DME no appeal process.
- Oversight stops at contract?
- Does the appeal process only go to the MCO?
- My worry is that the humanity is lost.
- MCO are used to doing these services for the aged population and end of life plan rather than services that should be appropriate for the individuals trying to access community, life integration, quality of life. We want DDD for our members.
- Don't mess with our waiver! We have created an amazing system. DDD understands our families not a medical model. That again focus and are experience with aged population.
- Would like DDD to do it all.
- We are going to be nobody if we go corporate.
- Another parent has better experience with MCO managers.
- Bad experience with MCO, DME, and MCO assisted, but put me in the ringer.
- LTSS needs to stay with DDD.
- AZ has an amazing system rated #1 in nation, why are we trying to fix it, feels like we don't care about quality.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- None.

What does your blue sky look like?

- Working inclusively not segregated.
- No sheltered workshops.
- People have heart no aberration for DS.
- Zero sub minimum wage.
- More understanding from community in general also use diagnosis to low expectations.
- Schools fully included.
- More options DTA programs.
- Environment of no distinction.
- Dignity of risk.
- More training for professionals inclusive practices.
- Acceptance in society.
- More coordination of care deaf/blind.
- Less meetings two times a year.

Forum: Glendale Date: April 25, 2019 Attendees: 20

What is going well with DDD LTSS?

- Summer programs.
- Access to Aug Com device and other things to help make member independent.
- HAB and Respite allows to keep kids at home.
- SC continuity.
- DDD provides flexible services with AZ dollars, it has better outcomes than most states (measured metrics shows AZ as successful).
- CRS United healthcare community is going well medical and Behavioral health.
- Access to day program group homes.
- Likes SC that listens to member and understand where we are coming from (Don't want to see DDD go away).

What needs to be improved?

- Jumping through hoops to replace Aug/Com devices.
- Consistency of SC.
- Told things by SC without a reason why.
- Lack of transparency with the division.
- If you don't know what to ask for you may not get it.
- Inconsistency.
- I keep hitting a wall for getting services for my son.
- Not enough residential options for both behavioral and medical.
- CPI de-escalation techniques needed for my son (no options).
- Agency not releasing hours.
- High caseloads for SC.
- SC not well informed, not communicating.

What are the solutions for improvement?

- Look at family in a holistic way.
- Retain SC.
- Educate SC.
- Suitable placements for people with dually diagnoses.
- Required yearly SC to observe a family to see firsthand what it is like in members home.
- When children coming out of hospital mobilize wrap around services.
- Shared social resources for SC to share knowledge.
- Respite to be able to support member while in hospital.
- Pay caregivers more x2.
- \$20 an hour for direct caregivers for better quality, day programs and group homes.
- Incentives to have family members do respite.
- Potentially easier for family member to become respite.
- Brochure of all DDD services available.

- Better job training about what medically necessary means.

What are your thoughts on the Alternate Service Delivery Model?

- How does reimbursement work?
- Insurance not there for my child.
- No.
- From a Case management stand point this could be easier for my family.
- What would happen with SC, fear it would not be as good.
- Hard to comment without the “how-to’s”.
- May help with continuity.
- If this would improve payout for vendors, it would be beneficial.
- Insurance is out for the money.
- If this would improve caseloads it would be beneficial.
- Would take percentage from vendors.
- Difference of EPD ALTCS vs. DDD ALTCS different older vs young starting life.
- DDD spend their budget down to zero on DDD member.
- The motive for profit is to maximize return.
- Turn our back on system delivery model built over years.
- Medical treatment vs having a life.
- Would there be quality assurance with in the insurance?
- We have legislature on our side with DDD. Because government funded, we can complain to legislature.
- MCO not run by legislature.
- How can insurance do LTSS, like going out to dinner and a show for DDD members?
- Will the insurance look at the member’s services the same? Their needs?
- Group home are uniquely funded so is there continuity of care with new model?
- What is the motive behind option?
- Opposed to change, Will it be seamless? More stress having to learn a new system.
- We are #1 in nation, why are we looking at an alter option x6.
- Why fix if it is not broken?
- My daughter is happy I don't want to see it change.
- We have had 46 years of good.
- Oct 2019 option looks better.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Really happy it was brought to light.
- Unfortunate that it happened.
- Happens when opportunity arises.
- Statistics show this will especially happen with this vulnerable population.
- These things may actually happen in our home.
- Why is a record of registry not being kept?

- Educating family to educate children on “what is appropriate?” and “what is not appropriate?”
- This is a big deal, worried we may do it with overkill. Possible stomping on people’s rights. It may be expensive for extra super vision, camera, etc.
- Legislature should pay for the added expense.
- Will this include schools?
- Could the providers require they pass a lie detector test?
- Personality profiling is the only effective way.
- Background check on all that work with youth and vulnerable members.
- Nobody works until level 1 clearance card is issued.

What does your blue sky look like?

- Everyone accepted for who they are.
- World peace.
- Human kind to have compassion and love for one another.
- System that want to cheer our daughter on and see her succeed.
- Has wonderful family, living alone with two dogs, next step is finding true love.

Forum: Show Low Date: April 26, 2019 Attendees: 5

What is going well with DDD LTSS?

- Health plans going well and getting access to Doctors.
- Respite has been helpful.
- Attendant care helps to give siblings independence.
- Teaching kids to advocate for themselves.
- AT devices help with communication.

What needs to be improved?

- Communication between LTSS, Group Home, providers and family.
- Rates are too low for therapy services.
- Billing schemes (30 mins 15 mins) medical billing vs LTC.
- Contracting for qualified members.
- OT services are limited.
- Good services are limited in this area.
- Outings need to be more focused on educational and provide physical activity.

What are the solutions for improvement?

- Make outing fun.
- Consistent recreational and group activities.
- Having at least Medicaid and Medicare rates.
- Fully fund the rate rebase.
- Have billing system to align with AHCCCS.
- Better MDT coordination and collaboration.
- DDD needs to develop a list of local community events resources activities.
- To provide stimulating activities.

What are your thoughts on the Alternate Service Delivery Model?

- As long as there is good communication.
- Misalignment of incentives.
- Strong No on Alternative Service Delivery model.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- We would rather have our children close to home and not worry about our kids being in a group home.
- Identifying expectations across all monitoring agencies.
- Look at staff retention, staff turnover in group homes.
- Need good relationships between caregivers, providers and clients.

What does your blue sky look like?

- My daughter could live on our property with good medical care.

- Good quality support services that is not a catch all but understand unique needs of members.
- Have providers and services ask and understand member's blue sky.
- People with disabilities wouldn't be treated differently.
- More community opportunity for families.
- For members to feel needed and contributing to community.
- Support for DDD member who are incarcerated.

Forum: Payson Date: April 27, 2019 Attendees: 7

What is going well with DDD LTSS?

- SC staff work with families, to help meeting be easier.
- SC they listen.
- Array of services available to help keep family members at home together.
- Respite helps keep me sane.
- Members and families are engaged and open to what is available.
- 90 day are worth it.
- DDD willingness to be here in our community.
- Like the flexibility of meeting families out in community.
- DDD takes the time to learn the unique needs of families by educating themselves.

What needs to be improved?

- Vendor calls do not get answered.
- Crisis call responsiveness (no response).
- There is nothing we can do per community bridges.
- Only two QVA's in the area.
- Lack providers, shortage of therapies, OT, PT, speech both in home and center based.
- No center based therapies are available.
- No head start programs are home visiting.
- Shortage of DCW.
- Basic educating for families and community regarding eligibility.
- DDD is not following the recommendation of physicians for services needed.

What are the solutions for improvement?

- Advocate to help with application for eligibility of DDD and ALTCS.
- Job fairs recruitment outreach to community to find quality people (workers).
- Policies should take into consideration the unique needs of rural community due to lack of providers, exceptions should be considered.
- Suggestion to health plan, an indicator on member services, how to identify providers with expertise in specific diagnosis and disability.

What are your thoughts on the Alternate Service Delivery Model?

- Concern health plan manipulates services. Health plan has harmed the continuity of care for my family member.
- In order to go to a provider with expertise (understand) the unique needs of my child. I have to go to Phoenix.
- Health plan is not building relationships with providers in our area with expertise (capacity building).

- Physicians struggle with understanding the unique needs of families with kids with disabilities. Feel they understand physical needs, but do not understand the HCBS needs.
- DDD takes the time to learn the unique needs of families, they help families to educate themselves.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Mandated reporting the agencies are not taking action, still seeing vulnerable children at risk.
- Just because we are in a small town, we hope the outcomes of the order are enforced here too! (Good ole boy).
- Training and education are needed and appreciated. Taught signs and symptoms, but when we report the agencies don't respond.

What does your blue sky look like?

- Horseback riding everyday, at least weekly.
- Our kids can just be kids.
- Splash pad please.
- Accessible park.
- Getting a break.

Forum: Flagstaff Date: April 30, 2019 Attendees: 25

What is going well with DDD LTSS?

- SC is going well.
- We get lots of respite, but turnover in providers makes it difficult to get the services.
- Great experience with SC very responsive.
- Coordination with DDD and AZEIP warm handoff.
- Aug com is better than before.
- A lot of positive things with Long term care, especially when it comes to intentions.
- Love the high number of respite hours, so much help.
- Happy with current SC.
- DDD has my daughters and my best internet at heart with no thought of profit.
- Happy with OT, PT, Speech and ABA.
- DDD is better than other states.

What needs to be improved?

- Need to use a lot of different agencies in Flagstaff and other smaller areas.
- Turn over with providers and case managers.
- Information lost when there was changes in SC.
- Referral process (web based).
- Overloaded staff.
- Staffing is an issue, many horror stories, Continuity in caregivers.
- Member is home with family, but needs to be place.
- No OT providers.
- New ISP form is confusing.
- Availability of summer programs.
- Vendor call process- limited time to make a decision.
- Supporting caregiver burnout.
- Lack of DTA community based services, transportation, group homes.
- Quality of care providers needs to improve.
- DDD rates need to go up.
- Consistency in ABA therapy.
- Make information more convenient and available for families need to know therapies services are available from the beginning.
- With support coordinator turn over, active vendor calls get dropped, and is difficult in rural communities.
- Aug com transparency in the process.
- Nonexistence services on Navajo Nation.
- Communication under these forums, IOC members did not know about this forum.
- No respite in months had to go out and find our own provider.
- Need laptops for staff with preloaded info.

