We are Jamie and Natalie Gunnells. We live in Tupelo and are owners of two businesses that collectively employ 20 plus citizens. (Mississippi Senior Care and Chilly Willy Hawaiian Shave Ice) Our written comments have questions, concerns with lack of transparency, and recommendations in regards to **the IDD/DD Medicaid Waiver 2023 proposal.**

Our son, Xxxxxx, has been on the IDD/DD Medicaid Waiver since 2001. He has a rare genetic disorder, 5P-. He is mentally challenged and severely autistic. He has an ICAP score of 4/5 and is total care.

Xxxxxx xxxxxx Medicaid # xxxxxxxx

He and hundred’s like him are **languishing** in the IDD Medicaid Waiver without a caregiver (direct support professional-DSP) for years. For Xxxxxx, it has been **seven** **years.**  There is a national caregiver crisis shortage which began before covid-19 and is expected to continue.

The IDD/DD program states it is designed to **offer assistance and services** in a home or community-based setting for those who meet the criteria and qualify for Medicaid. It goes on to state the program allows persons **to receive services and supports** in their home as an alternative to intermediate care facility for individuals with intellectual disabilities.(ICF/IID)

Data proves that the home is the least restrictive environment for these adults. It saves the State millions of dollars per year not having to institutionalize them.

For 100’s like Xxxxxx on the IDD/DD program who are allocated in home respite or HCS respite the program has failed them for years. Why has DMH and Medicaid for years turned a blind eye to reforming the respite programs?

IDD/DD Medicaid Waiver allocated $50K-75K in services/supports for Xxxxxx each of the last seven years yet he has not received them. If Xxxxxx were placed in Behavioral Supervised Living it would cost the State $173,352 per year. Where has Xxxxxx’s unused allocated funds been reallocated too?

Autism is mentioned only two times (page 20 and 35) in the 2023 IDD Medicaid Waiver proposal. This waiver is not designed to meet the specialized needs of the autistic community.

The following questions were submitted Jan 3, 2023 to Medicaid by a sitting State Senator. He has repeatedly followed up with no response from Medicaid. These questions were also submitted by a sitting State House Representative and Head of Medicaid committee/representative and they have followed up with no response from Medicaid. The lack of transparency and accountability is concerning.

* The total number of people in the IDD Medicaid waiver program who have a diagnosis of Autism and of those how many have an Inventory for Client and Agency Planning Assessment (ICAP) score of 4 or 5.
* The total number of people in the IDD Medicaid waiver who have an (ICAP) Score of 4 and 5.
* How many of the 2806 individuals on the IDD Medicaid waiver waiting list have a diagnosis of Autism?
* How many individuals currently in the IDD waiver program qualify for in home respite?
* Home and community support respite?

**There must be a Bureau of Autism Services** that would employ specialists who would then inform other agencies, including Medicaid, about **the infrastructure required to serve the** **autistic population**.

According to Medicaid.ms.gov., Autism Spectrum Disorder Services end at age 20. Because MS does not have an Autism Bureau to balance the needs and services, no reliable data is even available to calculate the number of adults with ASD and the anticipated growth.

MS is 43rd in the provision of services to people with ASD.

The model states include: Colorado, NY, NJ, PA, and Connecticut.

1 in 44 children born in the US were identified with ASD estimates from the CDC’s Autism and Developmental Disabilities Monitoring Network.

It is the #1 diagnosed developmental disorder.

Last year there were 1,000 births in MS that will be autistic.

Our son, Xxxxxx, lost much needed services (Adult Day Services) because of decisions made by unqualified directors that do not have the specialized qualifications to understand his unique needs as well as they didn’t follow the waiver’s policies. This is addressed in more detail with supporting facts and evidence below.

Medicaid has not raised the caregiver (Direct Support Professional) hourly rate since the early 1980’s? Before Covid-19 our State lacked enough agencies that hired DSP. Since covid-19 many agencies have left the State never to return. The remaining agencies cannot get applicants at job fairs or through advertising because of the low hourly wage. Chi fil A in Tupelo starting pay for full time employees is $19 per hour. Mississippi has the lowest projected future job total (2,200) and the second lowest hourly wage in the country.

The DSP hourly wage should be higher when caring for an adult on the moderate to severe autism level.

MS IDD waiver Fee Schedule for Behavior Supervised Living:

$466 per day

The Governor appoints the DMH Board. Does any member on this board have a child with severe disabilities?

Reading through the IDD/DD Medicaid Waiver proposal; the DMH Operational Standards for Mental Health, I/DD and Substance Abuse; and the DMH Record Guide for Mental Health, IDD, and Substance Use Disorders Community Providers, **I found almost every policy that would pertain to the oversight of Xxxxxx’s care to have been repeatedly ignored; lack of oversight and accountability; lack of monitoring; lack of safeguards; no checks and balances…..from the Support Coordinator to the BIDD.**

Black print: 2023 IDD Medicaid Waiver Proposal

Blue print: My written comments

Yellow highlighted: Utilization reporting

Changes the waiver should immediately implement are……

 **Appendix C: Participant Services C-1/C-3: Service Specification**

Page 43 **Day Habilitation**

Page 44 “Be integrated in and supports full access”

“People who require one-on-one assistance must be offered the opportunity to participate in all activities, including those offered on site and in the community.”

 **Adult day habs lack the infrastructure required to serve the** **autistic population.**

Moderate to severely autistic adults who required a one-on-one in their IEP, the entire school day, to access and participate in this environment, should be allowed a one-on-one person trained by Behavior Supports to access Day Hab per the stated policy. My son was not allowed a one on one support person therefore he could not access the Day Hab. My son also had a one on one RBT when he attended The Autism Center for 30 hours per week.

There was dialogue between Betty Pinion, Matthew Gordon, Andrew Day and others from July 30, 2020-Sept. 29, 2020 in Support Coordinators Service Notes.

Sept 9th, 2020 Matthew Gordon stated, “What one on one training is she referring too? I see that she currently receives 120 hr/month of HCS, 31 hr/month of DSA(at the highest support level for that service, and it could easily be increased), and 30 hr/mon of Behavior Supports. What exactly is she wanting? ……….one on one is probably not going to happen. The provider is not reimbursed for that level of care.

Finally, it was determined just to tell Mrs. Gunnells. “The service was not designed for one-on-one staffing.” This decision is not what is stated policy in the IDD waiver.

