

December 30, 2019

Samuel Wagman SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail - Samuel.Wagman@SAMHSA.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Mr. Wagman:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. The Arizona Center for Disability Law (ACDL) believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

Annually, ACDL is required to produce a Program Performance Report (PPR) for the PAIMI program as well as seven other programs. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited staff resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA),

Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

We applaud SAMHSA for working with a number of P&As (including ACDL) and NDRN over the last couple of years to incorporate much of the One PPR framework into this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing</u> <u>Board, Advisory Council, and Program Staff</u>

We believe the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Second we believe the choices should be the following four: Male, Female, Not Listed, and Chose Not to Answer.

<u>Page 3, Section A, #12 – List of Mental Health Professionals on the Advisory Council</u>

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a) (6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

As ACDL's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PR and would need to be adjusted to reflect that this is the PAIMI PPR.

	Board
TOTAL Numbers of Members (non-	
duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary	
Consumers	
PAIMI or PAIR or PABSS Other Eligible	
Secondary Consumers	
Other Members	

Page 5, Section B, #2 - Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a

person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our fist suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second we also again believe the choices should be the following four: Male, Female, Not Listed, and Chose Not to Answer

<u>Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI</u> Program Funds

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in ACDL's caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

<u>Section C (Instructions): Complaints/Problems of PAIMI-eligible</u> Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 10, Section C, #5 – Areas of Alleged Rights Violation

ACDL agrees with the additions made to the tracking of alleged rights violations. Specifically, the additions of employment discrimination, housing discrimination, and failure to provide educational services in the least restricted environment. The ability to capture this work in our reporting will give SAMHSA and the public a better understanding of the nature, scope, and importance of our work.

Page 12, Section C, #8 - Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. Because if they are not, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

- 1. **Self-Advocacy Assistance**: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self-advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.
- 2. **Limited Advocacy**: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include

communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.

- 3. **Administrative Remedies**: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. **Negotiation**: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.
- 5. **Mediation/Alternative Dispute Resolution**: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.
- 6. **Litigation**: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

<u>Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals</u>

ACDL suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.

Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

Abuse and Neglect Investigation - An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multiplaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of ACDL PAIMI work that is done to ensure that an individual receives community based services so that the individual can **remain** living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for ACDL's individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, these are all contained on our 990 filings. We are generally hesitant to post staff salaries and have these be common knowledge in the organization. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please contact me if you have any questions about this letter.

Sincerely,

J.J. Rico

Chief Executive Officer Arizona Center for Disability Law jrico@azdisabilitylaw.org



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January 6, 2020 Submitted by e-mail summer.king@samhsa.hhs.gov

Summer King SAMHSA Reports Clearance Officer 5600 Fishers Lane, Room 14E57B Rockville, Maryland 20857

Re: <u>Agency Information Collection Activities: Proposed Collection;</u> <u>Comment Request 84 Fed. Reg. 59836 (November 6, 2019)</u>

Dear Ms. King:

Thank you for the opportunity to comment on the proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. The Alabama Disabilities Advocacy Program (ADAP) believes this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs we prepare for all similar federal formula programs while ensuring the data collected is as clear and useful as possible.

ADAP is required to produce an annual Program Performance Report (PPR) for the PAIMI program as well as at least seven other programs administered by ADAP. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals whom we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources we have, people with disabilities would benefit immensely if PPRs could be standardized so limited federal grant resources could be used to provide direct advocacy services to people with disabilities instead.

For all the foregoing reasons, we appreciate SAMHSA's efforts to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN), and P&As have worked for several years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A

agency while providing AOD and Congress the information they need to evaluate properly these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and provides AOD and Congress the information they need to evaluate properly each referenced individual program. Likewise, the One PPR was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to streamline existing reports.

Use of the One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with a number of P&As and NDRN in recent years to incorporate much of the One PPR framework in to the new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well as adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we support overall the new version of the PAIMI PPR, we would propose a couple of suggestions for SAMSHA to consider before finalizing the new PAIMI PPR.

Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board, Advisory Council, and Program Staff

We believe neither the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex." Second, we believe the choices should include: Male, Female, Not Listed, and Chose Not To Answer.

Page 3, Section A, #12 - List of Mental Health Professionals on the Advisory Council

Only including mental health professionals as choices for individuals who may serve on the advisory council ignores other potential categories of individuals who are allowed to serve on the council, as referenced in the PAIMI statute. Section 10805(a)(6)(B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc., that are not reflected in the proposed list on Page 3, and should be captured somehow in the PPR.

If you wish to break out the different types of mental health professionals, as referenced in the statute, we are concerned the list of mental health professionals is too narrow for the scope of individuals that may serve on a PAIMI Advisory Council. As SAMHSA's own website illustrates, https://www.samhsa.gov/workforce, the list of mental health professionals is much broader than the limited list found at Page 3. At a minimum an "Other" category should be added as an appropriate answer which would include other types of mental health professionals who may serve on a PAIMI Advisory Council. We also strongly suggest Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery is growing and developing.

Page 4, Section A, #15 - Governing Board Composition

Because a P&A's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of a P&A is not restricted to individuals or family members of individuals who receive or have received mental health services. We agree it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table below. We understand the referenced table is written from the perspective of the Administration on Community Living and the One PPR and, thus, would need to be adjusted to reflect that this is the PAIMI PPR.

Board

TOTAL Number of Members (non-duplicative)

PADD Eligible Primary Consumers

PADD Eligible Secondary Consumers

PATBI Eligible Primary Consumers

PATBI Eligible Secondary Consumers

AT Users

PAIMI or PAIR or PABSS Eligible Primary Consumers

PAIMI or PAIR or PABSS Other Eligible Secondary Consumers

Other Members

Page 5, Section B, #2 – Sex of PAIMI Eligible Individuals Served

As addressed earlier in Section A, #11, we believe the use of the term "sex" does not appropriately reflect the time in which we live nor address the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

As was the case earlier, our first suggestion for this section is to change the title to "Gender of PAIMI Eligible Individuals Served." Second, we believe the choices should include the following: Male, Female, Not Listed, and Chose Not to Answer

Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program Funds

Our concern about this question is focused on item #5 in which you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in ADAP's caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this

specific data point regarding evaluation of the PAIMI program. Thus, we first would suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, please do not limit the term "co-occurring disability" to I/DD.

Finally, while the question, if expanded, may yield beneficial information, it seems misplaced in the eligibility section. I believe the question would be more useful in describing the demographics of a program, as co-existence of any other disability does not reflect the person's eligibility for the PAIMI program.

Section C (Instructions): Complaints/Problems of PAIMI-eligible Individuals

As mentioned in the introduction, we appreciate SAMHSA's willingness to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 10, Section C, Part 5 – Areas of Alleged Rights Violations

Number 5(s) describes an education complaint as "Failure to provide educational services in the least restricted environment for PAIMI-eligible individuals." This description seems to limit education complaints to Least Restrictive Environment (LRE) matters, thus not allowing for matters related to, e.g., inappropriate discipline, use of school-based seclusion and restraint, denial of eligibility, etc., all of which can lead to catastrophic school failure including by retention, drop-out, or pushout. We recommend that SAMHSA utilize the education complaint descriptions in the One PPR for consistency's sake or, in the alternate, retain the current PAIMI description which reads as follows: "Failure to provide special education consistent with state requirements."