- SC referring to inappropriate resources like out of state or out of area.
- Only given 3 days to choose a group home that really needs to change.
- Misinformed that there was not group home list. I felt lied to.
- At first ISP, I felt like I was just given a menu with no explanation.
- Has been needing to remind SC to add authorization.
- Concerned about the new eligibility process.
- Could work at Walmart and get the same pay with less stress.

What are the solutions for improvement?

- Pay them more.
- Smaller caseloads.
- SC need laptops with Wi-Fi.
- Transparency with DDD services. DDD to do presentation for families so that they understand what is available.
- Provider report cards.
- Go back to online referrals.
- Provider training statewide credentialing.
- Wage increase with experience.
- Find staff who have a passion for their job.
- DDD needs to pay providers higher rates.
- Legislature, write letters, phone calls etc. for all in appropriations and budget.
- Prohibit cell phone use for staff, only for emergency.
- All areas of services from SC to respite providers and everyone in between (retain staff and stop rapid turnover).

What are your thoughts on the Alternate Service Delivery Model?

- Healthcare motive for profit.
- Concern with ASD, may lose services for members.
- With ASD, how will (what we just discussed) be addressed?
- DDD works with families, would a healthcare plan do the same?
- In Alternative model is there school advocacy?
- Not satisfied with fully integrated model.
- I need someone who knows my child.
- Prefer current model, quality would go down with Alternative Model.
- Health plans don't have LTSS experience, such as employment.
- Don't have trust in an insurance company, DDD is independent.
- How will the Independent Oversight Committee change in ASD model; justification and protection of rights?
- Non-healthcare needs would have be addressed ex: How would they do: social, emotional, employment, etc.?
- If it is not broken don't fix it.
- Better to improve what exist.
- MCO's do not know DDD services.
- What is the impact to very rural communities?

- Alt model seems like there will still be case management.
- What happens to DDD funding in the alternate model?
- We are the number #1 in the nation. Health plans are under a medical model and DDD is not. We are concerned that we will lose what we can provide for the member now.
- Do not see how it would benefit us.
- We count on this service to have a better life and health plans focus on medical health.
- I feel protected by DDD from the Health Care.
- For profit Health care would have complete control over the members programs, it worries me that DDD would not be the authorization for services.
- Alt model would cut out the middle man.
- Other states are not reporting success.
- Keep DDD, but integrate only if it helps.
- Seems very far-fetched to think a healthcare plan can meet our need. Afraid of losing what I have today.
- I don't like the idea of DDD only having an oversight role.
- Fear of the alternative model.
- Why are we changing something that is working well? If something needs changing address that, but don't throw out the entire system.
- Would a change to a managed care system retain all the positive aspects of the current system? Would a change to a managed care system fix any negative aspects of the current system?
- Would there be a change in the philosophy regarding service delivery? Currently DDD provides service and support coordination. A managed care system, most likely through an insurance company, may state that they will do the same, but their bottom line is profit driven. Having had some problems getting medically necessary items approved through insurance we have done some online research and found that this concern is warranted. The following is from the azauditor.gov website: "Monitoring the quality of care and services provided within a managed care system is important to ensure that members receive needed services. AUS (General Accounting Office) report found that managed care can create an incentive to under service or even deny beneficiaries access to needed care, since plans can profit from not delivering services. Another study has found that monitoring quality of care may be especially important for programs serving the Medicaid population because they contain many disadvantaged and vulnerable individuals."

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Stop cutting staff from APS, CPS, and DDD.
- Executive Order looks at the alt service delivery model and how the executive order will be affected.
- Allowing lowest qualified people to care for individuals who are most vulnerable.
- Better people to care for loved ones.

- Personality profile every worker.
- Increase funding qualified caregivers (fully fund)
- Two APS workers in all NAZ.
- We need organization structure to support the executive order.
- How do I get on a work group?
- Do not want them to be over burdensome, want to be able to fund any changes
- Need a training academy.
- Taking people out of their area increases their vulnerability. Need an interest in community participation and oversight.
- Personality profile every worker.
- 2008 funding has not been restored.
- Raise taxes for the wealthy, slash defense budget, treat people the same as in the hospital with extensive training and certification programs like nursing and law enforcement.

What does your blue sky look like?

- Providers to stay with us.
- Same services across the board
- One person to talk to every health care provider.
- Qualified providers.
- Electronically track the process a portal to access anything.
- Keep up with technology.
- Maintaining nonprofit motivated services.
- Build up DDD infrastructure on their tribal nation.
- Put control of paying for services directly to families.
- To ensure our kids will have peace and safety in their lives.
- Incentivize providers to provide services in rural AZ.
- Cultural based service in all areas.

Forum: Cottonwood Date: May 1, 2019 Attendees: 21

What is going well with DDD LTSS?

- AZ disability services are the best.
- If a family is not supported can they get state funding services?
- In 18 years of having DDD we have had a good experience. I can call with my problem and they have always been timely. They are a good sounding board, they have been there for us.
- 13 years they have been great. Every 90 days I fear will lose something, but we don't.
- Have had two SC always make me feel like they are on my team and supportive.
- SC are wonderful.
- SC is connected.
- SC is involved.
- SC is local so it makes it easy to access her. Local office.
- DDD good job of turning money intended for medical purpose and turning into services that don't feel prescriptive, treatment feels meaningful.
- Flexibility of provers have is a good fit for our family.
- SC goes to CFT meeting to be involved, give input and be informed.
- Customer service center provider has been great.
- Nationwide DDD is number 1.
- Providers are wonderful.
- Can call them with problem never had a time when an issue has not been addressed timely.
- Most all of our services have been excellently coordinated.

What needs to be improved?

- 10 years with wrong diagnosis to fit DDD eligibility.
- Case reassigned to Flagstaff SC.
- SC from Flagstaff, not wanting to help because we were in Cottonwood
- Case reassigned to Payson SC.
- Not presented with all services available.
- Lack transparency on services.
- Didn't know about ATT.
- Still waiting on SC to get a medallion.
- When wheelchair was broken, United healthcare struggles to get it fixed, they were non responsive.
- Parents pay on out of pocket for services due to United Healthcare and its run around getting services approved, etc.
- SC overload.
- New ISP document the SC are not properly trained to fill out.
- Who can diagnose children with Autism to get eligibility to DDD LTSS (From school psychologist).
- Not fully funded system.

- SC having family do homework to prepare before 90 day meeting to make process go by quicker due to new ISP document.
- Redetermination difficult.
- Hate the new plan document. Intended to be a person centered approach, but definitely is not. Not enough time dedicated to this concept.
- Better way to do document.
- Multiple children with DDD so doing a 3 hours document for each is not good.
- Aug Com struggling to get devices, transparent in process of getting these device.
- Families don't know what to ask for or where to get it. (Aug Com devices).
- Overlapping services with community bases services, school, medical, and they are not communicating, causing double dipping.
- DDD who can determine eligibility for cognitive disability, as a school Psychologist my diagnosis is not eligible?
- Seems like providers are doing a lot of training due to SC not being knowable about services.
- Reviews are not as effective as they could be, case load ratios are too high.
- ISP forms/planning doc are being used inconsistently.
- ALTCS is inconsistent, member moved out of town eligible, came back into town and not eligible.
- Providers do not get paid enough.
- DDD needs to pay higher rate, not keeping up with minimum wage.
- DDD Provider list are not accurate information from, inconsistent.
- Very difficult to fill para professional position.

What are the solutions for improvement?

- Fully fund DDD.
- More training SC on ISP documents.
- ADE to talk to DDD for a seamless transition, communicating with schools so there is flow from school to home.
- Rural areas need more providers.
- Incentive for OT, PT ABA, specialty services, Respite, HAB, etc. to come up to Cottonwood.
- Get employment in rural areas for respite and other LTSS.
- DCW were considered a professionalized position.
- DDD and RSK work together to educate communities of services which organizations does what? How to approach appeals, etc.?
- \$20 minimum pay for DCW.
- Pay more.
- Educational services, has availability to hire clinicians (collaboration).
- Providers list needs to be updated.
- Easier website to get information about services, information, and all the things that are available.

- Partner in community to share resources like respite, para pro from school to family.
- DDD needs to be transparent in how obtaining a communication device.
- DDD needs to be more transparent about services.
- More communication with the school district so that we can help families.
- Get approval for plenty of service hours, but no one to work them.
- Through a combined service model and shared expense you may be able to be more creative to address needs.

What are your thoughts on the Alternate Service Delivery Model?

- What is MCO's motivation to get involved with DDD members?
- MCO not invested like DDD.
- How long will they be in it for?
- Concerned we will lose good people in the community, so if it is not the best thing for my kid I may have to move from AZ.
- SC are advocates for families, we will no longer will have that. I feel insurance company will not have my back.
- We will lose our local presence of a DDD support Coordinator.
- MCO is counting on dragging out process, so parent gives up on trying to get services.
- MCO makes money on this, that money should be spent on the members. DDD motive is to spend all its money on members, no profit for DDD, but definitely for insurance company.
- Vendor will not go through Medical.
- Will lose providers.
- Insurance not easy to get paid through.
- We will lose the little services we have here.
- Not good for rural communities outside a large city.
- Would have to contractually make sure Insurance Company have services in rural area.
- Insurance company don't have your back like SC has had.
- DDD customer service model would need to be guaranteed through the insurance.
- Motives, for profit, shareholder, make a profit for return, they have public trade.
- MCO is just a health plan.
- No confidence the MCO will have my daughter's interest at heart and spend money to improve her life.
- DDD at the end of each years uses all money because it's a nonprofit.
- MCO is responsible to stake holders, they are not interested in our members.
- Anything making a profit on this community is not ok.
- When talking about the Alt model with out details it is hard to give real feedback.
- Group homes and dealing with multiple MCOs and the possibility of splitting up family in group homes bases on different MCO plans could be difficult.