 Mr. Gordon and all the professionals making the decisions didn’t refer to the UTI report where Xxxxxx was allocated 120 hours of respite per month but had not had for 5 ½ years! Also, did anyone making this critical decision have any expertise and credentials with the severely autistic population?

Was this denial of one on one support important enough that it rose to the level of remediation? This decision prohibited Xxxxxx from access adult day hab.

Was the fact that Xxxxxx had been without a caregiver for several years before the decision was made to not allow him a one on one to attend day hab on anyone’s radar? Had these issues been identified during the BIDD’s monitoring process per Monitoring Safeguards page 119-121?

**Appendix C: Participant Services C-1/C-3: Provider Specifications for Service**

Page 45 **in Home Respite-Caregiver Support**

Page 47 “Specify whether the service may be provided by…..Legal Guardian.”

Page 46 “In-Home Respite cannot be provided in the provider’s residence.”

Many individuals with severe disabilities (ICAP score 4/5) are homebound and cannot access activities and community outings.

There was a caregiver crisis before Covid. Caregivers are almost nonexistent to the severe individuals with an ICAP score of 4 or 5 and severe autism. Adults with severe disabilities are most likely being cared for by their guardian. Parents who are caring for adults with severe disabilities and qualify for In Home Respite have languished for years without much needed respite.

**Please allow the legal guardian to be the individual’s caregiver. Please allow In Home Respite services to be provided in the provider’s residence if the provider is the parent/legal guardian**.

A Medicaid waiver is a provision in Medicaid whose intention is to allow individual states to accomplish certain goals, such as reducing costs, expanding coverage, or improving care for a “**certain target group**” i.e., the IDD Medicaid waiver

1. The IDD Medicaid waiver is the only waiver that is specific to Intellectual Disability.  Caring for these individuals requires a guardianship unlike the other four Medicaid waivers.   Guardianship is the foundation for caring for someone who has an intellectually disability.
2. If one qualifies for the Independent Living Waiver; Elderly & Disabled Waiver; Assisted Living Waiver; and the Brain/Spinal Cord Injury Waiver, these individual most likely are in their competent mind and do not require a legal guardianship.
3. Putting all five waivers under this one policy does not improve care for the individuals in the IDD waiver.
4. The national caregiver shortage preceded Covid and is predicted to continue.
5. Mississippi has the lowest projected future job total (2,200) and the second lowest hourly wage.  The recent requirement that all agencies pay an hourly wage of $12 to DSP, made little to no impact.  REM agency was already paying this rate with little to no qualified applicants.
6. If there were data on the individuals in the IDD waiver program regarding guardianship, I would almost guarantee that the guardians were parent(s) or sibling.  If they don’t have guardianship, then most likely they can’t afford the attorney fees.
7. Most likely the guardian providing care for the adult in the IDD Medicaid waiver is a parent(s) or sibling who has cared for this individual since birth.  By the time this adult with IDD is grown there is no other adult in the home except the guardian.
8. Fraud was brought up as a concern by Mr. Cody Smith (policy attorney Medicaid).  Anytime the government undertakes to provide services for the masses i.e... Free school lunch; WIC; Medicaid waivers, etc., there is always going to be a risk of fraud.  Government agencies always plan a certain percentage of any program will be fraudulent.   Fraud is endemic in **all** public programs.  It makes no sense to exclude the legal guardian from being the paid caregiver of their adult with IDD because of fraud.  The agency employing the guardian is responsible for monitoring potential fraud.
9. There is no data that supports paying parents to be caregivers will lead to fraud.  You can’t go on a gut feeling about this.   In fact, there should be less fraud.  If an individual is allowed a certain number of respite hours, it would be hard for a parent to clock in more.  Again, the assisting agency is tasked with enforcing this.
10. The DMH and Medicaid doesn’t enforce its own fraud policy in regards to the Utilization reporting. Evidence stated in the comments.

https://nashp.org/state-approaches-to-reimbursing-family-caregivers-of-children-and-youth-with-special-health-care-needs-through-medicaid/

**Appendix C: Participant Services C-1/C-3: Service Specification**

Page 55 **Support Coordination/Case Management**

Page 57 **Service Definition: Support Coordination activities include**:

 Page 57 “Information about the individual’s satisfaction with current service(s) and provider’s(s) (IDD/DD waiver and others)”

What does the Support Coordinator (SC) do when the guardian reports continual dissatisfaction every month for years that they need a caregiver? From January 2020-present, I expressed over 30 times to SC about needing a caregiver. Please refer to SC Service Notes. This is just a brief outline….

Pull SC Service Notes even as far back as 2017.

Support Coordinator’s Service Notes as follows:

1/17/20 “She voiced frustration that she cannot find anyone who is equipped to work with someone who has autism. She is having a hard time finding someone to come and work the hours. Mrs. Gunnells said they do not have any relatives that could do the hours.”

5/22/20 Rem not looking for caregiver due to Covid 19. Mrs. Gunnells remains frustrated.

7/17/20 Mrs. Gunnells expressed frustration that they have not been able to find a caregiver for Xxxxxx. She said they have gone through Millcreek, Lilly Pad, and Brandi’s Hope. She said the system has failed Xxxxxx.

10/20 Xxxxxx has a caregiver. (For the next 9 months Xxxxxx’s caregiver was his one on one RBT at The Autism Center. Shortly after Covid 19 hit, she left The Autism Center to come be Xxxxxx’s caregiver. This was the last and only caregiver that Xxxxxx ever had that was trained in working with Autistic individuals. She became pregnant shortly after starting and quit before the baby was born.)

1/26/21 Caregiver is pregnant, need a second caregiver.

2/12/21 Mrs. Gunnells makes a Facebook post about needing a caregiver.

3/16/21 Mrs. Gunnells request overnight respite.

4/7/21 Caregiver plans to take off before the birth in July. Need a backup caregiver.

5/21/21 Still need a backup caregiver and request short term overnight respite for Xxxxxx,

6/16/21 Requested again overnight respite for Xxxxxx.

7/16/21 transitioning to back up caregiver. Transition caregiver would be fired July 20th.

Caregiver out from maternity leave and will not return as caregiver.

8/30/21 New caregiver. Requested information on funding to make room modifications for Xxxxxx.

11/10/21 Caregiver quit to go to another job.