Page 12, Section C, #8 – Intervention Strategies

Again, this represents another section where we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to reflect more accurately

P&A advocacy, but that did not occur in the way this section is currently written. It appears the PAIMI PPR continues to retain the "Technical Assistance" option. We believe this could be confusing to staff to have different intervention strategies across programs. This concern is magnified when considering that the One PPR defines Technical Assistance as a non-client directed activity. Cases that otherwise would be classed as PAIMI Technical Assistance could be addressed as Limited Advocacy and, thus, eliminate the confusion.

Additionally, we ask that you add "Negotiation" as an intervention strategy. Negotiation is an important strategy for our staff who routinely seek to obtain good outcomes for P&A clients as quickly as possible and at the least intrusive level. Limited Advocacy could potentially include the Negotiation strategy, but we believe including Negotiation better reflects a regular manner by which we obtain productive outcomes for our clients.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. If the definitions are not the same, the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR that could be used in the instructions on this question.

- 1. <u>Self-Advocacy Assistance</u>: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that may include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights, coaching the client in self-advocacy, reviewing information, counseling a client on actions one may take, or assisting the client to prepare letters or documents and/or disseminating information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other similar material.
- 2. <u>Limited Advocacy</u>: Limited Advocacy is a level of intervention that includes providing a discrete task to a client or a discrete contact on behalf of a client with a third party. Upon completion, such activities require no further or ongoing actions, either formal or informal. Limited Advocacy may include communicating by letter, telephone or other means to a third party, preparing a simple legal document, or assisting a client to prepare documents that are submitted by the client *pro se* to a third party.
- 3. <u>Administrative Remedies</u>: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision-making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. <u>Negotiation</u>: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision that addresses their common concerns.
- 5. <u>Mediation/Alternative Dispute Resolution</u>: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.

6. <u>Litigation</u>: Litigation is any lawsuit or action in the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also laws governing procedures to be followed to properly litigate a claim. There are numerous rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it, among others.

Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals

ADAP suggests the definitions for group advocacy interventions be consistent with those in the One PPR which more accurately reflect the work of the P&As. These definitions follow.

<u>Group Advocacy Services</u>: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors.

<u>Abuse and Neglect Investigation</u> - An investigation is a systemic and thorough examination of information, records, evidence and circumstances related to an allegation of abuse/neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including activities such as interviewing witnesses, gathering evidence, and generating a written report which may or may not be made public.

<u>Systemic Litigation</u> - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation or, in some cases, individual litigation when the relief sought has the potential to affect many people with disabilities.

Educating Policy Makers - A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Advocacy efforts may be directed at the local, state, or federal level. Educating these individuals helps make them aware how their actions may impact people with disabilities. Information reported should include only work done in accordance with relevant limit(s) on federal funding.

Other Systemic Advocacy - Other Systemic Advocacy refers to concerted action by the P&A agency to promote and effectuate change in policies, rules, and laws that impact groups of people with disabilities, and to remove barriers that prevent or impede them from leading full, productive lives in the community, that does fit elsewhere in the form. Other Systemic Advocacy typically addresses the establishment, support, improvement, or expansion of programs that provide services or benefits to persons with disabilities, and the legal rights, protections, and entitlements of persons with disabilities. Other Systemic Advocacy may involve opposing efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - Monitoring includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the use of a P&A's access authority to visit and seek information in other ways from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by: a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; c) observing and evaluating the physical conditions of the setting; and d) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in item "a" implies the individual is receiving a P&A's help to move from a segregated to a community-based setting to achieve integration and independence. However, much of ADAP's PAIMI work is done to ensure an individual may receive community-based services so the individual may remain in the community (e.g., in their own home) and be integrated and independent. Thus, we believe item "a" should specifically reference maintaining already existing community integration. Thus, for example, item "a" could be drafted with language like: *PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence.*

Page 21 - Section G #1 - PAIMI Personnel

We are unclear how important it is for SAMHSA to have salaries reported for ADAP's individual PAIMI staff. While we understand it may be beneficial to have higher salaries reported, these are contained in relevant 990 filings. It seems that aggregate salary information would accomplish SAMHSA's needs while also maintaining the integrity of other related data. We applaud the change to WebBGas to black out the salary information.

Conclusion

Again, we appreciate the opportunity to comment on the proposed collection of information and believe the new PPR constitutes a significant step toward development of a streamlined data collection process that will provide necessary data to demonstrate the effectiveness of the PAIMI program to both SAMSHA and Congress. Please feel free to contact me if you have any questions about this letter.

Sincerel

James A. Tucker, Esq.

Director





Tom Masseau, Executive Director

January 3, 2020

Samuel Wagman SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail - Samuel.Wagman@SAMHSA.hhs.gov

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Mr. Wagman:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Disability Rights Arkansas, Inc. (DRA) believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

Yearly, Disability Rights Arkansas is required to produce a Program Performance Report (PPR) for the PAIMI program as well as eight (8) other programs administered by Disability Rights Arkansas. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national

association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with a number of P&As and NDRN over the last couple of years to incorporate much of the One PPR framework into this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing</u> Board, Advisory Council, and Program Staff

We believe the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Second, we believe the choices should be the following four: Male, Female, Not Listed, and Chose Not to Answer.

<u>Page 3, Section A, #12 – List of Mental Health Professionals on the</u> Advisory Council

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a) (6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

As Disability Rights Arkansas' impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of Disability Rights Arkansas is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PR and would need to be adjusted to reflect that this is the PAIMI PPR.

	Board
TOTAL Numbers of Members (non-	
duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary	
Consumers	

PAIMI or PAIR or PABSS Other Eligible	
Secondary Consumers	
Other Members	

Page 5, Section B, #2 – Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our fist suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second, we also again believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer

<u>Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI</u> Program Funds

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in our caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

<u>Section C (Instructions): Complaints/Problems of PAIMI-eligible Individuals</u>

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the

new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 12, Section C, #8 – Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. Because if they are not, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

- 1. **Self-Advocacy Assistance**: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.
- 2. **Limited Advocacy**: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a

client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.

- 3. **Administrative Remedies**: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. **Negotiation**: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.
- 5. **Mediation/Alternative Dispute Resolution**: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.
- 6. **Litigation**: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

<u>Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMIeligible individuals</u>

Disability Rights Arkansas suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.

Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

Abuse and Neglect Investigation - An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multiplaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policymakers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of our PAIMI work that is done to ensure that an individual receives community-based services so that the individual can **remain** living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for Disability Rights Arkansas individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, these are all contained on our 990 filings. We are generally hesitant to post lower level staff salaries and have this common knowledge in the organization. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress.

If you need additional information or have any questions, please don't hesitate to contact me at tmasseau@disabilityrightsar.org or 501-296-1755.

Sincerely,

Tom Masseau Executive Director

CC: Susan Pierce, DRA Grants Manager



Disability Rights Connecticut

"Connecticut's protection and advocacy system"

846 Wethersfield Avenue Hartford, CT 06114

January 5, 2020

Samuel Wagman SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B Rockville, Maryland 20857

Submitted by e-mail – samuel.wagman@samhsa.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Mr. Wagman:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Disability Rights Connecticut believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

Yearly, Disability Rights Connecticut is required to produce a Program Performance Report (PPR) for the PAIMI program as well as eight (8) other programs administered by Disability Rights Connecticut. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

Phone: (800) 842-7303 (toll-free in CT), (860) 297-4300 (voice) - www.disrightsct.org

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with a number of P&As and NDRN over the last couple of years to incorporate much of the One PPR framework in to this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board, Advisory Council, and Program Staff</u>

We believe the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like "gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Our second suggestions is to change the choices to the following four: Male, Female, Not Listed, and Chose Not to Answer.