- If my Doctor does not contract with my insurance plan, we have to use another vendor or Doctor, we would be out of luck.
- Nationwide AZ scores 1st and 2nd in measuring metrics of outcome with members with disability and the money spent.
- If it's not broke don't fix it.
- Insurance is about cost sharing (deductibles, copays).
- Like to see some scrutiny that is put on vendors now, gets put on insurance company.
- If we are not happy now with DDD, we can complain to the governor's office, we will not have that option with MCO because it is private.
- Insurance wants constant re-evaluations for services, like speech for a nonverbal child. The scrutiny put on our kids would be too much.
- More transparency about what this means (alternative model).
- If DDD has control over insurance company it will work, will not work if left up to the insurance companies.
- SC are the resources that is needed in this area. We will be just a number to the insurance company.
- Health insurance company as a provider, I may not be able to compete with a company that could provide it cheaper.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Surprised that executive order had to be rendered it seem like common sense.
- Why did it take something so extreme to bring people to the table?
- Public places like football games should have security with cameras and walkie-talkies to protect people.
- Why did this not exist already?
- Wage for LTSS is too low, that allows employees to do minimal.
- There will always be a place without cameras.
- Everything in place to prevent these things to happen, but there is no follow through like the physician in this case.
- Cameras would catch an offense after the fact, but would allow the predator to be prosecuted.
- Body cams on employees.
- Qualified vendors spend a lot of time making sure procedure are set.
- Order is well intended.
- Psychological profiling is recommendation to governor for providers, it is the most effecting way to protect member.
- Videos surveillance.
- Smaller groups homes have less staff and they are more vulnerable.
- We need to protect our people but we need to be cautious that we do not go overboard.
- Oversight positions have been eliminated.
- Physicals need to happen for our members.
- Mandated reporting spend a lot of time training providers.

- Less daily oversight can add to the problem.

What does your blue sky look like?

- Transparency.
- Fantastic communication about changes coming.
- Keep DDD active for long run.
- Let member have therapy whatever is best for the member.
- Enough providers to go around and get well paid.
- Quality and Qualified.
- If you pay them more, they will come.
- SC hire more so the case loads are more manageable.
- Complete coordination of all services Medical, schools, therapist.
- Proactive prevention of abuse.
- Avoid excessive sexual harassment or bullying though out society.

Forum: Paradise Valley and Scottsdale Date: May 2, 2019 Attendees: 19

What is going well with DDD LTSS?

- Consistent SC for three years.
- Learning how to best communicate with SC.
- Smooth transitions from AzEIP to DDD.
- 90 Day reviews are positive.
- Supervisor very helpful when issues arise.
- Hearing parents voice at these forums.
- Great communication from SC with scheduling.
- Therapy interventions available for kids and teen with autism (Options).
- Community forums like this where we can ask any question and get an answer.
- SC having cell phones has been major.
- Seems like there is a lot more acceptance of therapies now then there was when my son was little (he is now a teenager).
- AZ typically scores #1 in nation. We do more with less than anyone else. Can you imagine if DDD were fully funded?
- I am so grateful for all the services we have. My heart is full.

What needs to be improved?

- Providing more detailed information regarding health insurance options.
- Better communication with roll out of new technology.
- Lack of therapies available.
- Rates need to be higher for providers.
- Struggle to find respite providers.
- Direct care worker pay is not paid enough.
- Parents are finding their own providers and sending them to agencies.
- Struggle to have right DX label for eligibility.
- Need better training for SC (Behavior Plans & HAB).
- Large turnover.
- Services eligibility we need education on appeals process (Adverse Benefit Determination).
- Coordinating care between AZEIP, DDD and Insurance plan.
- Better training for district nurses in looking at family as a whole.
- Less cases per SC.
- Need better pay scale for therapist. Therapist say DDD does not pay enough.
- Parents need to get DX prior to age 18.

What are the solutions for improvement?

- Paying SC more money as well as (Providers and Direct Care Workers).
- Treat family as a whole.
- Less cases for SC.
- Fully fund DDD by legislature.

- Have parent perspective be a paid position as they are making policy and decisions. There should be parents involved. DDD should establish a paid parent advisory board.
- Teach families about all services available.
- More information about dual complete health care option.
- DDD determine what the rate should be, but they never pay what it actually cost to do the service.
- Can't we pay SC, providers and direct care workers more money?
- Everyone work as team. There are a lot of services available, but they are not offered unless you know about it. List of what is available.

What are your thoughts on the Alternate Service Delivery Model?

- Like the Support from DDD.
- Concerned that the caseworkers would make decisions based on health plan funding.
- Concerned that the health plan would not contract with current providers.
- What training does the caseworker have?
- Could work if caseworker understands the need of the DDD member.
- I would like the ALTCS health plan to be my point of contract to simplify the process.
- Potential pay rate by ALTCS insurance plan being less.
- Health plans could be for profit.
- Concern majority of EPD model may have more of a focus on the elderly than DDD member.
- What happens to my SC that I love?
- My daughter is not medically involved, if she were maybe I would be attracted to this, but I am not because EPD only pays 90% of DDD published rate.
- DDD goal is to spend every penny every year and not for profit.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Should have been caught earlier.
- Who is monitoring the monitoring? We should utilizing cameras, don't our most vulnerable deserve our best?
- Doing psychological profiling of employees.
- Better monitoring and auditing of facilities.
- Doing unannounced drop in visits.
- Mandate cameras.
- Having a second employee accompany staff.
- Concern of the expense that this would incur.

What does your blue sky look like?

- That every person that enters our house has an idea of what we go through.
- A community that does not look down on our child and family.

- That our child is given endless possibilities.
- Have a "champion of care" person.
- Everyone work as a team.
- Tell us resources.

Forum: East Mesa Date: May 7, 2019 Attendees: 11

What is going well with DDD LTSS?

- Transition to employment program has been helpful.
- SC have included the whole family. Recognizes the option and the value of the whole family being involved with providing in home care for adult child.
- Appreciates the option of being able to be a paid provider as a parent of adult child.
- PT, OT services have helped and have taught us how to do these things at home. Real life.
- I like the fact that AZ isn't operated in a waiver system like other states.
- Having a SC that sticks around they are timely responsive knows our family.
- Length of SC 8 years we love her!
- Very excited at DTS in Queen Creek.
- City of Mesa - Parks and Recs OTS we love it.
- Best DTS themselves with the families.
- Day programs allows us to stay and help with our son's anxiety.
- I feel that DDD is providing the correct amount of hours for our community (HCBS).

What needs to be improved?

- Turn over with SC.
- SC seem overwhelmed with their paperwork and too high of care loads.
- SC seemed young and inexperienced with crisis scenario with our son. Had to file a complaint.
- Expectation that family member be taken out in community for a least 4 hours. Not individualized DT.
- Concerned that at 18 years of age majority of members becoming their own guardian could there be a gap.
- Concern reported that ATT Supervision hours are being cut without explanation.
- SC cut hours due to provider shortage (other remote areas) Lack of consistency outside Maricopa.
- Focus on vendor call process. I don't feel I can monitor the vendor calls. We need transparencies.
- Eligibility criteria at age 6 (would like to see chromosomal defects added as an eligibility category).
- Need group homes specific to Prader-Willi Syndrome, lack of is causing life changing affects and life ending consequences.
- Behavioral health Prader-Willi Syndrome placement concerns and having trained staff.
- Need for Prader-Willi Syndrome group homes for safety reason, Tucson has home, need some in the valley.
- Pharmacy restriction for behavioral health meds, causes a delay in receiving meds.
- Very difficult to work with difficult adults.

- Didn't know how to file a complaint.
- Families are desperate for a break. Especially with behavior members, Need out of home respite, with staff that are specifically trained (emergency respite).
- Behavioral health unsafe discharges, only keep members for short periods of time.
- Agency accountability at what point do they get shut down? Who are they accountable to? How many substantiated claims does it take?

What are the solutions for improvement?

- Use chain of command for problem solving file complaint.
- Parent portal to track vendor calls, hours and authorization - would cut down on calls and e-mails to SC - Empowers parents - Supports SC - Adds another criteria -Including chromosomal defects XXXX.
- DCW incentivized to take additional training pay increase, bumps in wage.
- Rating system for providers.
- Training for families on how to file a grievance.
- Getting the hours is contingent on parents taking the training on DDD.
- Trained DTA providers with expertise personal care Respite HAB and ATT.
- Pay higher rates to DCW commensurate complex need or behavioral challenges.
- Emergency respite for crisis situations (like Ryan House for young adults or teens) with trained Behavioral Health staff.
- Future planning concern and care for the caregiver.
- SC meets with family every 90 days ask question to recognize symptoms checking on entire family.
- I would like to see article 9 prevention & support given to parents for free. Parents don't know their rights.
- DDD partner with RSK to provide training to parents about member and family rights.

What are your thoughts on the Alternate Service Delivery Model?

- Health plans are for profit trying to save money, they are not familiar with unique needs of the DD population.
- Philosophical difference - community services (Government vs. Health plan).
- There is no assistance with accessing care with Alt Model.
- Disconnect and not local.
- Grave concerns... Current experience with health plan does not return calls.
- Doesn't provide enough options for disagreeing (Health Plans) didn't even listen or comply with court order. No! Wouldn't want Health Plan - they don't understand.
- I feel my SC is there for me and my child.
- I am concerned the case worker would be loyal to the health plan.
- DDD SC are trained with historical knowledge like willow brook.
- What does DDD oversight mean?
- I feel like this take us backwards. I am concerned that the health plan SC would be incentivized monetarily for saving money.

- We would lose oversight, I'm worried.
- Physicians can't get approvals/authorizations from health plans how this would be any different.
- Hope families are smart enough to be afraid of this model.
- If DDD writes the contract for a private/for profit agency to run as the SC then they are bound to the contract. There will be no wiggle room. DDD is a government agency, if we don't agree we can go to the legislation.
- May not know the valley Health plan may be aced in another state.
- Afraid that the Health plan will put all the responsibility on family that and that would put added stress on the family.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Loaded question.... My daughter is a vulnerable person like this. Systematic error!
- This facility was not being appropriately monitored, good ole boy.
- Checks and balances - monitoring oversight.
- Personnel credentialing.
- Increases visits from SC six months is too long.
- Two person for care and medical checks.
- Patient advocacy.
- Pop in visits.
- What did oversight look like? It failed. Not appropriately monitored.
- Cameras and more security.

What does your blue sky look like?

- More parent support and training earlier in the process. Learn tricks sooner how to navigate things.
- Regional meet ups no disability criteria necessary.
- Gathering the collective "we".
- Providers that are there to provide care QV that follows thru with covering hours.
- What is going to happen when we are gone?
- I hope I out live my child.