11/21/21 Mrs. Gunnells sends an email to Dr. Edith Hayles about being devastated with the caregiver quitting. Her daughter is getting married Dec. 4th and they need a caregiver desperately. Dr. Hayles had no suggestions except refer back to SC. **We received a referral of a certified teacher with autism credentials in South Haven, MS (approx. 90 miles away) that was able to come the weekend our daughter get married and care for Xxxxxx. It cost us $900 to pay for this specialized care**. **Yet Xxxxxx is allocated $50k-$75K yearly in unavailable services/supports.**

11/21/21 Mrs. Gunnells expresses frustration….”But what about when there are no caregivers? No agency has any…. And there is a crisis…..”

12/15/21 REM has no prospects.

1/19/22 REM has not interviewed any potential caregivers for Xxxxxx. Xxxxxx has not a caregiver in quite some time now. Mrs. Gunnells Request UTI.

1/21/22 Mrs. Gunnells reported over charges on UTI and said it was very concerning.

3/17/22 Request UTI’s Dec ’21-Feb’22 and Jan’21-Sept’21 No caregiver.

4/27/22 No luck finding caregiver.

5/6/22 Kerry Nichols (Assistant Director of NMRC) inquiries about caregiver status. SC gives him the **wrong** information. “SC explained that the 180 hours **are used** per month.”

5/25/22 No caregiver

5/27/22 Betty Penion inquiries about caregiver hours. This was in response to the May 9th Appendix K meeting she attended at our business in Tupelo.

6/23/22 No caregiver.

7/27/22 No caregiver

8/29/22 No caregiver. “All agencies are short staffed. Worried because it may take months to train someone who can take care of someone with severe autism like Xxxxxx. She is stuck and doesn’t know what to do.”

Request UTI reports March to current. Told SC Behavior Services had not been to house.

The guardian needs relief and respite but there is a caregiver shortage/crisis for those caring individual’s with severe disabilities?

**Page 57 “Review of service utilization via a report generated by the State**.”

There needs to be additional training of Support Coordinator in the importance of reviewing UTI report with guardian each month. The Support Coordinator assigned to my son did not review for 3 or more years. I started requesting UTI’s Jan 2022. UTI reporting is mentioned at least 8 times in this waiver.

Page 57 “Ensuring all services an individual receives, regardless of funding source, are coordinated to maximize the benefit and outcome for the individual.”

What about when an individual qualifies for a service (respite) for years and can’t utilize for lack of providers? Who and how does the Support Coordinator notify? How can the Support Coordinator ensure the individual is getting the maximum benefit out of allocated services where there are no providers?

**Page 57 The following items must be addressed during QUARTERLY VISITS:**

“Information about the individual’s satisfaction with current service(s) and provider’s(s) (IDD/DD waiver and others)”

What does the Support Coordinator do when the guardian reports every month for years that they need a caregiver? The guardian needs relief and respite but there is a caregiver shortage/crisis for those caring for individuals with severe disabilities.

Page 57 “Ensuring all services an individual receives, regardless of funding source, are coordinated to maximize the benefit and outcome for the individual.”

What about when an individual qualifies for a service (respite) for years and can’t utilize for lack of providers? Who and how does the Support Coordinator notify? How can the Support Coordinator ensure the individual is getting the maximum benefit out of allocated services where there is no providers/caregivers?

**Page 57 “Review of service utilization via a report generated by the State.”**

There needs to be additional training of Support Coordinator in the importance of reviewing UTI report with guardian each month. The Support Coordinator assigned to my son did not review for 3 years. UTI reporting is mentioned at least eight times in the waiver.

page 57 “Information about the individual’s satisfaction with current service(s) and provider(s) (ID/DD Waiver and others);”

SC was told over 30 times from 1/20-present about needing a caregiver, overnight respite, home modifications, and a one on one to be able to access Adult Day Hab.

Page 57 “Information addressing whether the amount/frequency of service(s) listed on the approved Plan of Services and Supports remains appropriate;

The next question should be are you **receiving** this amount?

Page 57 Ensuring all services an individual receives, regardless of funding source, are coordinated to maximize the benefit and outcome for the individual;”

What about when an individual qualifies for a service (respite) for years and can’t utilize for lack of providers? Who and how does the Support Coordinator notify? How can the Support Coordinator ensure the individual is getting the maximum benefit out of allocated services where there is no providers/caregivers?

**Appendix C: Participant Services C-1/C-3: Service Specification**

Page 78 **Crisis Intervention**

Page 79 2. **Family/Other Issues**

4. “The primary caregiver is in need of relief that cannot be met by other ID/DD Waiver services.”

Crisis Intervention, at its current state, is not able to accommodate individuals with moderate to severe autism. It does not have **the infrastructure required to serve the** **autistic population.**

 Families caring for a severely autistic individual (ICAP 4/5) have languished in the IDD waiver for years without allocated respite due to the shortage of caregivers. These families are needing overnight respite and the current ICF/IID facilities do not have the trained staff required to meet the specialized unique needs of the moderate to severe autistic individuals in this IDD Waiver. The current crisis support staff at NMRC would not be able to provide the Behavior Supports that are needed to care for an individual with severe autism.

I requested 3/16/21 and 6/16/20 overnight respite. We took a tour of the facilities at NMRC and even Dr. Hayles said it was not an environment suitable for individuals like Xxxxxx. They just were not equipped with the staff or facilities suitable for individuals with severe autism.

We would like to request the following data for the last 5 year period:

1. What is the budget for Crisis Support for the last 5 years allocated under this waiver?
2. What was the utilization of this service? How many beds were utilized and by how many different clients?
3. What was the expenditure of the budgeted amount for this service?
4. How many of the clients had an ICAP score of 4/5?
5. How many of those clients had a diagnosis of Autism?

**Appendix C: Participant Services C-1/C-3: Service Spécifications**

**Home and Community Supports-Caregiver Support**

Page 80-81 I. “HCS cannot be provided in the provider’s residence.”

Page 82 “Specify whether the service may be provided by…..Legal Guardian.”

There was a caregiver crisis before Covid-19. Caregivers are almost nonexistent to the individuals with an ICAP score of 4 or 5. Adults with severe disabilities are most likely being cared for by their guardian. Parents who are caring for adults with severe disabilities and qualify for home and community supports have languished for years without much needed respite.

**Please allow the guardian to be the individual’s caregiver. Please allow HCS services to be provided in the provider’s residence if the provider is the parent/legal guardian**.