Page 3, Section A, #12 - List of Mental Health Professionals on the Advisory Council

The PAIMI regulations require the seats on the PAIMI Advisory Council to be filled by certain types of individuals including attorneys, providers, current and former recipients of mental health services and family members of such individuals. The proposed PAIMI PPR only includes mental health professionals as choices for individuals that serve on the advisory council and, therefore, ignores these other categories of individuals who are required to serve on the council

in accordance with the PAIMI statute. It is DRCT's suggestion that all required categories should be reflected in this section of the PPR.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum, an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

As Disability Rights Connecticut's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of Disability Rights Connecticut is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PPR and would need to be adjusted to reflect that this is the PAIMI PPR.

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PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary	
Consumers	-
PAIMI or PAIR or PABSS Other Eligible Secondary	
Consumers	
Other Members	

Page 5, Section B, #2 – Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our fist suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second we also again believe the choices should include following four: Male, Female, Not Listed, and Chose Not to Answer.

Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program Funds

Our concern in this question is in #5 where you ask for the number of individuals with cooccurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in Disability Rights Connecticut's caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, Disability Rights Connecticut suggests dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

Section C (Instructions): Complaints/Problems of PAIMI-eligible Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 12, Section C, #8 – Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

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<u>Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals</u>

Disability Rights Connecticut suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.

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Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of Disability Rights Connecticut PAIMI work that is done to ensure that an individual receives community based services so that the individual can **remain** living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for Disability Rights Connecticut's individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, these are all contained on our 990 filings. We are generally hesitant to post lower level staff salaries and have these common knowledge in the organization. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please do not hesitate to contact me if you have any questions about this letter. I can be reached at (860) 469-4463 or gretchen.knauff@disrightsct.org.

Sincerely

Gretchen Knauff
Executive Director



January 6, 2020

<u>VIA EMAIL</u>: Samuel.Wagman@SAMHSA.hhs.gov

Samuel Wagman SAMHSA Reports Clearance Officer 5600 Fishers Lane, Room 14E57B Rockville, MD 20857

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Mr. Wagman:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Disability Rights Florida (DRF) believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

DRF had an opportunity to review the comments to be provided to SAMHSA by National Disability Rights Network (NDRN). DRF is in full support of the recommendations proposed by NDRN. In addition to NDRN's comments, DRF would appreciate SAMHSA's consideration related to the following areas.

Timing of proposed changes to PAIMI PPR reporting

Like most other P&A systems, DRF utilizes electronic data entry systems to track virtually all elements of a case file, from opening through development and case closure. Because we use automated systems for reporting purposes, the timing and execution of the proposed PAIMI PPR changes is critical. DRF requests that all final changes be announced well in advance of the fiscal year for which the changes will be implemented. This will provide P&As with ample time to apply the necessary changes to case management databases and thereby capture all pertinent information for the entire affected fiscal year. SAMHSA's proposed PAIMI PPR changes affect case work on multiple levels, including dispositions, interventions,

and outcomes that are not currently available for selection under the PAIMI grant. To implement these changes mid-fiscal year would likely require many hours of staff time to apply retroactive revisions to case files that have previously been completed or closed.

Page 13, Section C., #9 - Death Investigation Activities

It appears that "The State" has been removed as an option from the section with heading, "The number of deaths reported to the P&A for investigation by the following entities." It is unclear whether this removal was intentional or in error. The majority of reports of deaths come to DRF from state agencies. DRF proposes that SAMHSA continue to include "The State" as selection "a" in this category as it has been in prior PAIMI PPRs.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. If you have any questions about this letter, please do not hesitate to contact me directly by phone at 850-617-9775 or via email at PeterS@disabilityrightsflorida.org.

Sincerely,

Peter P. Sleasman

Acting Executive Director

Peter P Sleasman



December 27, 2019

Summer King SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail - summer.king@samhsa.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Ms. King:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Indiana Disability Rights believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

Yearly, Indiana Disability Rights is required to produce a Program Performance Report (PPR) for the PAIMI program as well as eight other programs administered by RSA, ACL/AIDD, and SSA. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with



Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with a number of P&As and NDRN over the last couple of years to incorporate much of the One PPR framework in to this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board,</u> Advisory Council, and Program Staff

We believe the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Second we believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer.

Additionally, the "Race" Category is not consistent with the Race options under A. 17 breaking down program staff demographics. We recommend adding "Native Hawaiian/Pacific Islander" and "Unknown" to the list of Races to make it consistent with the list of Races in A. 17.

Ethnicity should also consistently have an "Unknown" option as well.



<u>Page 3, Section A, #12 – List of Mental Health Professionals on the Advisory Council</u>

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a) (6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

As Indiana Disability Right's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of IDR is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PR and would need to be adjusted to reflect that this is the PAIMI PPR.

	Board
TOTAL Numbers of Members (non-duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	



PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary	
Consumers	
PAIMI or PAIR or PABSS Other Eligible Secondary	
Consumers	
Other Members	

Page 5, Section B, #2 - Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our fist suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second we also again believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer

<u>Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program</u> Funds

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in IDR's caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in



describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

Section C (Instructions): Complaints/Problems of PAIMI-eligible Individuals
As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 12, Section C, #8 - Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. Because if they are not, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

1. **Self-Advocacy Assistance**: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and



counseling assistance includes informing a client of their rights; coaching the client in self advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.

- 2. **Limited Advocacy**: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.
- 3. **Administrative Remedies**: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. **Negotiation**: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.
- 5. **Mediation/Alternative Dispute Resolution**: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.
- 6. **Litigation**: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

<u>Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals</u>

Indiana Disability Rights suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.



Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

Abuse and Neglect Investigation - An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with

disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek



information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of IDR's PAIMI work that is done to ensure that an individual receives community based services so that the individual can **remain** living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for IDR's individual PAIMI staff. As a state agency, employees' salaries are available as a matter of public record. We are generally hesitant to post lower level staff salaries and have these common knowledge in the organization. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please be in touch with Melissa Keyes if you have any questions about this letter.

Sincerely,

Melissa Keyes, MS, JD

Medissa Jenes



Executive Director, Indiana Disability Rights mkeyes@indianadisabilityrights.org (317)722-3463

From: <u>Jane Hudson</u>

To: Wagman, Samuel (SAMHSA/OFR/DOB)

Cc: "eric.buehlmann@ndrn.org"; Whitney Driscoll; Cyndy Miller

Subject: Disability Rights Iowa Comments on Proposed PAIMI PPR

Date: Monday, January 6, 2020 4:40:57 PM

Mr. Wagman-

Thank you for giving us the opportunity to comment on the proposed PAIMI PPR. We agree with the comments submitted by the National Disability Rights Network. In addition, we request that you consider the comments below. If you have any questions, please do not hesitate to contact me. Thanks again. Jane Hudson