Forum: Page Date: May 9, 2019 Attendees: 2

What is going well with DDD LTSS?

- Eligibility for DDD services.
- Are there funds available to assist family to attend conferences specific to rare diseases?
- Group home eligibility criteria.
- Homeschool coordinating of services is going well.
- Try to coordinate services with CRS.
- Families are happy with services provided by therapists .

What needs to be improved?

- Care coordinating.
- Families are told they have limited therapy services after age 22.
- Not seeing referrals for DME, training for caregivers.
- Not receiving PT vendor calls.
- Families think they cannot appeal ALTCS/SSI/denials.
- Need more specialist in outlying areas such as pediatric eye dr.
- Need responses from SC.
- Lingo difficult for families to understand.

What are the solutions for improvement?

- Transparency in DDD services & supports.
- Aug com specifically and Resident services.
- More support for single parent home at meetings. SC to share as much as possible during SSI meetings.
- Funding for families to attend diagnosis specific forums.

What are your thoughts on the Alternate Service Delivery Model?

- Families may not see a big difference with the ASD.
- Depends on who the coordinator is.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Mandatory reporters need to report.
- Repeat and remind anonymous reporting.
- Cultural competency training given to staff.
- Advocate to stop violence against Native American woman.
- Amber alert on Navajo land.
- Data and stats on violence against woman, suicide, social issues and abuse of Native American woman.
- Need information exchange data sharing?
- Tribes are represented in the work groups?
- Respect issue for the Native American Population.

What does your blue sky look like?

- Resident facilities in Kaubeto for members.
- After 18 years, after 22 years parents feeling that their kids are safe and being advocated for.
- Just knowing where to go, parents and caregivers know the next steps.
- Use of technology apps for services, Q and A about services.
- Combine all services (Growing in Beauty/AzEIP).

Forum: Colorado City Date: May 10, 2019 Attendees: 9

What is going well with DDD LTSS?

- DDD SC comes to the home.
- Like DDD and Coordinator very prompt.
- Good health plan and services.
- Long term support coordinator.

What needs to be improved?

- No provider under health plan.
- Have to travel long distances for specialties ex: neurology.
- DDD specialties need to be more available in NW AZ.
- Need more respite hours.

What are the solutions for improvement?

- More than 600 hours per year.

What are your thoughts on the Alternate Service Delivery Model?

- It would be weird.
- Easier to use with DDD as the coordinator.
- Would health plan coordinators offer the full services and supports?
- I want a DDD coordinator.
- Health plans may not have families best interested at heart.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Training for owner and administrators of long term facilities.
- Background clearance time frames (6 years) is too long.
- Random drug testing mental health checks and other checks, especially if you work in high stress jobs.
- Inspiration classes how to deal with stress.
- Heightened security in facilities.
- Nonverbal and vegetative state individuals need to have more severity.
- Support groups with families.

What does your blue sky look like?

- Having my kids come to a point where they live independently.
- Walking into a doctor's office and getting services.

Forum: Kayente Date: May 11, 2019 Attendees: 2

What is going well with DDD LTSS?

- Happy with sons group home and school.
- Support Coordinator is new, but doing okay.

What needs to be improved?

- Consider clients feeling, about traveling long distances for community outings.

What are the solutions for improvement?

- Client has input and choice on travel outings.
- Training employees on new changes with DDD.
- Navajo speaking DDD staff to interpret new changes updates to parents and care givers.
- Navajo speaking training to provider staff.

What are your thoughts on the Alternate Service Delivery Model?

- I am happy with the way things are.
- Billing may be more difficult.
- Unsure who the person will be (to work with families).
- Will they have a personnel connectors?
- Will rates change?
- Concern that health plan may take admin cost of the top.
- I would rather stay with current model.
- I like working with DDD.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Encourage parent to parent support.
- Parent advisory groups to advocate for family members in homes.
- Ensure security and safety in community.
- Concern of moving members out of the Chinle Valley school community.
- Stranger danger type of education for members.
- Nonverbal and non-mobile members need to be where people know them, especially when nonverbal and non-ambulatory.
- Empower parents to advocate for the best care.

What does your blue sky look like?

- Want families and members everything to be 100%.
- No disability challenges.
- Family member to be taken care of.

Forum: Date: Maryvale Date: May 13, 2019 Attendees: 5

What is going well with DDD LTSS?

- IDLA (Golden Sun) where daughter lives is good and mother is happy.
- Consumer understands what food she can and cannot have (diabetes).
- AZ scores well, is #1 in service delivery services for consumers with developmental disabilities.
- We do more with fewer dollars than other states.

What needs to be improved?

- More parent education from DDD regarding services and options.
- Providers don't pay their staff a proper livable wage direct care should be \$20.
- Increase in pay for DDD coordinators.

What are the solutions for improvement?

- Reach out to legislature to increase funding to DDD.
- Teach DDD coordinator about the concepts of habilitation, ISP, etc.
- Wish we had options as member age, for example, assisting members in maintains weight and watching health.
- Sharing resources available in the valley we can connect to, they can be identified in the ISP.
- Increase rates of pay for SC.

What are your thoughts on the Alternate Service Delivery Model?

- Feels overwhelming and scary.
- Feels overwhelming to coordinate under insurance health plan.
- Bad idea because insurance is medically based - it doesn't fit for me.
- Health plan may only give minimal services as necessary.
- Current DDD model does amazing stuff.
- Let's not throw it away, if it's not broken don't fix it.
- Motives for profit insurance company and DDD are different.
- Insurance is motivated to make money for shareholders.
- What benefit does this bring to our members lives? I do not see one.
- The mentality is to give only as much services as medically necessary, minimal services.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Impressed about the call to action.
- Fully fund any recommended changes.
- Pre-employment psychological profile done for providers prior to employment.

What does your blue sky look like?

- Enough money for everything.

- Get DDD coordination to give out consumer HAB goals.
- Support Coordinators would be more educated about person centered planning - providers as well.
- My daughter learns enough skills to be independent.
- My child will find the power to try new things and blossom.

Forum: Chandler Date: May14, 2019 Attendees: 19

What is going well with DDD LTSS?

- No wait list to access services (placement) new resident to AZ.
- Wonderful therapist (PT, OT, Speech).
- Back office response to authorization are smoother.
- Vendor call was successful.
- SC great communication and good follow through.
- SC is here for more than a year.
- Love the SC technology.
- Respite.
- Extra HAB, ATT to meet individual's needs, flexibility based on circumstance
- Daughter was able to receive therapies with no problem, including 3 hours of speech and 2 hours of OT.

What needs to be improved?

- SC not trained with Information regarding upcoming changes, this creates anxiety with families.
- Disconnect of what Division reports that SC should do, can do, and should know.
- We have had 30 SC child is only 11 (SC high turnover).
- Prescriptions and documents were lost.
- Confusion, inconsistent messaging from SC regarding therapies.
- Agency not notifying DCW in time to take required training certificate.
- Lack of providers ATT, RES, HAB, PT, OT (parents burdened with recruiting).
- Inconsistency in SC stability.
- Inconsistency in SC formulation of determination of hours HAB, ATT, RES.
- SC judging the family and their personal perspective.
- SC retention.
- Many personal visits could these be combined.
- SC telling families they need to go to Customer Services, then telling families to go to their SC for the same question.
- Inaccurate information about evaluation from therapist.
- Moving hours from provider to provider, splitting them can get messy.

What are the solutions for improvement?

- Don't make new policies without family input.
- Include parent & family perspective in new SC training.
- Check evaluation documentation prior to authorization and scripts being submitted (Parent Education).
- Central registration for available providers.
- Central reposting for hours.
- Hire a parent benefit liaison that helps parents understand their benefits, Medicaid paid parent to keep their private plans.
- Pay parents to do HAB and ATT prior to Turing 18.

- Process to place vendor call, when put on notice of provider leaving.
- SC case load too high could benefit from case aide.
- Weekend 90 day meetings.
- SC should know their job responsibilities they should be qualified.
- Partner new SC with seasoned staff.
- Offer parents that are seasoned to provide coaching and training for SC staff.
- Provide community resources to parents ex: videos and social media.
- Training for SC in professional development and customer service.
- Maybe centralized visits between SC, providers, etc.
- When new, DDD families should have a seasoned worker who can explain what is available.
- Do not give an answer that is untrue, it is ok to say you don't know and follow up in a timely manner.
- If there are videos that tell you how to navigate the system very helpful.
- Hold focus groups with parents especially with new policies.
- Possibly do video chats to save time and money.

What are your thoughts on the Alternate Service Delivery Model?

- Loss of providers, fear, anxiety.
- Insurance company would not understand the progress of my child.
- Worried about member choice PCP.
- Potential conflict of interest.
- DDD understands the best needs for daily living, but Health plan not necessarily.
- Conflict of interest from having a case manager from the health plan.
- Would remove an extra layer of protection that is the best interest of kids.
- Worried about case managers wouldn't have the same expertise (interest in kids) home daily living.
- Black hole of horror to file a grievance.
- Experience of case manager with health plan has been negative for this family.
- This feels like we are moving to this model no matter what. Is this the better model then?
- Worried about care coordination.
- Prior to decision, provide more parent training before this change is made. Need more transparency on it.
- What does DDD oversight mean?
- This will hurt the small qualified vendors.
- Anxiety of the unknowns.
- Three years is not enough time to see if a system is working to make an informed decision, need more forums for discussion.
- Is there going to be a, non-bias, outside consultant being engaged?
- Need Member engagement feedback during the next three years.
- Health plan should not take on traditional services that they have no experience in or understanding of.
- Model has served AZ families for all these years.