A Medicaid waiver is a provision in Medicaid whose intention is to allow individual states to accomplish certain goals, such as reducing costs, expanding coverage, or improving care for a “**certain target group**” i.e., the IDD Medicaid waiver

1. The IDD Medicaid waiver is the only waiver that is specific to Intellectual Disability.  Caring for these individuals requires a guardianship unlike the other four Medicaid waivers.   Guardianship is the foundation for caring for someone who has an intellectually disability.
2. If one qualifies for the Independent Living Waiver; Elderly & Disabled Waiver; Assisted Living Waiver; and the Brain/Spinal Cord Injury Waiver, these individual most likely are in their competent mind and do not require a legal guardianship.
3. Putting all five waivers under this one policy does not improve care for the individuals in the IDD waiver.
4. The national caregiver shortage preceded Covid and is predicted to continue.
5. Mississippi has the lowest projected future job total (2,200) and the second lowest hourly wage.  The recent requirement that all agencies pay an hourly wage of $12 to DSP, made little to no impact.  REM agency was already paying this rate with little to no qualified applicants.
6. If there were data on the individuals in the IDD waiver program regarding guardianship, I would almost guarantee that the guardians were parent(s) or sibling.  If they don’t have guardianship, then most likely they can’t afford the attorney fees.
7. Most likely the guardian providing care for the adult in the IDD Medicaid waiver is a parent(s) or sibling who has cared for this individual since birth.  By the time this adult with IDD is grown there is no other adult in the home except the guardian.
8. Fraud was brought up as a concern by Mr. Cody Smith (policy attorney Medicaid).  Anytime the government undertakes to provide services for the masses i.e... Free school lunch; WIC; Medicaid waivers, etc., there is always going to be a risk of fraud.  Government agencies always plan a certain percentage of any program will be fraudulent.   Fraud is endemic in **all** public programs.  It makes no sense to exclude the legal guardian from being the paid caregiver of their adult with IDD because of fraud.  The agency employing the guardian is responsible for monitoring potential fraud.
9. There is no data that supports paying parents to be caregivers will lead to fraud.  You can’t go on a gut feeling about this.   In fact, there should be less fraud.  If an individual is allowed a certain number of respite hours, it would be hard for a parent to clock in more.  Again, the assisting agency is tasked with enforcing this.
10. The DMH and Medicaid doesn’t enforce its own fraud policy in regards to the Utilization reporting.

https://nashp.org/state-approaches-to-reimbursing-family-caregivers-of-children-and-youth-with-special-health-care-needs-through-medicaid/

**Participant Services** Page 101

**e. Other State Policies Concerning Payment for Waiver Services Furnished by Relatives/Legal Guardians**

**\*\*\* Relatives/legal guardians may be paid for providing waiver services whenever the relative/legal guardian is qualified to provide services as specified in Appendix C-1/C-3.**

**Relatives/legal guardians may be paid for In-home Respite and Home and Community Supports.**

Proof of address for the family member seeking to provide services is required. Proof of address is considered to be a copy of a lease, rental agreement, or utility bill that includes that person’s name. If required documentation cannot be obtained, the family member seeking to provide services must provide a signed and notarized affidavit that includes his/her current address, **evidencing the fact that he/she does not live in the same home as the person receiving services.**

**The bold type states that “legal guardians” may be paid for providing services…………….. Which conflicts with Page 81 Home and community supports and page 45 in home respite caregiver supports.**

**Legal Guardians NEED TO BE ALLOWED to provide in home respite and home and community supports respite IN THE HOME as referenced on pages 45-47 and 81-82.**

 **Family members/legal guardians DO NEED to be allowed to provide respite services in the same home.**

**Appendix C: Participant Services C-4: Additional Limits on Amount of Waiver Services**

PAGE 113 “Each year, before the person’s PSS meeting, he/she and the PSS team are notified of the **individual budget allocation**. Therefore, decisions can be made at the PSS meeting regarding the services and supports that best meet the person’s needs to ensure they remain at home and in the community.”

My son has had the IDD waiver since 2001 and the above has never been done at our PSS meeting. We have never been told our son has an **“individual budget allocation**.”

“The **State ensures** that services will be provided in an amount necessary to meet each person's support needs.”

The State **failed i**n ensuring that my son would receive allocated respite services. In the last 8 years he has had respite for 14 months (three different caregivers). Medicaid has not raised the hourly rate of caregivers (DSP) since the early 1980’S. There was a caregiver crisis before Covid 19. The State **failed** to raise the hourly rate of caregivers and have failed 100’s of individuals on the IDD waiver needing respite.

**APPENDIX D : Participant-Centered Planning and Service Delivery (3 of 8) (4 of 8) (5 of 8) (6 of 8) (7 of 8) (8 of 8) CANNOT BE IMPLEMENTED OR ENFORCED UNLESS SERVICES AND SUPPORTS ARE AVAILABLE AND UTILIZED. 100’S OF INDIVIDUALS HAVE BEEN WITHOUT ALLOCATED RESPITE FOR YEARS.**

**Page 115 Appendix D: Participant-Centered Planning and Service Delivery**

**D-1: Service Plan Development (3 of 8)**

Each person is meaningfully and actively engaged in the development and maintenance of the PSS in several ways. The person, either alone or with assistance from a chosen representative, chooses the individuals he/she would like to have attend the development/review of the PSS. It is held at a time and place convenient for the person. The person, through the person centered planning process, determines the outcomes he/she would like to happen as a result of receiving ID/DD Waiver services and supports. Additionally, he/she requests the types and amounts of service(s) he/she would like to receive within his/**her Individual Support Budget**, as well as the provider(s) he/she would like to have render the services.

**Individual Support Budget—what is this? My son has been on the waiver since 2001 and this is the first time I have seen or heard about this.**

**What happens to the Individual Budget when services and supports are not available? What happens to the individual’s budget when they have been allocated respite for years and is hasn’t been provided due to lack of providers/caregivers?**

**Appendix D: Participant-Centered Planning and Service Delivery**

 **D-1: Service Plan Development (4 of 8)**

**Page 116** Support Coordinators are also required to inquire about each person’s healthcare needs and any changes in such during monthly and quarterly contacts.

Additionally, the Division of Medicaid provides a Monthly Utilization Report to Support Coordinators that lists all Medicaid services a person receives each month.