- 1.) Under "Areas of Alleged Rights Violations" add "Failure to provide a reasonable accommodation (e.g., service animal access denials, testing environment)." DRI has had several cases involving alleged denial of service animals for individuals with mental illness. DRI has also been asked to represent individuals who are requesting reasonable accommodations with respect to professional and licensing examinations. Neither of those issues fit any of the current listed rights violations. We would prefer to have these listed, rather than placing them in the "other" category, which is limited to 1% of our total cases.
- 2.) In Section C.10.5 consider adding additional specialized target populations such as "youth involved in the juvenile justice system," "children and youth in foster care," "prisoners," "inmates in jails", and "involuntarily institutionalized in mental health facilities."
- 3.) In Section D.3 add in a field allowing reporting of the number of individuals who received information from public awareness activities/events. Currently the PPR only allows reporting of the number of individuals trained, but we disseminate a lot of information in outreach/awareness events, so it would be beneficial to report the outcome of those efforts immediately following where we report on the number of those events, similar to the reporting of that information for trainings.
- 4.) In Section H (Statement of Priorities) there is currently suggested a 500 word/character limit for narratives. It would be helpful the instructions to the section clarified whether we should only list one exemplar case narrative, or whether we have to very briefly list all of the cases under the priority in order to accurately report yet stay within the short word limit. Currently the wording of the instructions is not clear.
- 5.) In Section H, it would be helpful if "Partially Met" was an option when reporting outcomes on Priorities. "Partially met" had been an option on previous PPRs and allowed us to explain the progress made as well as any reason for not meeting a specified goal.
- 6.) With the proposed changes to Intervention Strategies it would be helpful to have language clarifying the differences between Self-Advocacy Assistance, Technical Assistance and Information/Referrals.

Jane Hudson, J.D. Executive Director



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Our Mission: To defend and promote the human and legal rights of lowans with disabilities

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January 6, 2020

Sam Wagman SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail - Samuel.Wagman@SAMHSA.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Mr. Wagman:

Disability Rights Maryland is pleased to have this opportunity to comment on SAM-HSA's proposed changes to the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program's annual Program Performance Report (PPR). Disability Rights Maryland believes that this iteration of the PAIMI PPR takes positive steps to further the goal of standardizing the PPRs that the state Protection and Advocacy systems complete annually for many of their formula grants, as well as to ensure that the data collected is as clear and useful as possible.

Yearly, Disability Rights Maryland is required to produce a PPR for the PAIMI program, as well as six other programs administered by Disability Rights Maryland. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs and organizing our data collection activities to collect information in many different ways. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate SAMHSA's efforts to consider modeling updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A

agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with a number of P&As and NDRN over the last couple of years to incorporate much of the One PPR framework into this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board, Advisory Council, and Program Staff</u>

We believe the choices for the sex demographic question, which includes just two possible answers, does not reflect the time in which we live. It is not uncommon for our board or PAIMI Council members to feel constrained by the traditional definitions of female and male, and it is uncomfortable for us to ask them to choose from just two options. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term, like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex." Second, we believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer.

<u>Page 3, Section A, #12 – List of Mental Health Professionals on the Advisory Council</u>

Including only "mental health professionals" as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a)(6)(B) includes other categories, like attorneys, providers, individuals receiving or who have received mental health services, etc. that are not reflected in the list on Page 3 and should be captured in the PPR.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum, an "Other" category needs to be

added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that "Peer Support Specialists" be added as a specifically enumerated choice, as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

As Disability Rights Maryland's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of Disability Rights Maryland is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answer choices should be added to this question to capture the participation of other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is diverse representation on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table below for your reference. We understand that this is written from the perspective of the Administration on Community Living and the One PPR and would need to be adjusted to reflect the requirements of the updated PAIMI PPR.

	Board
TOTAL Numbers of Members (non-duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary Consum-	
ers	
PAIMI or PAIR or PABSS Other Eligible Secondary	
Consumers	
Other Members	

Page 5, Section B, #2 - Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

As stated above, our fist suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second, we also again believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer

<u>Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program</u> <u>Funds</u>

Our concern in this question is with #5, where the PPR requests the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in Disability Rights Maryland's caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

Section C (Instructions): Complaints/Problems of PAIMI-eligible Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 12, Section C, #8 - Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option.

We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. Because if they are not, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

- 1. **Self-Advocacy Assistance**: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.
- 2. **Limited Advocacy**: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.
- 3. **Administrative Remedies**: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. **Negotiation**: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.

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- 6. **Litigation**: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

<u>Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals</u>

Disability Rights Maryland suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.

Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

Abuse and Neglect Investigation - An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with

disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of Disability Rights Maryland's PAIMI work that is done to ensure that an individual receives community based services so that the individual can **remain** living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for Disability Rights Maryland's individual PAIMI staff. We are generally hesitant to post lower level staff salaries and have them become common knowledge in the organization. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGAS to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please reach out to me at RMurphy@DisabilityRightsMD.org or 410-727-6352 x2482 if you have any questions about this letter.

Sincerely,

Robin Murphy Executive Director

Lobin Musply

Luciene Parsley
Luciene Parsley
Legal Director



DISABILITY RIGHTS MISSISSIPPI

Protection and Advocacy for Individuals with Disabilities

January 2, 2020

Sam Wagman SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail - samuel.wagman@samhsa.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Ms. King:

Phone: (601) 968-0600

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Disability Rights Mississippi (DRMS) believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

We appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline those PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with NDRN over the last couple of years to incorporate much of the One PPR framework in to this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new

5 Old River PI, Ste 101, Jackson MS 39202 Fax: (601) 968-0665 version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #12 – List of Mental Health Professionals on the Advisory</u> <u>Council</u>

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a) (6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 - Governing Board Composition

As DRMS' impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of DRMS is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals.

<u>Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program Funds</u>

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in DRMS' caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

<u>Section C (Instructions): Complaints/Problems of PAIMI-eligible</u> Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 12, Section C, #8 - Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs.

<u>Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals</u>

DRMS suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As.

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for DRMS' individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, these are all contained on our 990 filings.

Again, I appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress.

Sincerely,

Polly Tribble

Executive Director



210 South Broad Street, Third Floor Trenton, New Jersey 08608 800.922.7233 | 609.633.7106 (TTY) 609.292.9742 | 609.777.0187 (FAX) www.drnj.org

Gwen Orlowski, Executive Director

January 6, 2020

Samuel Wagman SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail – samuel.wagman@samhsa.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Mr. Wagman:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Disability Rights New Jersey believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

Yearly, Disability Rights New Jersey is required to produce a Program Performance Report (PPR) for the PAIMI program as well as seven other programs administered by Disability Rights New Jersey. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting

Advocating and advancing the human, civil and legal rights of persons with disabilities

processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with a number of P&As and NDRN over the last couple of years to incorporate much of the One PPR framework in to this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board, Advisory Council, and Program Staff</u>

We believe the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Second we believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer.

<u>Page 3, Section A, #12 – List of Mental Health Professionals on the Advisory Council</u>

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a) (6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 - Governing Board Composition

As Disability Rights New Jersey's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of Disability Rights New Jersey is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PR and would need to be adjusted to reflect that this is the PAIMI PPR.

	Board
TOTAL Numbers of Members (non-duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary	
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Page 5, Section B, #2 – Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our fist suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second we also again believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer

<u>Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI</u> Program Funds

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in Disability Rights New Jersey caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

<u>Section C (Instructions): Complaints/Problems of PAIMI-eligible Individuals</u>

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of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.

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Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multiplaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of Disability Rights New Jersey's PAIMI work that is done to ensure that an individual receives community based services so that the individual can **remain** living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for Disability Rights New Jersey 's individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, we are generally hesitant to post lower level staff salaries and have these be common knowledge in the organization. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please be in touch with Lycette Nelson, PAIMI Coordinator, at lnelson@drnj.com, if you have any questions about this letter.