- DDD was my advocate for insurance company, when it came to medical necessity for equipment.
- We don't want to see current model changed.
- What we have now is what we want to keep.
- Have we talked to or researched other states?
- Will there be consistency of contracts? Adequate timely compensation?
- Why are we even considering this option?
- Worried about caps.
- I am worried about going to a call center and not having one point of contact. Now I have a dedicated SC one point of contact.
- Historically physical and behavioral health plans understand the unique needs for DD population, it is not up to the payer to make the determination for medical necessity.
- Human rights committees need to stay activated.
- Why would we minimize DDD? We need the right delivery system not just one.
- ASD kiddo do not trust anyone, it took a lot of time to find the right provider, we do not want to lose provider with alternative service delivery.
- HP is for profit and about money.
- Who would be looking out for kids on alt model?
- Will rates be the same? Will all providers want to switch? Will we have non continuity of care?
- AZ is number 1 why change model works?
- Integration question, Will PCP have authorization to prescribe specific needs? Will it have to go through Behavioral Health home? (Example: SW network JFCS).
- Any changes with Indian health?
- Coordination of benefits questions for DDD liaison, mercy care, UHC?
- FAQ bedside aide instructions.
- Continuity of care instruction for non-contracted provider.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- What does that collaboration look like?
- Experts to provide training.
- Caring for the caregiver. What causes a caregiver to snap? Where can I go if I am getting ready to snap? Look for signs and symptoms for at risk warning signs.
- Provide training on self-advocacy and self-defense.
- Sounds like too many hands involved, worried about all working together.
- Wish families could be paid for providing service to our children before 18.

What does your blue sky look like?

- More parent choice and control over services.
- Pot of dollars that parents can oversee personalized budget.

Forum: Kingman Date: May 16, 2019 Attendees: 30

What is going well with DDD LTSS?

- Overall DDD system working well.
- Couple great therapists (PT, Speech).
- Agencies that train providers.
- Excellent Agency –Abrio.
- National Representation.
- All of the services offered.
- Some very knowledgeable SC.
- Family member is getting services needed.

What needs to be improved?

- Options for overnight, respite needs to be local (skilled nursing).
- Nurse proactive act in AZ is too restrictive.
- Family's opinions matter.
- Case worker turnover and case swap every 2 years. Caseloads are too big.
- Finding therapist.
- Transportation (health plan transportation) not reliable (GSE) mile markers.
- Getting respite took 1 year, provider concerned agencies don't have enough workers.
- Misinformation from SC and not getting returned calls or getting wrong information.
- UHC use of preferred healthcare diaper delivery.
- SC not knowledgeable of ALTCS intake process.
- Better communication and process between DDD & ALTCS, DES.
- Better working relationship between DDD & VR.
- Needs more knowledgeable SC.
- Meetings can seem pointless at times, no changes and no new information.
- Limited interaction with client.
- Too much turnover with workers.
- Rural services and traveling out to areas.
- Concerned that providers don't have enough workers.

What are the solutions for improvement?

- Provide agency lists to families in area.
- Provide more training to families.
- Move VR services back to DDD.
- Recognition of good SC.
- Better communication to family about wait time, process, what is going on, etc.
- Meetings via phone.
- Well rounded education and knowledge for SC including strong focus on HAB.
- Training for DDD to respect therapist evaluations and recommendations.
- Higher wages.

- Legislature needs to fully fund DDD and agencies.
- More geographic rate enhancements "windshield time".

What are your thoughts on the Alternate Service Delivery Model?

- Seems like it will be tough on parents, more hassle.
- Doesn't like idea of case workers from health care provider (best interest from DDD not Insurance).
- Continue through DDD so things aren't taken away.
- Insurance won't work well with individual needs, disabilities and services.
- Insurance is about the money.
- Will Insurance case worker specialize and do specific training.
- Negative affect on rural areas, economy of scale, Insurance may not make an investment in the rural areas.
- Fear of long waits to contact someone.
- How many clients per case load?
- Insurance culture and philosophy is not in best interest of children and individual with disabilities.
- It is not cost effective.
- Would Insurance set their own rates?
- We would have to jump through more hoops, current experience with EPD program.
- Would there be separate SC for the families with children same diagnosis?
- Who sets goals for individuals? Is there trained SC for individuals with disabilities?
- Hard to do with less money.
- Current system you can call representatives and governor.
- Some benefit with contacting provider directly.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Appreciate the protection.
- Oversight is mandatory to make sure everything is in order.
- Standardize process for qualify (possibly enhance process).
- Complete background of all individuals interacting.
- Quality checks on vendors periodically.
- Psych profiling.

What does your blue sky look like?

- Everything and all needs are covered.
- Transition from HS to work.
- Assistance in getting equipment covered.
- Local or coordination of appointments services.
- Streamline process of getting equipment.
- Living independently and working.

- More workers, helpers, therapist dependable.
- Increase wages to increase quality (\$20 and hour) Kingman.
- Living without fear.
- Education program for businesses in community connected to schools transition.
- For all to follow Article 9 including police and schools.
- Further education opportunities for college and career.
- Know safety and secure will exist even after parent are gone.

Forum: Bullhead City Date: May 17, 2019 Attendees: 13

What is going well with DDD LTSS?

- Overall idea of DDD services and supports is a great idea.
- SC has been consistent.
- Allowing parent to be paid for care (after 21 years of age).
- Local vendor agency.
- Appointment setting and reminders with SC.
- DTT is going well.
- Happy to have DDD in our city for the first time in 18 year.

What needs to be improved?

- Getting adequate staff and services (no ABA or music therapy).
- Incorrect information being given or not at all.
- More information on transition (medical).
- Better understanding of ATT.
- Turnover of SC in Lake Havasu.
- Provider pay.
- Know kids who are in need but not legal residence.
- Services authorized, but cannot find a provider.
- No speech therapy for two months due to no provider.
- No respite care providers in the area.

What are the solutions for improvement?

- Better pay rate and information on lower cost of living for potential providers.
- Better process to become DDD vendor how to get an access ID number?
- Directory for doctors educated with special needs and disabilities.
- Specific rural modifiers.
- Fully fund DDD.
- Incentives for staff to keep employees.
- Better quality of how to implement training and knowledge.
- Members over 21 years need continued hearing services, hearing aids for adults needs to be a covered benefit.
- Psych help for Family caregiver EAP options for caregivers.
- Medical doctors need to be educated on special populations.
- Recommend someone in the community to assist with guardianship.

What are your thoughts on the Alternate Service Delivery Model?

- The 2nd option if you don't know what is available, there will be a cost savings for the insurance, and at least DDD lets us know what is available.
- DDD is a safety net. Dangerous to take DDD out.
- Don't want to go with Alt Model, indirectly creates less supervision, become victims and system fails, contradiction to DDD mission statement.
- Decline in opportunity and conflict to mission statement.

- May be difficult to file a grievance in the new process.
- Alternate option is a way to save money for?
- Communication will be difficult.
- Health plans has shareholders for profit, DDD funds spend on members. Bad idea.
- Builds barrier to families.
- Disability individuals roll into entitlement program with funding; people with DD have conditions since birth and did cause health issues receive EPD.
- Health plans want families to give up and quit.
- Emotional health of caregiver jeopardized by Alt Model.
- When you change an entire highway, it is very difficult to navigate, don't change. How do you know what route to take?
- DDD knows what is going on with Developmental Disabilities.
- Do not want to go with alternate plan.
- DDD service is to be more independent, health plan is more medical.
- 2nd option will make it very difficult to access supports and services, emotional health of caregiver due to no support from health provider.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Fear and nervous about putting children in facilitates.
- Order is appropriate, need more trainers, monitors, need neutral people to report how it is, secret shoppers like Spy monitoring system (high quality).
- Need hotlines.
- Pre-employment psych screening testing.
- Family and care giver need emotional/mental support/break.
- Hope my child goes before me.
- Can't see putting my daughter in a facility where I am not with her.
- Need to take a better look at what we have DTA's in AZ suck. High school and DTA's do not do a good job changing member's diapers (which should be a top priority).
- Unannounced visits and monitoring.

What does your blue sky look like?

- Live next door to work with car and boat, auto, pool, electric gate (close to home).
- Adventures (monthly).
- Learning more about spec needs, giving what best for brother.
- Be able to help family members through life.
- Pay increase for care givers (\$20 per hour).

Forum: Lake Havasu Date: May 18, 2019 Attendees: 2

What is going well with DDD LTSS?

- Great SC, back up for everything accompanies for IEP x2.
- Good OT and speech.
- Good day treatment program (mile markers).
- SC values guardian/parent input.
- Consistent SC.
- Great services in Havasu (OT, Speech, PT, HAB, Respite).

What needs to be improved?

- No PT, made appointment and then never showed up.
- Limited respite workers.
- No response from agencies or limited.
- Need more providers for all therapies (PT, Speech, and OT).
- Also specialized Audio Verbal therapy, feeding therapy needed.
- More training for DDD staff SC to DPM to Medical review team on and for specialized therapy.
- Provers tell families that they are not receiving vendor call.
- 90 day review too frequent.
- More medical specialist and staff for disabilities (developmental pediatricians, pediatric and general dentist who specializes in special needs and neuro psychologist).

What are the solutions for improvement?

- Bring back option for PPL in rural areas.
- Rate increase for all providers, DDD staff in order to create stability and longevity.
- Easier process to contract providers (therapies, respite). There are providers in rural areas, but not contracted with DDD.
- Training around the need for a provider is not available, wait list (provider's data of need for providers).
- Improve vendor call process.
- Phone check-in and review as options especially when annual and review are due around the same time.
- Internal supplies back to auto shipment instead of monthly call in by parent (M-F 8-5).
- Siblings support groups.
- Peep to peer integration, mainstreaming outside of school (SARRC model).

What are your thoughts on the Alternate Service Delivery Model?

- Don't like it, it has flaws.
- Hard to get services now, health plan makes it difficult for member to receive services and supports.

- SC is a go to neutral 3rd party, rather than someone working for a business making decision for members.
- Don't want to lose local support from SC.
- Losing a lot of relationships on a local level.
- Can and will Health plans case manager attend IEP meetings?
- The understanding knowledge of home and community based services by health plan and case manager is foreign.
- Sister's experience from other state was that it was very confusing (Ohio).
- Current services on local level are invaluable.
- Ability to navigate system, fragments this navigation.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Great order, collaboration of AZ including individuals with disabilities advocates.
- Great to background checks all professionals working with individuals with disabilities (employees at every level).
- 2 plus staff members required in a room when personal care is being provided.
- Higher level of training education for people that work with individuals with disabilities.
- Better training on mandated reporting and what to look for. Consistent monitored and accountable staff.
- Empathy training for all involved with individuals with disabilities and care givers, DDD staff all every level (skilled nursing, facility, custodial staff, medical doctors, nurses, front office staff, and medical record staff, billing personal).
- Include schools and ADE into executive order.