 The report has a lag time of two (2) months. This is one (1) tool the Support Coordinator can use to determine if the person has been to the doctor, been hospitalized, or changed medications.

Healthcare needs are also addressed with providers. Providers are contacted as part of quarterly contact documentation to ascertain how their services are assisting the person in meeting stated outcomes.

How does this policy work when there’s been a caregiver shortage years before Covid-19?

One of the questions is to review any changes in a person’s health status.

(e) The coordination of waiver and other services is a constant activity for Support Coordinators. Through at least monthly contacts, the Support Coordinator is able to determine which services are being utilized, what new services may be needed, and what services may need to be reviewed to determine if the provider is supporting stated outcomes in the PSS.

How can providers provide caregivers when individuals will not care for our most vulnerable for $8-10 per hour? This policy can’t be followed when the State fails to recognize and address the caregiver shortage.

Through at least quarterly face-to- face contacts in the person’s service setting(s) Support Coordinators are able to observe the person, talk with him/her and talk with provider staff to ensure all services he/she receives are adequate and appropriate to support outcomes in the PSS.

Again, this policy can’t be followed when the State fails to recognize and address the caregiver shortage.

 (f**) page 117 The Support Coordinator is responsible for ensuring all services are implemented** as approved on the person’s PSS. This is accomplished through monitoring service provision during monthly phone contacts, on-site and face-to-face visits, and **Monthly Utilization Reports** from Medicaid.

The above highlighted statements were not done or are not being done by our SC for years. These policies are not being enforced or monitored. Please refer to SC Service Notes which also are not being monitored or reviewed.

**Appendix D: Participant-Centered Planning and Service Delivery**

**D-1: Service Plan Development (5 of 8) page 117**

**e. Risk Assessment and Mitigation**

Support Coordinators must, in conjunction with the person and his/her service providers, complete the Risk Assessment Tool annually at the PSS meeting. The tool identifies risks and mitigation strategies. The Risk Assessment Tool is completed by the Support Coordinator with input from the person, others important to the person and all providers. The information gathered is included in the PSS.

Any needed back up arrangements are discussed during the development of the Plan of Services and Supports. Types of back up arrangements include: emergency contact information for staff; provider arrangements for an additional staff person if the regularly scheduled one cannot be present; natural supports including families, neighbors and friends; use of generators in case of power outages if the person requires electricity powered medical devices; other individually tailored arrangements, depending on each person’s identified risks.

**How can an effective risk assessment be made when there are no providers or caregivers? We are in a caregiver crisis with the State turning a blind eye. Does the SC just ignore the elephant in the room and make up backup arrangements? How can providers provide additional staff for back up emergencies when they can’t provide staff initially? 100’s on the IDD waiver have languished without a caregiver for years. What is their risk assessment?**

**Mitigation: the action of reducing the severity, seriousness, or painfulness of something.**

 **How does a SC mitigate the severity, seriousness, or painfulness of no caregivers when an individual’s family has languished for years without one? How does a SC make a backup plan when existing allocated services aren’t being provided due to a caregiver shortage crises?**

**Appendix D: Participant-Centered Planning and Service Delivery**

 **D-1: Service Plan Development (6 of 8) page 117**

 **f. Informed Choice of Providers**. Describe how participants are assisted in obtaining information about and selecting from among qualified providers of the waiver services in the service plan.

 Support Coordinators provide people with a list of certified providers for the service(s) they are requesting on their Plan of Services and Supports.

There is a caregiver shortage. This was years before Covid-19. Handing the individual a list of qualified providers that have stopped trying to recruit and hire caregivers years ago because they know that the hourly rate will not attract and keep quality caregivers.

**Appendix D: Participant-Centered Planning and Service Delivery**

**D-2: Service Plan Implementation and Monitoring page 119**

During monthly contacts, the Support Coordinator talks with the person to:

1. Determine if needed supports and services in the Plan of Services and Supports have been provided.

Refer to my SC service notes. He assumes supports and services have been provided but doesn’t ask guardian. This would be accomplished by giving the UTI report to guardian and reviewing it like is stated in waiver policy at least 8 times. This wasn’t done for over 3 years.

From 1/02 20-10/224/22 I expressed over 30 times I was without a caregiver; 2 times requested overnight respite; requested one on one support to access adult day hab; information on how grants/agencies that provide help with home modifications for the handicap……but no help/support/or services were provided.

d. Review the person's satisfaction with services and providers

How can a SC review satisfaction with services and providers, ie caregivers, when there is a shortage?

f. Identify the need to change the amount or type of supports and services needed or to access new waiver or non-waiver services.

The effectiveness of back up plans is monitored by the Support Coordinator. Monitoring methods include talking with the person at least one (1) time per month to determine if back-up plans have been needed and if so, how were they utilized, did the plan work appropriately, and what changes, if any, need to be made to the back-up plan.

How can there be a backup plan when initial services and supports already allocated are not being utilized due to lack of providers and caregivers?

Additionally, the State provides **a monthly utilization report to** Support Coordinators that lists all services a person receives each month. This is one tool the Support Coordinator can use to determine if the person has been to the doctor, been hospitalized, or changed medications.

The effectiveness of back up plans is monitored by the Support Coordinator. Monitoring methods include talking with the person at least one (1) time per month to determine if back-up plans have been needed and if so, how were they utilized, did the plan work appropriately, and what changes, if any, need to be made to the back-up plan.

How about ensuring that current services and supports are being utilized? Respite is the cornerstone of this waiver. Yet the State has allowed 100’s to languish without a caregiver and being able to utilize the allocated service/support for years. How can a SC make a backup plan when the current PSS plan has failed for years to deliver on what it states the individual needs and is allocated for?

**b. Monitoring Safeguards page 119-120**

**Quality improvement at the individual level is focused on monitoring and improving care support** **outcomes for the individual**. The person’s Support Coordinator is primarily responsible for quality improvement at the individual level. Individual level discovery takes place through the monthly and quarterly contacts that a Support Coordinator makes with the individual/legal guardian and his/her providers. **When a Support Coordinator discovers an issue** related to the person’s Plan of Services and **Supports**, he/she is responsible for addressing the issue with the person’s provider and developing remedial actions to address the issue.

Does the SC keep asking the providers about hiring caregivers when he/she knows they have tried for years and have basically quit trying to recruit and hire because of the low hourly rate?