Sincerely,

ycette Nelson

Managing Attorney/PAIMI Coordinator



DISABILITY RIGHTS NEW YORK



www.drny.org



(⋈) mail@drny.org



January 3, 2020

Summer King SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, MD 20857

Submitted by e-mail - summer.king@samhsa.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Ms. King:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Disability Rights New York (DRNY) is the Protection and Advocacy System for New York State. The proposed PAIMI Program Performance Report (PPR) standardizes the data collected across P&A programs to better capture the work we perform.

As you are aware, yearly DRNY is required to produce a PPR for the PAIMI program as well as 7 other federally funded programs. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed

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with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with DRNY, other P&As and NDRN over the last couple of years to incorporate much of the One PPR framework in to this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board, Advisory Council, and Program Staff

We believe the choices for the sex demographic question and the two answers, do not appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Second we believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer.

Page 3, Section A, #12 - List of Mental Health Professionals on the Advisory Council

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a) (6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

DRNY's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of DRNY is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to

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this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PR and would need to be adjusted to reflect that this is the PAIMI PPR.

Board

TOTAL Numbers of Members (non-duplicative)

PADD Eligible Primary Consumers

PADD Eligible Secondary Consumers

PATBI Eligible Primary Consumers

PATBI Eligible Secondary Consumers

AT Users

PAIMI or PAIR or PABSS Eligible Primary Consumers

PAIMI or PAIR or PABSS Other Eligible Secondary Consumers

Other Members

Page 5, Section B, #2 - Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our first suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second we also again believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer

Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program Funds

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see

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the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

Section C (Instructions): Complaints/Problems of PAIMI-eligible Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 12, Section C, #8 - Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and would eliminate this confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. Because if they are not, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

1. Self-Advocacy Assistance: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.

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- 2. Limited Advocacy: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.
- 3. Administrative Remedies: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. Negotiation: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.
- 5. Mediation/Alternative Dispute Resolution: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.
- 6. Litigation: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals

DRNY suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.

Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

Abuse and Neglect Investigation - An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals,

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through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, some of DRNY's PAIMI efforts are spent ensuring that an individual receives community based services so that the individual can remain living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, these are all contained on our 990 filings. We suggest that aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

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Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. We would welcome the opportunity to discuss any of the above concerns and thank you for the opportunity to share our comments.

Very truly yours,

7imothy A. Clune Timothy A. Clune, Esq. Executive Director



December 30, 2019

Summer King SAMHSA Reports Clearance Officer 5600 Fishers Lane, Room 14E57B Rockville, Maryland 20857

Submitted by e-mail - summer.king@samhsa.hhs.gov

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Ms. King:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Disability Rights North Carolina (DRNC) believes that this iteration of the PAIMI Program Performance Report (PPR) is an opportunity to ensure that the data collected is as clear and useful as possible, and advance efforts to standardize the PPRs that are required for all our federal grants.

Annually, DRNC is required to produce a Program Performance Report (PPR) for the PAIMI program, in addition to the 7 other federal programs that DRNC conducts. These PPRs contain a wealth of information, including an evaluation as to whether the program has met the goals and priorities we have established with input from the community and individuals we serve. Unfortunately, data requested in the various PPRs is not standardized, which requires us to spend an even greater amount of time compiling and drafting the PPRs. Given our limited resources, it would directly benefit people with disabilities if the reports could be standardized and streamlined, so additional resources could be directed to the provision of direct services to people with disabilities.

We very much appreciate SAMHSA's efforts to consider modeling your PPR updates on recommendations from the Protection & Advocacy (P&A) network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over recent years with the Administration on Disabilities (AOD) to standardize the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The goal was to produce one PPR that effectively and efficiently documents the work of each P&A while providing AOD and Congress the information they need to properly evaluate these four programs. This work led to the creation of the "One PPR" to capture and report the outcomes of the P&As and provide AOD and Congress the necessary

information. The One PPR was designed with the idea that all P&A programs, including the PAIMI program, could use this concept to help streamline the existing reports. Use of this One PPR started in Fiscal Year 2019.

We applaud SAMHSA for working with a number of P&As and NDRN over the past years to incorporate much of the One PPR framework into this new version of the annual PAIMI PPR. We specifically support the inclusion of a number of important data points that were removed from the last version of the PAIMI PPR, as well as adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs.

While we generally support this new version of the PAIMI PPR, we submit for SAMHSA's consideration the following suggestions before finalizing the new PAIMI PPR.

Overall, the PAIMI program would be improved by enhanced tracking of specific rights violations work, including housing, education and employment. The ability to capture this work in our reporting would give SAMHSA and the public a better understanding of the scope and importance of our work.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board, Advisory Council, and Program</u> Staff

There are only two binary choices for the "sex" demographic question which does not appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while an individual's overall experience and identity requires a more encompassing term like gender.

We suggest changing the title to "Gender" rather than "Sex" and that the choices could be the following four: Male, Female, Not Listed, and Chose Not to Answer.

Page 3, Section A, #12 - List of Mental Health Professionals on the Advisory Council

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the Council pursuant to the PAIMI statute. The PAIMI Act at 42 USC Section 10805(a)(6)(B) mandates other categories, attorneys, providers, individuals who are receiving or have received mental health services, etc. that are not reflected in this list on Page 3.

Should you find it useful to break out the statute's reference to "mental health professionals" into specific subcategories, we are concerned that the list of mental health professionals provided for this question is much too narrow for the scope of individuals that may serve on the PAIMI Advisory Council (PAC). As SAMHSA's own website shows (https://www.samhsa.gov/workforce), the list of mental health professionals is considerably broader than the limited list on Page 3. At a minimum, an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the PAC. Finally, we strongly suggest that Peer Support Specialists be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

As DRNC's service to the disability community includes, but extends beyond, individuals with mental health disabilities, DRNC's governing board not limited to individuals who have received mental health services and

their family members. We agree that it is important to capture the number of individuals and family members of individuals with disabilities on the governing board, but to properly reflect the board's composition, we believe additional options must be added to this question to reflect other individuals with diverse disabilities their family members. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. That table is set forth below. We understand that this is written from the perspective of the Administration on Community Living and the One PPR, and would need to be adjusted to reflect the PAIMI PPR.

	Board
TOTAL Numbers of Members (non-duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary Consumers	
PAIMI or PAIR or PABSS Other Eligible Secondary	
Consumers	
Other Members	

Page 5, Section B, #2 – Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" is inappropriate. Additionally, the third answer of "unknown/would not disclose" does not cover the range of individuals concerned.

Again, our suggestion is to change the title to "Gender of PAIMI Eligible Individuals Served" and offer the choices: Male, Female, Not Listed, and Chose Not to Answer.

Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program Funds

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is very common in DRNC's caseload for one individual to identify with multiple disabilities and we see no need or utility in collecting this specific data point when it comes to evaluating the program. We suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Should you decide to keep the data point, do not limit the co-occurring disability to I/DD, and note that places additional burdens on our clients without known rationale.

Finally, the question seems misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as in co-existence of any other disability. It is not reflective of the eligibility of that person, which is specified in statute.

Section C: Complaints/Problems of PAIMI-eligible Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 12, Section C, #8 – Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur as this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under Limited Advocacy to eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain favorable outcomes for our clients. While Limited Advocacy could possibly describe this strategy, it is more accurate to add the Negotiation category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. If they are not, the increased efficiency sought through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

- 1. **Self-Advocacy Assistance**: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.
- 2. **Limited Advocacy**: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.
- 3. **Administrative Remedies**: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.