What does your blue sky look like?

- Family supported not just child (e.g. respite, to clean house so family can spend time with child).
- Better rural community and family activities.
- Being able to have consistent services.
- More local training for advocacy for both caregivers and individuals (advertising through a variety of sources).
- Training on history laws of disabilities (Partners and Policy making) available in more areas throughout the state.
- Sibling support groups

Forum: Parker Date: May 18, 2019 Attendees: 11

What is going well with DDD LTSS?

- 90 Day visits - information and personal approach and communication.
- Answer phone quickly and or returned phone calls.

What needs to be improved?

- No services available in Parker, AZ the closest is Lake Havasu and Havasu is limited.
- Limited internet access to obtain information and application.

What are the solutions for improvement?

- Build a network of providers and services in rural areas.
- More outreach information on: How to start (step by step) tools.
- Limited internet and faxing options.
- Training for families and community members.

What are your thoughts on the Alternate Service Delivery Model?

- Worried that members will choose health plan that does not best fit their individual needs, DDD currently works as 3rd party to inform and connect.
- Concerning to lose current SC.
- DDD SC is there when needed and informative.
- Could increase travel distance to receive services and medical.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Good idea in providing more protection in facilities for individuals with special needs.
- Concern that caretakers don't have much information about individual like when EMT's come in. Medical professionals depend on care taker's input when called in.
- Continued education is very important for care takers in DDD home facilities.

What does your blue sky look like?

- Open communication.
- Support and appicate assistance.
- More training for everyone involved with special needs.
- More training for DDD process.
- Better school and communication with parent.

Forum: Wickenburg Date: May 20, 2019 Attendees: 20

What is going well with DDD LTSS?

- I commend the state of AZ for the best supports for DDD members.
- Transportation, Respite, Transportation to Day program to Surprise.
- Respite for week of at a time.
- Health care took care of balance from what private insurance didn't cover.
- Thankful for ducks in a row supporting community.
- Respite.
- Great SC now
- Respite, HAB, offered socialization 1 on 1 direct care for during summer which was very helpful.
- More access to website, website is consumer friendly, love the new website lots of great info.
- Getter newsletter.
- Can bring family/friend into home to work with my son so family can go out of town.
- Been in AZ since son was 11, son is now an adult and the transition was flawless with DDD.
- Son has had a lot of surgeries, never saw a bill, great insurance.

What needs to be improved?

- SC turnover.
- We the families are training our SC.
- Hard to find providers on website DDD, it does not have current providers list.
- Can't tell when vendor in new or taking new members.
- Transition from child to adult is difficult. We do not know what to ask for (guardianship, DTA, housing options).
- SC did not know answers to all the transition options.
- Miss information regarding GSE.
- 90 day meeting nothing happens in between. Not offered info about Aug com initially until way after the need.
- We need transition for AZIEP to DDD & ALTCS understanding.
- 1st DDD meeting was all paperwork, they did not explain what was happening, and we need more information of what the SC goal is.
- Need to travel to urban area for therapies, can be challenging and frustrating.
- Need ABA out here.
- Qualified for more hours, but no one to provide them.

What are the solutions for improvement?

- Visual, graphic and pamphlets with all services for DDD member and transition options.
- More family training with the community.
- DDD liaison to understand DDD process application, denial, appeals.

- Literature to inform families of services.
- Services need to be local.
- Speech, OT and feeding therapy are not local.
- Encourage getting ABA and other specialized services to come out to Wickenburg a few times a month.
- Wickenburg needs a local SC.
- Survey's on how is SC doing?
- Possibly a 2-3 tiered system for home visits rather than every 90 days, based on need, maybe a phone contact rather than an in person every 90 days.
- Maybe have a checklist on different stages on what families may need, silver tree set up, a special needs trust and have wonderful info to share regarding transition to adulthood.
- Should share information with families, need to start early with transition
- Would like to understand transition from age 3, there is not enough information, it is very confusing to navigate, AZIEP to DDD to ALTECS. There is a lot of paperwork, but little explaining.
- Needs to be more information shared by DDD in the beginning, cannot rely on SC due to high turnover and lack of knowledge.
- Recommend a map for all transitions.
- Webinars to exist parents and sharing of information.

What are your thoughts on the Alternate Service Delivery Model?

- Not enough faith in Health Care Plan to do what is best for the members.
- Need a lot more information.
- What is the benefit of this alt model? -to save money? -better services?
- Seems like a lot to put it all in the same basket.
- Health care plan is about saving money.
- MCO may not give info on services available to save money.
- Conflict of interest x2.
- No one is proposing just having the state DDD do it all?
- Free market will get best option and more vendors.
- Fear of losing providers already hard to find. May narrow our options.
- Makes me uneasy to lose SC who helps me as an advocate.
- Health plans want to save money, Family has a lot of input on what is going on.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Foster care and education taught to not be alone with member.
- More oversight and system of checks and balances.
- Grateful the governor is doing the executive order.
- You should not be alone with members in facilities, not sure how this would work in homes?

What does your blue sky look like?

- Family has a lot of input on what is going on.
- Abundance of services.
- Thankful for day program to go to.
- My son's 22 would like an apartment with his buddies.
- Public awareness of the needs.
- Faith things are improving.
- Happy to have a group of people in the community (advocates) that have been through it.
- Worry goes away.

Forum: Surprise Date: May 21, 2019 Attendees: 16

What is going well with DDD LTSS?

- Nursing, respite, PT, speech, OT, HAB, music therapy, all going well.
- Daughter has a good group home, clean, well rounded activities, VR work in shop.
- Two stable providers one for 21 years.
- Parent can do attendant care.
- Amazing SC x2.
- Good OT, speech person.
- Happy with Agency provide group home.
- Thank you DDD for covering medical cost.
- Agency was on phone with me while interviewing a care provider.
- Love SC.
- Agency rep comes over with person when I meet provider for the first time.
- Services going well, providers are good.

What needs to be improved?

- SC not helpful to family asking for Habilitation.
- Wages for Direct care workers.
- Difficult to find HAB providers, Physical therapy in West valley.
- AZIEP turnover.
- Specialist local in Surprise area are needed (Neurologist).
- Services after age 18 need more therapist.
- Health plan have more contracted dentists need a dentist in the west valley to take DDD health plan.
- Transportation to get family member driven home for visit (group homes).
- More info on Aug Com training in schools.
- SC turnover and pay are a problem.
- Not enough pay SC direct care workers.
- Worried SC reduce HAB hours.
- Need more medical provider's special needs clinics in Avondale and Surprise.

What are the solutions for improvement?

- More options for in clinic therapies.
- Agency allow and opportunity for a phone interview before a direct care provider come out.
- Parent training.
- SC that is vested to do training for new SC.
- More training before SC work with families.
- SC need on-going support.
- Providing list of staff it should be current.
- More pay for SC, direct care worker.

- Every 90 day meeting not necessary for all member (phone calls, FaceTime, DocuSign).
- Interview SC to choose one.
- Health plan need more dentist in Surprise.
- Retirement options for our aging community.
- Good SC to mentor others.

What are your thoughts on the Alternate Service Delivery Model?

- Like having middle man (DDD).
- Who decides if you get services?
- I don't want the alternative model.
- I don't want it to be completely done by health plan. I don't trust them.
- SC is a personal relationship and an advocate and without them it would be harder.
- Stay with what we got.
- MCO advocate for themselves.
- Services might be cut to save money.
- I don't want the one where the case manager is the employee of the health plan.
- SC get to know us and a health plan will not do the same thing.
- We are going to have to fight even harder.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Fingerprint every 6 years is too long.
- Does it include additional funding?
- How do you protect members?
- Putting cameras all around may be senseless because there is always going to be thievery.
- What kind of training do caregivers get?
- Required training to work with members. They don't seem to know, much maybe corners are being cut.
- Wages are too low.
- More children with DD in foster care homes and not in DD homes.
- How do agencies get away with not getting trained?

What does your blue sky look like?

- See my daughter a little more active, given opportunities to go for a walk.
- There is enough money.
- Inclusion in schools, society and the workforce.
- Safe and healthy.
- Not having to jump through hoops for services.
- Community training and understanding of our kids, Awareness.
- Leaders in our country demonstrating the most of accepting of our community.

Forum: Queen Creek Date: May 22, 2019 Attendees: 22

What is going well with DDD LTSS?

- SC come to home and the day program involved in individualized supports.
- Therapies provided in home PT, OT, Speech and feeding.
- Respite and HAB very helpful to have when children in homes, it keeps our kids out of institutions.
- Co pays covered not out of pocket is a relief. Blissful unawareness of billing issues.
- HAB masters was suggested by SC. HAB masters is wonderful for my child see huge improvements.
- SC is parent family focused rather than clinical.
- SC for over 10 years.
- DDD is able to modify status quo to fit the member's needs.

What needs to be improved?

- SC did not provide info regarding services like Hab. 13 years waiting and unsure why SC makes the parents feel like they were asking for too much.
- Need more cohesive approach, consistency, should not be all left to the case workers.
- Shouldn't be like pulling teeth to get what the child needs.
- More transparency with services available, feels like they are hiding services. Transparency with time calculate for HAB/AT hours.
- Not enough therapy providers, waitlist therapy offices are closing (OT, PT).
- No Therapist available that serve over 18.
- 4 SC in one years, we need less turn over with SC Staff.
- Increased options for transportation, clarification of transportation services.
- Inconsistence with information from SC.
- Coolidge office SC supervisors denies HAB for all members.
- Misinformation regarding HAB service provision. Was said by the high needs case manager.
- 90 day meetings too long.
- We need more developmental homes to keep folks out of institutions.
- How to calculate HAB/AT hours some families have 3 others have 19 hours.
- My son was kicked off AHCCCS/ALTCS and the Case Manager could not stop it. The reason was for not applying to SSI, why is member required to apply for something he will not qualify for.
- SC seems to not know what to offer HAB and transportation.
- Appointment times are not convenient. Appointment are now running 3 hours.

What are the solutions for improvement?

- Therapist that service over 18.
- Transition planning assistance.
- Website with all of the service Providers definitions.