When the Support Coordinator determines that there are no providers hiring caregivers because they cannot recruit and retain caregivers (DSP) at $8-10 and hour. What is the next step? How does a Support Coordinator develop remedial issues out of nonexistent supports/providers?

Who does the Support Coordinator escalate the issue to?

In addition to individual level discovery and remediation that occurs as a responsibility of Support Coordinators, **DMH is also responsible for discovery related to individual level remediation**. Through **BIDD’s monitoring process**, conducted through LTSS**, which includes individual record review**, **issues are identified in individual records.** **The Support Coordination Director and his/her Supervisor are notified about the issues identified that require remediation by the person’s Support Coordinator**. These issues include, but are not limited to: follow up regarding accessing community resources; **identification of** **additional support needs**; etc.

The BIDD’s monitoring of my son’s Service Notes would have shown that he was without a caregiver for 7 of the last 8 years. He had a three different caregivers for approx. 14 months in the last 8 years. I have to assume that the BIDD wasn’t monitoring respite because 100’s have languished without a caregiver for years. Does this not rise to the level of requiring remediation?

The BIDD’s monitoring also failed to identify that my SC didn’t review UTI reports in over 3 years. He just assumed.

We have been without a trained caregiver for 7 years. Monitoring Safeguards FAILED MY SON.

**Individual level discovery and remediation also occurs through DMH’s serious incident reporting/tracking processes and grievance process. Data from the results of provider monitoring, serious incidents, and grievances is available on an individual, provider or system level basis dependent upon the format needed for remediation and quality improvement.** DMH submits annual reports to the State summarizing issues identified during reviews of Plan of Services and Supports.

In our situation being without a trained caregiver for 7 years never rose to the level of a serious report warranting tracking and following of a grievance process. It never rose to the level of remediation.

Respite is the foundation of the IDD waiver and yet it’s not utilized because of a caregiver crises/shortage years before covid 19. 100’s have languished without a caregiver on the IDD waiver and yet this doesn’t rise to the level or remediation, serious incident or grievance. So what data is used on the annual reports if Monitoring Safeguards policy is blatantly ignored on the vital service/supports such as respite?

**Appendix E: Participant Direction of Services** page 130-135

 **Applicability** (from Application Section 3, Components of the Waiver Request):

 **No. This waiver does not provide participant direction opportunities. Do not complete the remainder of the Appendix.**

**CMS urges states to afford all waiver participants the opportunity to direct their services**. Participant direction of services includes the participant exercising decision-making authority over workers who provide services, **a participant-managed budget** or both. CMS will confer the Independence Plus designation when the waiver evidences a strong commitment to participant direction.

Page 1, second paragraph, last sentence….”A State has the latitude to design a waiver program that is…….**including participant direction of services.**

Page 4 The State does not utilize **Self-Directed Services**.

100’s of IDD waiver participants with ICAP scores of 4/5 have languished years without allocated respite. No relief for these families. CMS urges states to afford all waiver participants the opportunity to direct their services. Why does MS Medicaid not allow this? Please state specific reasons that guardians/parents will understand. Why does MS Medicaid turn a blind eye to 100’s of individuals in this program languishing for years with services and supports that have been allocated to them?

**Appendix H: Quality Improvement Strategy** (2 of 2)

**H-1: Systems Improvement**

1. **Systems Improvement page 165**

**Quality improvement at the individual level is focused on monitoring and improving supports** and **outcomes for the person**. The person’s Support Coordinator is primarily responsible for quality improvement at the individual level. **Individual level discovery takes place through the monthly and quarterly contacts that a Support Coordinator makes with the person, legal guardian (if applicable) and** **his/her providers.** **When a Support Coordinator discovers an issue** related to the person’s Plan of **Services and Supports**, **he/she is responsible for addressing the problem with the provider** and **developing remedial actions to address the issue. If a provider is not responsive to individual level remediation, a Support Coordinator is responsible for reporting the issue to BIDD.**

In addition to individual level discovery and remediation that occurs as a responsibility of Support Coordinators, DMH is also responsible for discovery related to Support Coordination activities. Through **BIDD’s record review system (LTSS), issues with Support Coordination are identified for remediation**. **These issues include**, but are not limited to, follow up regarding accessing community resources, identification of additional needs, etc. Individual level discovery and remediation also occurs through DMH’s serious incident reporting/tracking processes and grievance process. **Data from the results of** **monitoring Support Coordinators**, serious incidents, and grievances is available on an individual, **provider** or system level basis dependent upon the format needed for remediation and quality improvement.

 **Quality improvement at the provider level is focused on monitoring and improving** **services delivered by providers. DMH’s Division of Certification is responsible for coordinating the development of provider standards and monitoring**. All providers are certified for a three year period. During that three year period, onsite monitoring takes place to ensure compliance with DMH Operational Standards. As issues are identified through on-site monitoring, providers are required to submit Plans of Compliance for DMH approval. Additionally, all providers are required to have Quality Management Committees that are responsible for analysis of serious incidents, analysis of data at the individual level and oversight for the development and implementation of DMH required Plans of Compliance. Provider level data is collected through on-site monitoring, reporting of serious incidents, and reporting of grievances.

Quality improvement at the systemic level is designed to i**mprove** **the overall system’s delivery** of **services and supports. System level discovery incorporates data from multiple sources to develop a comprehensive view of service provision**. Data from the discovery processes at the individual and provider levels is utilized for system level quality improvement activities.

This Quality Improvement Strategy/Systems for Improvement can only produce true quality improvement in an individual’s Plan of Service and Supports when supports and services are available, accessible, and utilized.

Because of the lack of caregivers/providers, 100’s qualifying for respite have not utilized their allocated service for years. The following policies have failed to be enforced, monitored, etc….due to the caregiver shortage as well the policies concerning the UTI reporting being gross neglected and lack of monitoring.

**Appendix C: Participant Services C-1/C-3: Service Specification**

Page 55 Support Coordination/Case Management

Page 57 **Service Definition: Support Coordination activities include**:

**Appendix C: Participant Services C-4: Additional Limits on Amount of Waiver Services page 113**

**APPENDIX D : Participant-Centered Planning and Service Delivery (3 of 8) (4 of 8) (5 of 8) (6 of 8) (7 of 8) (8 of 8)**

**Appendix I: Financial Accountability**

**I-1: Financial Integrity and Accountability page 167-168**

Financial Integrity. Describe the methods that are employed to ensure the integrity of payments that have been made for waiver services, including: (a) requirements concerning the independent audit of provider agencies; (b) the financial audit program that the state conducts to ensure the integrity of provider billings for Medicaid payment of waiver services, including the methods, scope and frequency of audits; and, (c) the agency (or agencies) responsible for conducting the financial audit program. State laws, regulations, and policies referenced in the description are available to CMS upon request through the Medicaid agency or the operating agency (if applicable).