- 4. **Negotiation**: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.
- 5. **Mediation/Alternative Dispute Resolution**: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.
- 6. **Litigation**: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals

DRNC suggests that the definitions for group advocacy interventions be consistent with those in the One PPR, which again more accurately reflect the work of the P&As. These definitions follow.

Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

Abuse and Neglect Investigation - An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment,

support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community-based setting to achieve integration and independence. However, DRNC's PAIMI work includes ensuring that an individual receives community-based services to remain living in the community and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to the importance for SAMHSA to collect data on the salaries for our individual PAIMI program staff. If aimed at reviewing the highest salaries, these are contained on our 990 filings. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of personnel information. We do appreciate the change to WebBGas to black out salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is a major step toward uniform data collection processes that will provide the data necessary to demonstrate the effectiveness of the PAIMI program to SAMHSA and Congress. Please be in touch with me at 919-856-2195 or virginia.knowltonmarcus@disabilityrightsnc.org if you have any questions about this letter.

Sincerely,

Virginia Knowlton Marcus Chief Executive Officer

Virgin York My



We have the legal right of way.

Michael Kirkman, Esq.
Executive Director
614-466-7264, 113
mkirkman@disabilityrightsohio.org

January 6, 2020

Samuel Wagman SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail - Samuel.Wagman@SAMHSA.hhs.gov

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. As a member of the team that represented our national association, the National Disability Rights Network (NDRN), and the P&A network in drafting this PPR, I want to express my appreciation for the willingness of the staff at SAMHSA to listen to our concerns, and to work collaboratively to create a report that fairly and correctly captures the legal needs of PAIMI eligible clients and the work our network accomplishes on their behalf. In particular, I appreciate the willingness to correct several issues that were included in the current PPR that either misstated the legal requirements of the PAIMI Act (e.g. including the measure of within 90 days of hospitalization) or ignored significant rights issues that affect PAIMI eligible clients (e.g. housing, education, and employment). I also want to recognize Steven Dettwyler, Ph.D., for his interest in capturing accurate and representative data from the P&As that will allow for better reporting to Congress and the general public.

Beyond the corrections, this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible. Disability Rights Ohio is required to produce an annual Program Performance Report (PPR) for the PAIMI program as well as nine other P&A or CAP programs administered by Disability Rights Ohio. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling the updates to the PPR on recommendations from the P&A network. NDRN and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. That said, there are a few issues that we propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board, Advisory Council, and Program Staff</u>

We believe the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for our board, advisory council members, or staff to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, we request that you change the title to "Gender" rather than "Sex". Second we believe the choices should be the following four: "Male," "Female," "Not Listed," and "Chose Not to Answer."

Page 3, Section A, #12 - List of Mental Health Professionals on the Advisory Council

This listing ignores the specific language in the PAIMI Act. Section 10805(a) (6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow. There is no basis to collect information on only mental health professionals.

If you would decide to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an "Other" category needs to be added

as an appropriate answer for other types of mental health professionals that may serve on the advisory council. Additionally, we strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

As Disability Rights Ohio's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of Disability Rights Ohio is not constricted to individuals or family members of individuals that have received mental health services. Our board has a broad range of individuals with disabilities, family members, and interested professionals. This gives us a broader view of mission and also allows us to comply with requirements of multiple grants. While we agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PPR and would need to be adjusted to reflect that this is the PAIMI PPR.

	Board
TOTAL Numbers of Members (non-duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary Consumers	
PAIMI or PAIR or PABSS Other Eligible Secondary	
Consumers	
Other Members	

Page 5, Section B, #2 – Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our first suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served." Second we also again believe the choices should be the following four: "Male," "Female," "Not Listed," and "Chose Not to Answer."

Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program Funds

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in Disability Rights Ohio's caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

If you feel this type of information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-morbidity or "dual diagnosis" more typically refers to substance use and mental illness, which is not asked. In particular, as Ohio is at the center of the current opioid crisis, this oversight should be corrected.

Additionally, more recent research shows a high number of people with mental illness have experienced traumatic brain injury. This data would be valuable to have as our awareness of this phenomenon grows.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as co-existence of any other disability in no way limits PAIMI eligibility for the person.

Section C (Instructions): Complaints/Problems of PAIMI-eligible Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 12, Section C, #8 – Intervention Strategies

This is another section we appreciate SAMSHA's effort to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy. Unfortunately, that goal was missed as this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. This could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that

would be PAIMI Technical Assistance could easily fall under Limited Advocacy and eliminate the confusion.

Additionally, we strongly urge you to add "Negotiation" as an intervention. This is an important strategy for our staff and the most common form of dispute resolution across all of our programs. Staff is tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. If they are not, the increase in efficiency through harmonized PPRs is lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

- 1. **Self-Advocacy Assistance**: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.
- 2. **Limited Advocacy**: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.
- 3. **Administrative Remedies**: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. **Negotiation**: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.
- 5. **Mediation/Alternative Dispute Resolution**: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.

6. **Litigation**: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals

Disability Rights Ohio suggests that the definitions for group advocacy interventions be consistent with those in the One PPR. These more accurately reflect the work of the P&As. These definitions follow.

Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

Abuse and Neglect Investigation - An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of Disability Rights Ohio's PAIMI work that is done to ensure that an individual receives community based services so that the individual can **remain** living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

"PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;"

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to what basis SAMHSA has for obtaining the salaries for Disability Rights Ohio's individual PAIMI staff, and object to the inclusion of this section in the PPR. Salaries are private and proprietary, and SAMHSA may not ask for this information without clear statutory or regulatory support. Higher salaries are contained on our 990 filings. Aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is a big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please be in touch with me if you have any questions about this letter.

Best regards,

Michael Kirkman Executive Director



December 30, 2019

Summer King Samuel Wagman SAMHSA Reports Clearance Office 5600 Fishers Lane, Room 14E57B Rockville, MD 20857

SUBMITTED ELECTRONICALLY VIA EMAIL TO: SAMUEL.WAGMAN@SAMHSA.HHS.GOV

RE: AGENCY INFORMATION COLLECTION ACTIVITIES: PROPOSED COLLECTION; COMMENT REQUEST 84 FED. REG. 59836 (NOVEMBER 6, 2019)

Dear Ms. King and Mr. Wagman:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Disability Rights Oregon believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

Disability Rights Oregon is the Protection and Advocacy (P&A) agency for Oregon. P&A agencies are authorized under various federal statutes to provide legal representation and related advocacy services, and to investigate abuse and neglect of individuals with disabilities in a variety of settings. These statutes also require yearly PPRs documenting the work, activity, and outcomes through these various programs.

Yearly, Disability Rights Oregon is required to produce a PPR for the PAIMI program as well as nine other programs administered by Disability Rights Oregon. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked during the last several years

with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with a number of P&As and NDRN during the last several years to incorporate much of the One PPR framework in to this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board,</u> Advisory Council, and Program Staff

We believe the choices for the sex demographic question, nor the two answers, appropriately reflect the diversity of the Governing Board, Advisory Council, or Program staff. It is not uncommon for DRO's Board members, Advisory Council members, or staff, to feel constrained by the traditional definitions of female and male and that the term "sex" does not accurately reflect their demographic characteristics. Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Second, we believe the choices should be the following four: "Male", "Female", "Not Listed", and "Chose Not to Answer".