- More transparency.
- More parent education.
- More training for HAB providers (teaching strategies) regularly offered.
- Pay more money to HAB workers for attending training (continued education).
- Families should be offered Article 9, maybe webinar for parent that cannot get to class.
- More flexibility with SC appointments that are inconvenient.
- Alternative ways to have 90 days meeting.
- Keep meetings with alternative ways to do reviews such as phone calls or video.
- ABA through insurance and DDD do not coordinate with each other. Providers should coordinate ADA services after age 5.
- Raise provider wages.
- All agencies should pay the same, make it more consistency.
- Make sure SC clarifies with family language preference.
- All classes direct care workers take should be offered to families.
- Less turn over in SC.
- Need transportation to therapies.
- Maybe a portal to put in information ahead of time so the meeting is not so long.

What are your thoughts on the Alternate Service Delivery Model?

- Concerned about SC conflict of interest. Interested in saving the health plan money.
- Concerned that the Diagnosis will pigeon hole the services, not individualized.
- If it's based on a health care model, when will the person ever be cured? My child will never cured.
- Less autonomy.
- Worried that the insurance company will be more difficult to work with and disagree.
- I guess we would need to hire an attorney.
- Frustrated with how long the insurance plan he is on now took to provide wheelchair.
- Network is already challenged.
- Insurance company is trying to make a profit, DDD does not.
- We need more information, this feels overwhelming.
- I am worried I won't be able to recruit my own providers.
- This should be decision made by families not a big business.
- Feel this model could lead us into more institutionalization.
- Already difficult to navigate multiple health plans worried that this would be too confusing.
- Think this will be a conflict, need to be a 3rd party non bias like DDD to determine what is best for the member.
- Will be pigeon hole us when you go to the Doctor, especially with Autism
- Health plan is huge, you will get lost.

- "You have been on this long enough" or they are going to say "you are not rehabilitatable".
- Providers are closing shop due to low reimbursement rate. Will be paid even less if MCO takes over.
- I don't think I like it.
- Feels like health plan will fight with primary insurance and getting services will take longer, hard enough to coordinate now, delayed, and may get worse.
- Which state are we copying?

Executive order: What are your solutions to enhancing protections for individuals with disability?

- 24 hour access to families at any.
- Pay high.
- Incentivizing pedophiles when wages are too low.
- Automatic background checks every 1 to 2 years.
- Keep people in small community based facilities in all areas with high level care.
- Why hasn't this been investigated before?
- I am worried about safe option for my family.
- Finally....
- Executive order is finally bringing everyone to the table.
- Cameras and video surveillance.
- Need other options for our children as they age out.
- Continue on the Executive order committees not just thought November.
- Why can't we get our family member into homes such as group homes and child and adult development homes?

What does your blue sky look like?

- Well trained HAB provider.
- Jobs competitive training.
- Adult transition out of school.
- Employers should have more options for money at subminimum wage.
- More employers for work options, coordinated staffing including training specific to disability.
- More counselors with nonverbal expert providers.
- More eligibility options (broader).
- More info regrading diagnosis practitioners with experience with diagnosing.
- More folks than PCH with development pediatrics.
- Jobs at Marc Center.
- Special Needs boys' scouts troop Westwood LOS building.

Forum: Fountain Hills Date: May 23, 2019 Attendees:

What is going well with DDD LTSS?

- No waiting list.
- Like all services available (respite, HAB, ATT, day treatment, center base employment).
- Wonderful employment support.
- Employment supported aide.
- DDD employees help with housing IDLA (Megan, Barbi, Tonya) have been wonderful.
- Very happy with Mercy Care.

What needs to be improved?

- Transparency of services available.
- SC turnover.
- Feeling like the family has to justify for services.
- When a family has a problem to post 90 day review (would not give family flexibility).
- SC not responding to e-mails or phone calls.
- Lack of providers in Fountain Hills PT, Respite, HAB, family recruiting their own providers.
- Summer Day Treatment not available, too far had to create my own (no transportation).
- Dial a ride has changed, used to be individual, now group ride, many location stops.
- Vendor provider call no response.
- Difficulty finding provider.
- Not getting copies of progress reports from providers.
- Family feels CFT and DDD review at the same time are not working together (people cancel then when we do have meetings DDD and RBHA fight).
- SC inconsistency of knowledge.
- SC not proactive.
- SC overloaded with cases.
- No trust or faith in vendor calls.
- Feel like services are a secret.
- Feel like all the work is on her plate.
- Lack of qualified psychologist (list of providers is a failure) not quality Doctors.
- We really need someone who knows what they are doing and worried about the provider network and list that are given to families that are not accurate.

What are the solutions for improvement?

- Provider report cards (references from other parents, BIO, info, background of provider).

- More proactive training about parent training to be proactive, how deal with denials, and appeal process.
- DDD develop a "list serve" for families to opt in and have availability to interact with each other (family group).
- Create an app for the list serve to connect families.
- Video, short and sweet what does a SC do? What does the OT do? etc.
- Mentor for my son a young adult that does not have a disability (Need a non-disabled peer for my son to hang with).
- Classes to keep up with technology, and how to use a smart phone.
- ISP get forms ahead of time to be better prepared to make meeting go by quicker (2 weeks prior).
- Increase funding for better providers (medical) for quality care, quality Dr. (Psychology).

What are your thoughts on the Alternate Service Delivery Model?

- I'm skeptical.
- Insurance company is for profit, DDD is state and not for profit.
- More comfortable with SC thought DDD working with my family.
- What criteria is used to make determination that long term services are necessary?
- Will we see less services, will they access hours of LTSS the same, what does that look like?
- DDD has a hierarchy and an avenue to pursue if you are not happy.
- Would SC be random with new model or will we get consistency and SC that know the services for unique members?
- Feels like nobody will take insurance would this model have the ability to have Doctors, providers, etc.?
- Would there be a consistency with provider if Insurance changes, can we keep our current doctors.
- Potentially losing appeal rights.
- Experience with Health plan has been challenging in the past.
- Health plan I don't trust to make best decisions for my son (health care motive is money).
- I feel like I am already struggling so this plan would not be too different.
- There would not be the same sense of dependability.
- Long term care, how do you take that model difference between acute care and social services?
- Not sure if all under one umbrella gives you protections.
- Coordinating benefits has been difficult with Health Plan.
- What if your provider you have been working with for a long time does not have a contract with the health plan?
- Have other states done this?
- Concerned arbitrary decisions will be made.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Recognize signs of potential abuse.
- Training our members and families about sexuality.
- Group homes, there is a fine line of reporting every little thing (Maybe be able to discuss thing and it not be escalated to an incident report) Advocate, Mediator, HR, Consultant to talk to.
- Parent to know and understand incident reports and the process.
- Teach our members about abuse.

What does your blue sky look like?

- Transportation.
- Social groups for our members.
- As maximized independence.
- I wish I could read my son's mind (to know what he is thinking).
- A girlfriend for my son.
- Want my son to be normal, to behave, to be healthy, to communicate, to be part of the family, to get along with everyone.

Forum: Salt River Pima Community Date: May 28, 2019 Attendees: 6

What is going well with DDD LTSS?

- Very good case manager.
- Day treatment program, DTA, respite, HAB, speech therapy, going well.
- Case manager comes to the house every 90 days.
- HAB going well with family member because wife is doing it.
- Found Primary care and dentist.
- Good services with affinity.
- RSK helped with guardianship info and process.

What needs to be improved?

- Losing music therapy.
- Intake for DDD ALTCS took 6 months.
- No assistance in navigating DDD system.
- Members DTA was not following ISP and family had to remove him, DTA did not have a quiet area to accommodate the member.
- Turn over experience five SC in 1 year.
- Not proper training for new SC.
- Unable to find psychiatrist who accepts Medicaid and unable to find CBA/ABA for 28 year old.
- Had issues with VR, SC not returning calls, and VR showing up late to son's interview.
- Shortage of HAB providers in Phoenix South Mountain.
- Resources I have found are private pay.
- Not enough social opportunities of individuals with autism.
- System need to be prepared for amount of children aging out of school.
- Lack of in home providers, therapies, RES, HAB in the Salt River Pima community area.

What are the solutions for improvement?

- Identify and build legal aid assistance for parents of adult children with disabilities.
- More therapy HAB respite providers in, South Mountain Phoenix (Salt River Pima).
- Digital medical records that can be uploaded without having to complete paper work.
- Reaching out more to American Indian communities to help educate.
- More orientation for new existing families in DDD.

What are your thoughts on the Alternate Service Delivery Model?

- Do not like alternative option because there would be more "red tape".
- Wants SC with DDD.
- Experience with health plan is that they are not responsive.

- Not work because insurance are for profit entities.
- Individuals have little leverage with insurance plans.
- Insurance companies don't care about DDD mission statement.
- If you take the legal and legislative aspect out of the equation it makes it a purely profit making enterprise
- Concerns about prior authorization and accessibility to services and to reach the health plan for these services.
- Insurance companies squeeze the providers and put financial stress on the providers can be a slow to pay.
- Prior authorization through the insurance would be a shorter period of services.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Anything new that needs to be required needs to be fully funded and there is political power that will to enforce it.
- Two staff at one time for consumers that live in long term care facilities.
- Need to be regular and monitored oversight.
- Once a company loses their contract, they should not be allowed to reopen under a different name.

What does your blue sky look like?

- My son lives a 1st place has a job takes public transport to his job, attends art day programs and comes visit mom and dad every once in a while (INDEPENDENCE).
- Grandson would communicate more easily and everyone would understand him, no more seizures.
- College graduation.
- Child is able to express thanks of support of siblings.
- Get more sleep when he is on a high cycle.
- Earlier diagnosis to allow earlier intervention.

Forum: Avondale Date: May 29, 2019 Attendees: 8

What is going well with DDD LTSS?

- Everything fell into place (attendant care, Vocational, elementary, high school).
- Majority of consumers live in the community and receive their services there.
- 99% of interaction with DDD People genuinely care and the DDD service is there to help.
- AZ does it more effectively, cost efficiently, at low cost per capita without a wait list.
- Nobody does it better than AZ.
- We do not have Medicaid only providers you have a choice of the best providers.
- United Cerebral Palsy voted AZ number one for multiple years in a row.

What needs to be improved?