 The State maintains responsibility for ensuring financial audits of ID/DD Waiver providers are conducted. **The State operates two audit units to assure provider integrity** and proper payment for services rendered. **The Office of Program Integrity** investigates any suspicion of fraud or abuse reported or identified through the surveillance and **utilization reporting (SURS) program**. The Office of Financial and Performance Review conducts on-site annual post payment audits on 100% of waiver providers each State Fiscal Year (July 1- June 30) to ensure that staff providing claimed services are qualified, that services were provided to eligible individuals, and that those services were provided in accordance with the frequencies, amounts, and duration on the approved Plan of Services and Supports. Claims are sampled as required by the waiver application. A 95% confidence level random sample is selected from the universe of claims paid for the period utilizing a sample calculator such as Rat Stat. The universe is randomized with a random number generator and the appropriate number of claims is sampled. If anomalies are noted in the sample, such as claims with overlapping dates of service, additional claims may be selected for review.

The utilization reports were not offered to us for over 3 years by the Support Coordinator (Evidence in Support Coordinators service notes).

The **operating agency** is required to ensure that all ID/DD waiver providers meet the qualifications as defined in the waiver application. Post-payment audits are conducted by the Office of Financial and Performance Review to ensure that staff providing claimed services were qualified, that services were provided to eligible individuals, and that those services were provided in accordance with the frequencies, amounts, and duration on the approved Plan of Services and Supports.

The Mississippi Office of the State Auditor is responsible for annual audits in compliance with the provisions of the Single Audit Act. Additionally, every three (3) years an additional audit is completed by the Joint Legislative Committee on Performance Evaluation and Expenditure Review (PEER).

I would like to request a copy of the last audit performed by the Office of State Auditor as well as the last Joint Legislative Committee on Performance Evaluation and Expenditure Review (PEER).

**Appendix I: Financial Accountability**

 **Quality Improvement: Financial Accountability**

**b. Methods for Remediation/Fixing Individual Problems page 172**

i. Describe the State’s method for addressing individual problems as they are discovered. Include information regarding responsible parties and GENERAL methods for problem correction. In addition, provide information on the methods used by the State to document these items. The State is responsible for ensuring financial audits of providers. These audits verify that appropriate financial records are maintained and claims are coded and paid accurately. Systems edits in the MMIS prevent claims from paying when individuals are not eligible for Medicaid on the date of service. **DMH staff use** **the Monthly Utilization Report from the State to verify services provided were included in the individual's Plan of Services and Supports**.

The success of this system hinges on the review of utilization reports and if they are not validated then you have no real data to make decisions.

Once again, utilization reports were not validated with us regarding our son for over 3 years.

**I-2: Rates, Billing and Claims (1 of 3) page 173**

1. **Rate Determination Methods**. In two pages or less, describe the methods that are employed to establish provider payment rates for waiver services and the entity or entities that are responsible for rate determination. Indicate any opportunity for public comment in the process. If different methods are employed for various types of services, the description may group services for which the same method is employed. State laws, regulations, and policies referenced in the description are available upon request to CMS through the Medicaid agency or the operating agency (if applicable

**Both DMH and the State are responsible for rate setting and oversight.**

**Please explain how DMH and the State have justified not raising the hourly pay rate of caregivers (direct support professionals) since the early 1980’s?**

Immediately address the caregiver (DSP) crisis by raising the hourly wage to compete with Chic fil A, Hobby Lobby, Wal Mart, etc.

**The State has been in a caregiver shortage crisis years before covid-19. Now caregivers for individuals with an ICAP score of 4/5 and severely autistic are almost nonexistent. 100’s have languished without allocated respite for years.**

Taken from page 173 Appendix I of the IDD Waiver Regulation

Both DMH and the State participated in the **rate study** conducted in **2014.** The Memorandum of Understanding between

the State and DMH states that rate adjustments can be made as agreed upon by DMH and the State.

The rate-setting process for each service included:

• Conducting a series of focus groups with providers for each category of services (for example, there was a series of

groups for residential habilitation providers, for case management providers, etc.)

• Inviting all providers to complete a survey related to their service design and costs

• Identification of benchmark data, including Bureau of Labor Statistics cross-industry wage and benefit data as well as rates for comparable services in other CMS Region 4 states

**• Development of rate models that include the specific assumptions related to the cost of delivering each service, including direct care worker wages, benefits, and ‘productivity’ (i.e., billable time); staffing ratios; mileage; facility expenses; and agency program support and administration**

• Incorporating Inventory for Client and Agency Planning assessment data to create ‘tiered’ rates for residential and day habilitation services to recognize the need for more intensive staffing for individuals with more significant needs

• Emailing proposed rate models and supporting documentation, inviting the parties to submit comments, preparing written responses to all comments received, and revising the rates based on these comments

**One of the rate studies in 2014, 2015, and 2017 a meeting was held at NMRC in Oxford. Parents were invited to attend and give public comments. Ashley Lacoste led the meeting. The auditorium was full of parents caring for a total care child/adult and the unanimous consent from the parents was “we need a caregiver. We can’t find a caregiver. Agencies cannot find anyone reliable to work for $8-10 per hour with total care individuals.” Ms. Lacoste assured us this was the purpose of the rate study and they knew there was a shortage. She went on to say they were even studying prorating the hourly rate based on the ICAP score of the individual. I publicly ask, “Will agencies be monitored to ensure they are paying the caregiver the correct hourly rate per the ICAP score?” Ms. Lacoste said there would be no oversight.**

**Even after three studies, 2014. 2015, 2017 there was no hourly increase for DSP/ caregivers even when it was clear there was a shortage.**

**Which leads us to the caregiver crisis shortage were in today. It was a crisis then and it’s beyond a crisis now. The most fundamental purpose of the IDD waiver is to support families caring for a loved one by providing respite to prevent the individual from being institutionalized. THE IDD WAIVER HAS FAILED 100’S IF NOT 1,000’S OF PARTICIPANTS IN THIS MOST VITAL AREA, RESPITE!**