PAGE 3, SECTION A, #12 – LIST OF MENTAL HEALTH PROFESSIONALS ON THE ADVISORY COUNCIL

Only including mental health professionals as choices for individuals that serve on the Advisory Council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a)(6)(B) includes other categories such as attorneys, providers, and individuals receiving or have received mental health services that are not reflected in this list on Page 3 and should be captured in the PPR.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the Advisory Council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

PAGE 4, SECTION A, #15 - GOVERNING BOARD COMPOSITION

As Disability Rights Oregon's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing Board of Disability Rights Oregon is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing Board, but to properly reflect the governing Board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A Board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PR and would need to be adjusted to reflect that this is the PAIMI PPR.

	Board
TOTAL NUMBERS OF MEMBERS (NON-DUPLICATIVE)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary Consumers	
PAIMI or PAIR or PABSS Other Eligible Secondary	
Consumers	
Other Members	

¹ See https://www.samhsa.gov/workforce.

PAGE 5, SECTION B, #2 - SEX OF PAIMI ELIGIBLE INDIVIDUALS SERVED

As raised in Section A, #11, we believe the choices for the sex demographic question, nor the two answers, appropriately reflect the diversity of the people we serve in Oregon. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Similar to earlier, our fist suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second, we also believe the choices should be the following four: "Male", "Female", "Not Listed", and "Chose Not to Answer".

PAGE 6, SECTION B, #4 - PAIMI-ELIGIBLE INDIVIDUALS SERVED WITH PAIMI PROGRAM FUNDS

Our concern in this question is in #5 where you ask for the number of individuals with cooccurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in Disability Rights Oregon's caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

SECTION C (INSTRUCTIONS): COMPLAINTS/PROBLEMS OF PAIMI-ELIGIBLE INDIVIDUALS

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the

End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

PAGE 12, SECTION C, #8 - INTERVENTION STRATEGIES

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. Because <u>if they are not</u>, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

<u>Self-Advocacy Assistance</u>: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.

<u>Limited Advocacy</u>: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.

<u>Administrative Remedies</u>: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.

<u>Negotiation</u>: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.

<u>Mediation/Alternative Dispute Resolution</u>: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.

<u>Litigation</u>: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

PAGE 15, SECTION C, #11 - 5E - INTERVENTIONS ON BEHALF OF GROUPS OF PAIMI-ELIGIBLE INDIVIDUALS

Disability Rights Oregon suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.

<u>Group Advocacy Services</u>: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

<u>Abuse and Neglect Investigation</u>: An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant

allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

<u>Systemic Litigation</u>: Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

<u>Educating Policy Makers</u>: A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy: Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring: Monitoring includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

PAGE 15, SECTION C, #12 - END OUTCOMES OF P&A ACTIVITIES

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community-based setting to achieve integration and independence. However, there is plenty of Disability Rights Oregon's PAIMI work that is done to ensure that an

individual receives community-based services so that the individual can remain living in the community (such as their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this: "PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;".

PAGE 21 - SECTION G #1 - PAIMI PERSONNEL

We are unclear as to how important it is for SAMHSA to know the salaries for Disability Rights Oregon's individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, these are all contained on our 990 filings. We are generally hesitant to post lower level staff salaries and have these become common knowledge in the organization. I believe aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

CONCLUSION

Again, we appreciate the opportunity to comment on this collection of information and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please be in touch with me if you have any questions about this letter by calling me at (503) 243-2081 or by emailing me at jcornett@droregon.org.

Sincerely,

Jake Cornett
Executive Director

Disability Rights Oregon



Disability Rights Pennsylvania 301 Chestnut Street, Suite 300 Harrisburg, PA 17101 (800) 692-7443 (Voice) (877) 375-7139 (TDD) www.disabilityrightspa.org

December 30, 2019

Summer King SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail - summer.king@samhsa.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Ms. King:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Disability Rights Pennsylvania believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

Yearly, Disability Rights Pennsylvania is required to produce a Program Performance Report (PPR) for the PAIMI program as well as five (5) other programs administered by Disability Rights Pennsylvania. Included in the 5 is the new One PPR for the Administration on Disabilities that includes our Traumatic Brain Injury, Assistive Technology, Help America Vote Act, and Developmental Disabilities grant programs. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each

Protecting and advancing the rights of people with disabilities

report is not standardized, which requires us to spend a large amount of time reviewing data, drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with several P&As and NDRN over the last couple of years to incorporate much of the One PPR framework in to this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI</u>
<u>Governing Board, Advisory Council, and Program Staff</u>

We believe the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Second, we believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer.

<u>Page 3, Section A, #12 – List of Mental Health Professionals on the</u> Advisory Council

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a) (6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

As Disability Rights Pennsylvania's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of Disability Rights Pennsylvania is not constricted to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PR and would need to be adjusted to reflect that this is the PAIMI PPR.

	Board
TOTAL Numbers of Members (non-	
duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary	
Consumers	
PAIMI or PAIR or PABSS Other Eligible	
Secondary Consumers	
Other Members	

Page 5, Section B, #2 - Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our fist suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second, we also again believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer

<u>Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program Funds</u>

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in Disability Rights Pennsylvania's caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as coexistence of any other disability is not reflective of the eligibility of that person.

Section C (Instructions): Complaints/Problems of PAIMI-eligible Individuals As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated

outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 12, Section C, #8 – Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. Because if they are not, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

1. **Self-Advocacy Assistance**: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance include informing a client of their rights; coaching the client in self-

advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.

- 2. **Limited Advocacy**: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.
- 3. **Administrative Remedies**: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. **Negotiation**: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.
- 5. **Mediation/Alternative Dispute Resolution**: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.
- 6. **Litigation**: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

<u>Page 15, Section C, #11 - 5E - Interventions on behalf of groups of</u> PAIMI-eligible individuals

Disability Rights Pennsylvania suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.

Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

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Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multi-plaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with

disabilities. Information reported should only include work done in accordance with the limit on federal funding.

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Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of Disability Rights Pennsylvania PAIMI work that is done to ensure that an individual receives community-based services so that the individual can **remain** living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for Disability Rights Pennsylvania individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, these are all contained on our 990 filings. We are generally hesitant to post lower level staff salaries and have this information common knowledge in the organization. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please be in touch with me at pradecic@disabilityrightspa.org or at 717-236-8110 x302 if you have any questions about this letter.

Sincerely,

Peri Jude Radecic Chief Executive Officer

2222 West Braker Lane Austin, Texas 78758 MAIN OFFICE 512.454.4816 TOLL-FREE 800.315.3876 FAX 512.454.3999



Samuel Wagman National Disability Rights Network 820 First Street, NE Suite 740 Washington, DC 20002

RE: Agency Information Collection Activities: Proposed Collection Comment Request 84 Fed. Reg. 59836

Jan. 6, 2020

DRTx appreciates the opportunity to provide comment on the proposed collection activities for the PAIMI PPR. Specific recommendations are in **bold italics**.

Page 3.

11. Demographic Composition of Board, PAC and Staff

Race: DRTx recommends retaining the option of unknown.

Sex: DRTx supports the recommendation from NDRN to add an option of unknown or not listed as well as adding an option of chose not to answer.

12. Number of Mental Health Professionals on the Advisory Council It is disturbing that the proposed collection of information focuses exclusively on mental health professionals and ignores the other categories of individuals mandated by the PAIMI statute to serve on the PAIMI Advisory Council, particularly individuals who are receiving services as well as family members. The purpose of the PAC is to ensure the PAIMI program is advised by individuals who are recipients of services and their support systems. DRTx recommends that the current categories be retained and reflected for the PAC not just the Board. DRTx supports the NDRN recommendation to add a category for peer support specialists.