- More providers (speech, PT, OT) Respite/Attendant HAB far East and West Valley.
- Better consistency in SC.
- Better communicating needed from DDD professionals.
- High turnover in DDD coordinators.
- ISP process too long and not age appropriate.
- ISP focus needs to change, has turned paper rather than a life plan. DDD needs a culture change. The ISP is not to fill out paper work, there needs to be a paradigm change to focus on life plan.
- Families experience inaccurate information.
- DDD is too soiled and prevents personal responsibility.
- Timely responsiveness to messages from SC.
- DDD needs to understand that they are an MCO that contract to 3 health plans and buck stops at DDD.
- Training for coordinators and families to understand what services are out there
- Families need to understand that services are government funded and that they have a responsibility.
- Families need to be ready with a complete need and resource assessment for meeting with coordinators.
- It is up to the families to not abuse the resource available.
- There are good SC and not so good ones.
- Frequency of ISP two time a year is fine.
- Nothing in Behavioral Health is available including anyone that will take private pay.
- We need more network providers.

What are the solutions for improvement?

- Time for AZ to no longer have ICF, AZ is able to provide everything at home or in the community.

- ISP as needed, requested. To have 90 days for some families and options for 6 months for others.
- Create defined service levels agreement.
- DDD needs to behave like and AHCCSS MCO.
- Training for family for the roles and responsibilities regarding services.
- More training for DDD coordinators.
- Better communication.
- Address DDD SC attrition, pay more money.
- Survey DDD SC leaving and why.
- Provide DDD coordinators electronics to access records (electronic record system).
- SC should have an expectation to return calls timely such as within 24 hours.

What are your thoughts on the Alternate Service Delivery Model?

- Feel that SC with health plan may cause a conflict of interest due to the cost, feel health plan would decrease service to keep cost down.
- Concerns about services being approved (State or DDD have oversight and would need to mandate certain level of service) would have to be carefully regulated.
- The overhead for DDD to provide LTSS through a provider network, is less than the DDD health plan. Admin cost are less with DDD which allows more money to be spent on service.
- Through value based purchasing insurance may have better rates for provision of services, DDD does not get discretion on what they pay.
- Question about what experience insurance plans have with providing these support services to the DDD population?
- Would families have an option of either program?
- Unique model.
- The second model could address the turnover of SC, better pay and benefits, and be paperless.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Hold provider and professional accountable.
- Cultural shift of advocacy.
- Needs to be more oversight when a consumer is living outside the home.
- Standard policy in place where one providers is not alone with consumer.
- Agencies in charge of oversight need to be held responsible (where female patient not to be left alone with male).
- Citizens of AZ have a responsibility to be accountable for each other. Everyone deserves the right to dignity and kindness.
- Parents need to be proactive.
- The community needs to be more aware.
- Gain visibility through executive order and encourage advocacy.

- Someone, or outside agency needs to go in and get eyes on member that are vulnerable, we need more oversight, we need advocacy on the inside too.
- We have an obligation as a community to protect our folks.
- Need professional oversight.

What does your blue sky look like?

- Medical advances to improve medical conditions.
- State agencies that we can trust.
- Quality support services available.
- Legislation fully funded services and supports.
- Innovation to help everyone reach their full potential.
- Breakdown ... so that consumers can access any provider that they choose.
- Access to treatment for all.
- Healthcare is a right.
- Reasonable behavioral health services.

Forum: Sacaton Date: May 30, 2019 Attendees: 6

What is going well with DDD LTSS?

- Services are good.
- Speech PT going well.
- E-scripts.
- Large information packet with doctor and specialist don't have to go online for the specialist.
- Good information from support coordinator about changing size of diapers.

What needs to be improved?

- More options for OT in the area (Gila River Indian Reservation).
- Health plan is unable to provide sufficient transportation.
- Need physician on contract in the Gila River community that can diagnosis Autism that will accepted by DDD.
- Use laymen terms and not acronyms.

What are the solutions for improvement?

- Health plan should be contracted with Indian Health Service AHCCCS.
- Registered transportation provider's tribal transportation.
- Having translators that speak Native American languages.
- More private facilities more doctors, specialist needed for hearing on reservation.
- Recommend a physician on contract that can diagnosis Autism on reservation that DDD will accept.

What are your thoughts on the Alternate Service Delivery Model?

- Makes it easier to have everything under one plan.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- Having a smaller group of designated specific staff working with consumers.
- Be responsible and accountable for the people your caring for.
- Cameras should be installed in special common places even if they do have cameras who is watching.
- More monitoring.
- Transportation: using only one type of transportation service and one particular driver to transport consumer.
- Go out and see physicians rather than care given in the facility.

What does your blue sky look like?

- A whole month of myself.
- Not having to struggle with everything.
- Keep up with supply and demand.
- Someone to come do my laundry.

- Get paid for being a parent.
- Having a babysitter with still having respite.
- More recreational activities t-ball league.
- Bring Special Olympics to Sacaton

Forum: 1st WebEx Date: 2019 Attendees: 1

What is going well with DDD LTSS?

- DDD continued support we receive.
- New HAB program more tailored individually.
- Aug com program.
- DTA support improves quality of life.
- Summer programs.

What needs to be improved?

- None

What are the solutions for improvement?

- Raise the amount agencies are given allotment for provider agency.
- More pay for caregivers.

What are your thoughts on the Alternate Service Delivery Model?

- DDD looks out for the best of the member.
- Does not want to see current DDD program change.
- Feels like a for-profit for Insurance Company would not be good for members.
- Right now we have the governor to complain too, that would not work with the health plan handling everything.
- All about profit.
- Insurance company are for profit, saving money not good for members.
- This model would not be based on the member's best interest.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- We go through several checks already.
- Over reaction may be over board and not stop this from happening again.
- Staffing 2-1 but may be too expensive for agencies.
- The training and members would be a great consideration.
- I was appalled with the news so I think it is a good start to help prevent actions like this in the future.

What does your blue sky look like?

- Everyone loves and accepts everyone.

Forum: 2nd WebEx Date: 2019 Attendees: 18

What is going well with DDD LTSS?

- Working well doing the care with my daughter myself, she is getting the care I know she needs (ATT).
- Like the respite (for me to rest).
- The respite and HAB hours I currently receive are tremendously helpful.
- Lots of services due to DDD when he was born he was not supposed to live more than one year, he was diagnosed with rare disorder, born normal, virus triggered genetic disorder, he is now 17 year old 6'2" with a sense of humor, eats, drinks, walks, now thanks to all the various therapies, care and preventative he got thanks to DDD.
- Things are going well with services for my daughter (respite) she is 12 years old and meets all her goals.
- Currently SC is great and advocate to I hope to keep her because she is so knowledgeable.
- Satisfied with the service for my 25 year old daughter.
- You cannot put people in a box or make them fit a check list. If we had been in a box, our son would not have made such stride.
- Extremely happy with Respite, very helpful for their life.

What needs to be improved?

- Get music therapy back.
- ISP meeting are very long.
- Our services seem consistent, but other families have more needs, we could free up our 90 day visits so SC has more time to meet with other more needy families x3.
- Turnover rate is too high.
- Shortage of SC.
- Finding district nurse is hard, kids need consistency (North Phoenix, Scottsdale)
- We lost our HAB and AC providers.
- Worried that at every 90 day services can be taken away.
- Do not benefit from meeting every 90 days.

What are the solutions for improvement?

- AZ to offer an Article 9 class to help sibling and other family members better understand disabilities.
- Increase pay for nurse.
- HAB and ATT Care providers need more pay.
- Merit based pay.
- Individual service providers should not have to pay for training, CPR, DCW, fingerprinting out of their own pocket.
- Consistency in all things will help all in life, all providers will create success.
- We should not have a SC from another city come to our home when there is a local SC (zip codes changes?).

- Form used during 90 day review meeting is redundant.
- We need music therapy.
- Families should have the ability to choose the level of contact from their SC other families have more needs, we could free up our 90 day visits so SC has more time to meet with other more needy families x3.

What are your thoughts on the Alternate Service Delivery Model?

- Without the SC of DDD we would not know all the services available. Worried about not having DDD.
- Concerns that the issue when certain providers will no longer accept Insurance we have that our existing and good providers will not contract.
- Limited to just health plan that could limit our resources.
- I can see this effecting all our services.
- What impact will this have on doctors limiting our services?
- This is confusing DDD role.
- Who would have oversight on what benefits are needed per member?
- Entirely up to Insurance company to proactively offer services (don't trust that)
- DDD SC is the one that tells us what available Insurance is are not forthcoming with services available (especially for new members).
- Behavior therapy in looking and trying to navigate with the insurance they were not helpful (in regards to the Autism providers) as the SC was able to better assist.
- Health plan may not know or offer services.
- Limited services, I see it getting hard for families to get what they need.
- Insurance is out to get money, its fight with insurance company. What will the appeal process be?
- We are fighting for our kids all the time constantly so to deal with an Insurance over the phone seems cold. SC is so personal and helpful to our families x4.
- What are benefits of alternative model? Why is DDD considering this?
- We will lose personal connection with vendor agencies that help us?
- Would rather DDD to continue to provide SC not a behemoth health plan. I am not for this model.
- Who will take over Day Programs? Will the insurance have DTA, DTS programs?
- I work close with Insurance they do not look at individuals it is an algorithm (cost vs care).
- DDD SC to continue to do SC not oversight.
- The impact on the health plan will be allowed to bill, will folks not agree on contract, will we be limited in choosing service?
- Health plan will not tell you what is available, also limited to only contractors that will accept their health coverage, make it difficult to get the services people need
- What will happen to the qualified vendors?
- Difficult to navigate therapies with health plans, they don't know our children and their needs, are not familiar with children on the spectrum or with trauma issues, we get leads form DDD SC.

- DDD SC has a better understanding in what direction to point to regarding community resources.
- SC acts as an advocate, DDD is one of the supports. I feel like an alt model will make people less secure. Health plan would be distant.

Executive order: What are your solutions to enhancing protections for individuals with disability?

- If we got to the alt model who would be responsible for the care to members. How could this compromise going from DDD to Health plan?
- How are we choosing groups to collaborate in the executive order?

What does your blue sky look like?

- No limits to services, well paid providers, no providers or Doctors can say "no we are not contracted with your insurance."
- All agencies schools, police be trained with all disabilities (start in school).
- Job, community opportunities for my son.
- More community bases local support programs, special Olympics etc.
- Everyone fully integrated (no specific to disability) just all integrated.