**Appendix I: Financial Accountability**

 **I-2: Rates, Billing and Claims (3 of 3) page 174**

**d. Billing Validation Process.** Describe the process for validating provider billings to produce the claim for federal financial participation, including the mechanism(s) to assure that all claims for payment are made only: (a) when the individual was eligible for Medicaid waiver payment on the date of service; (b) when the service was included in the participant's approved service plan; and, (c) the services were provided:

There are systems edits in the MMIS to prevent claims from paying when individuals are not eligible for Medicaid on the date of service. DMH staff will validate claims paid reports to verify services provided were included in the participant's Plan of Services and Supports, until such time that edits can be put in place for prior authorization to prevent claims from paying for services not included on the Plan of Services and Supports. **DMH will review the Monthly Utilization Report with individuals/families to verify the services were provided according to the claims listed in the Utilization Report**.

The success of this system hinges on the review of utilization reports and if they are not validated then you have no real data to make decisions.

Once again, utilization reports were not validated with us regarding our son for over 3 years.

**Appendix I: Financial Accountability Quality Improvement: Financial Accountability**

1. **Methods for Remediation/Fixing Individual Problems page 172**

**DMH staff use** **the Monthly Utilization Report from the State to verify services provided were included in the individual's Plan of Services and Supports**.

**Financial Accountability** can only be achieved if the following Appendix’s and policies are followed. In the case of our son, these policies were **overlooked, ignored**…….These Appendix’s refer at least 8 times as to how important and vital the UTI report is for the following: Service Plan Development; SC responsible through the UTI that services and supports are being implemented; services and supports are being documented accurately; PSS is being monitored through the UTI; Financial Accountability and integrity is conducted through the UTI; and financial accountability and Quality Improvement; methods of remediation/fixing Individual problems is achieved through the DMH staff use of the monthly UTI report.

Yet, we were never shown a UTI report for over 3 years.

**Appendix I: Financial Accountability Quality Improvement: Financial Accountability cannot be achieved when the following Appendix’s and polices are not followed and when services/supports such as respite has been denied for years.**

Page 57 **Service Definition: Support Coordination activities include**

**“Review of service utilization via a report generated by the State**.”(Monthly and quarterly.**)**

**Appendix D: Participant-Centered Planning and Service Delivery D-1: Service Plan Development (4 of 8) page 116**

Additionally Page 55 Support Coordination/Case Management

, the Division of Medicaid provides a Monthly Utilization Report to Support Coordinators that lists all Medicaid services a person receives each month.

. Providers are contacted as part of quarterly contact documentation to ascertain how their services are assisting the person in meeting stated outcomes.

(e) The coordination of waiver and other services is a constant activity for Support Coordinators. Through at least monthly contacts, the Support Coordinator is able to determine which services are being utilized, what new services may be needed, and what services may need to be reviewed to determine if the provider is supporting stated outcomes in the PSS.

(f**) page 117 The Support Coordinator is responsible for ensuring all services are implemented** as approved on the person’s PSS. This is accomplished through monitoring service provision during monthly phone contacts, on-site and face-to-face visits, and **Monthly Utilization Reports** from Medicaid.

**Appendix D: Participant-Centered Planning and Service Delivery**

**D-2: Service Plan Implementation and Monitoring page 119**

During monthly contacts, the Support Coordinator talks with the person to:

1. Determine if needed supports and services in the Plan of Services and Supports have been provided.

Refer to my SC service notes. He assumes supports and services have been provided but doesn’t ask guardian. This would be accomplished by giving the UTI report to guardian and reviewing it. This wasn’t done for over 3 years.

From 1/02 20-10/224/22 I expressed over 30 times I was without a caregiver; 2 times requested overnight respite; requested one on one support to access adult day hab; information on how grants/agencies that provide help with home modifications for the handicap……

Additionally, the State provides **a monthly utilization report to** Support Coordinators…….

**Appendix I: Financial Accountability I-1: Financial Integrity and Accountability page 167-168**

The State maintains responsibility for ensuring financial audits of ID/DD Waiver providers are conducted. **The State operates two audit units to assure provider integrity** and proper payment for services rendered. **The Office of Program Integrity** investigates any suspicion of fraud or abuse reported or identified through the surveillance and **utilization reporting (SURS) program**

Summary:

IDD/D Medicaid Waiver has failed to provide the services and supports to 100’s of individuals in this program. Medicaid refuses to be transparent with the data that would support this claim. Hundreds of individuals have languished for years without receiving allocated In Home Respite and Home and Community Supports Respite.

How do you enforce policies of non-existing services and supports? We have proven through our experience; provable evidence; and countless testimonies of others in the program that enforcing the IDD/D policies from the Support Coordinators to the BIDD, is a pattern of gross negligence, lack of oversite/monitoring, and lack of accountability in this program.

Just as concerning are the policies regarding how the utilization reports are used to make critical decisions for the individuals. The foundation to this program is utilizing and reviewing the utilization reports MONTHLY with the legal parent/guardian to ensure services and supports are being utilized and for the detection of fraud. The monthly utilization report is so important in this waiver, that it is mentioned at least eight times in eight different policies. The DMH has FAILED to enforce any of these policies through lack of monitoring/lack of oversight.

Appendix K: Emergency Preparedness and Response and COVID-19 Addendum

Issued March 1, 2020 to all five Medicaid Waivers. A provision in the appendix-K allows for family caregivers or legally responsible individuals to be paid caregivers. It was immediately allowed for three of the five waivers, but not for the IDD/D Waiver. I stumbled upon this provision in January 2022 which put me on a path of urging anyone who would listen to allow parents/family/guardians/responsible persons to be the paid direct support professionals. Long story short, two and half years after Appendix K was given to the States, Medicaid did check the box in Appendix K and allowed family caregivers or legally responsible individuals BUT NOT THE GUARDIAN to be the paid caregiver to their severely handicapped adult.

As of today, according to those with whom I am in regular contact, still haven’t heard of this option. Immediately upon adoption of this provision Support Coordinators should have made contact with their clients to inform them of this very important development. Once again the SC’s failed to inform those families who need this program the most.

Please consider our written comments for incorporation into the renewal of the IDD/D Waiver.

Respectfully,

Jamie and Natalie Gunnells