Page 5 #1. Age of PAIMI-eligible Individuals Served

DRTx recommends that unknown be added. That is an infrequent but sometimes occurs when in collaboration with other entities, the P&A is asked to sign on to an amicus brief for an individual who is not specifically a DRTx client.

DRTx supports the addition of race unknown.

Page 6 #4. PAIMI-eligible Individuals Served with PAIMI funds

The revision adds the collection of data related to individuals with more than one intervention during the reporting year. Typically DRTx uses the most intense level of intervention in each case rather than

listing each intervention. DRTx recommends reporting the use of the most intense level of intervention instead of each intervention.

The revision adds the collection of information specific to individuals with IDD. DRTx supports the comments submitted by NDRN. With the PAIMI population, the co-occurrence is more often substance use than IDD. Many if not most individuals served by DRTx have multiple diagnoses. DRTx determines eligibility by the primary disability and does not list every diagnoses for each individual. **We do not understand the focus on Individuals with IDD or understand the need for collecting this specific data point and recommend not adding this data element.**

Page 7 Living Arrangements of PAIMI-eligible Individuals at Intake

DRTx supports the changes made to the combined Public and Private general hospitals including emergency rooms; jails; and Independent or parental or other family home, deleting the distinction of within or after 90 days.

Section C (Instructions) Complaints/Problems of PAIMI-eligible individuals

NDRN is familiar with the One PPR and indicates the instructions for this section do not reflect the updated outcomes for the One PPR. DRTx supports using the updated outcome for the One PPR.

Page 8 Areas of Alleged Abuse

DRTx supports the change to b. Inappropriate or excessive restraint and seclusion which combines physical, chemical, mechanical and seclusion.

DRTx supports the change to g. physical assault and h. sexual assault which deletes the reference to a serious injury (often the incident does not result in an injury but remains an important data collection point). DRTx also supports the deletion of the reference to alleged perpetrator. (FYI, if the alleged perpetrator was another person receiving services, the allegation would be investigated as potential neglect by the provider not as abuse.

The category of other limits the data to less than 1% of abuse complaints total. This has been deleted for neglect and rights categories. **DRTx recommends deleting the 1% limit just as it has been deleted for neglect and rights**.

Abuse Disposition – DRTx recommends adding the following outcomes:

- Lost contact (which occurs with individuals with a mental illness who are also involved with the criminal justice system and therefore may move from an institution to another entity. It cannot be assumed that the individual no longer need services and therefore does not fit in another category);
- Outcome unknown (which may occur when the P&A provides only short term assistance, or technical assistance); and

• Lack of resources (which may occur upon staffing or after an expanded intake investigation indicates a much more involved case for which resources are not available, or when a vacancy occurs in staffing patterns).

Page 9 Area of Alleged Neglect

DRTx supports the revision which moves the categories of a. Failure to provide necessary or appropriate medical (other than psychiatric) treatment and b. Failure to provide necessary or appropriate mental health treatment including access to prescribed medication, from abuse to neglect which is more appropriate!

Page 10 - Neglect Complaints Disposition:

DRTx recommends adding the following outcomes:

- Lost contact (which occurs with individuals with a mental illness who are also involved with the criminal justice system and therefore may move from an institution to another entity. It cannot be assumed that the individual no longer need services and therefore does not fit in another category);
- Outcome unknown (which may occur when the P&A provides only short term assistance, or technical assistance); and
- Lack of resources (which may occur upon staffing or after an expanded intake investigation indicates a much more involved case for which resources are not available, or when a vacancy occurs in staffing patterns).

Page 10 5. Areas of Alleged Rights Violations

DRTx recommends deleting b. Failure to provide written discharge plan which is a duplicate of category d. under neglect.

DRTx recommends adding Failure to provide access to personal property. This has become more of an issue as individuals on a forensic commitment remain for significantly longer periods of time. Personal property includes money, clothing, food, electronics and is not captured elsewhere.

Please note that e. The right to refuse to take prescribed medication is more specific but can be captured under d, right to refuse treatment;

DRTx supports the addition of: q housing discrimination; r the denial of access to administrative or judicial process (similar to h); s failure to provide educational services in the least restricted environment; t the denial of access to community based rehabilitation services and/or treatment; u the denial of access to transportation and v. employment discrimination.

Page 12 Rights Violations Disposition

DRTx recommends adding the following outcomes:

- Lost contact (which occurs with individuals with a mental illness who are also involved
 with the criminal justice system and therefore may move from an institution to another
 entity. It cannot be assumed that the individual no longer need services and therefore
 does not fit in another category);
- Outcome unknown (which may occur when the P&A provides only short term assistance, or technical assistance); and
- Lack of resources (which may occur upon staffing or after an expanded intake investigation indicates a much more involved case for which resources are not available, or when a vacancy occurs in staffing patterns).

Page 12 7. Reasons for Closing Individual Advocacy Case File.

DRTx recommends adding:

- lost contact (which occurs with individuals in the forensic system who may move from an institution to another entity but it cannot be assumed that they no longer need services), and
- lack of resources(which infrequently occurs when investigations indicate a much more involved case for which resources are not available to pursue).

Pg 12 # 8. Intervention Strategies

DRTx recommends adding a key to operationalize the outcomes which are not the same as the disposition. The distinction between self-advocacy assistance, limited advocacy and what has been short term assistance is unclear. We recommend clarification of the use of the terms and preferably using short term assistance or limited advocacy.

DRTx recommends that negotiation be retained and included along with mediation.

DRTx recommends retaining abuse/neglect investigations as an intervention. A significant percentage of work done in the PAIMI program involves performing or reviewing investigations of allegations of abuse or neglect which enable us to address individual cases but also to monitor the quality of investigations performed by other entities.

Page 13 #9 Death Investigation Activities

DRTx recommends retaining the reference to and expectation that the state report to the P&A deaths of individuals in their care.

- b) All death investigations conducted involving PAIMI-eligible individuals related to the following:
- c. number of deaths investigated not related to incidents of S&R
- d death investigations with a finding or determination
- e provision in policy added or prevented.

- c, d, and e are listed together in one cell which will be difficult to respond to accurately.
- d. it is not obvious what is trying to be addressed here. It would be rare to have an investigation with no finding or determination. If it is kept it should listed as a separate category but likely will duplicate the information in c, number of deaths investigated not related to restraint or seclusion.
- e. would be more appropriately listed as a disposition.
- **Pg 24 Section H Statement of Priorities (Goals)**
- C. Results narratives of P&A activities and accomplishments related to above priority.

Sections A&C are repetitive. Narratives may be duplicative for case level work.

DRTx appreciates your time and consideration of our comments. If you have questions or require additional information, please contact Aaryce Hayes, Policy Specialist, Disability Rights Texas. ahayes@drtx.org.



January 6, 2020

Mr. Samuel Wagman Substance Abuse and Mental Health Services Administration (SAMHSA) 5600 Fishers Lane Rockville, Maryland 20857

Submitted by e-mail - Samuel.Wagman@SAMHSA.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Mr. Wagman:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. The National Disability Rights Network (NDRN) and the 57 Protection and Advocacy (P&A) agencies we represent believe that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that the P&As do for all their programs as well as ensure that the data collected is as clear and useful as possible.

Yearly, P&A agencies are required to produce a Program Performance Report (PPR) for the PAIMI program as well as up to 7 other programs administered by P&A agencies. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that the P&A agency serves. However, the data requested in each report is not standardized, which requires the P&A agencies to spend a large amount of time drafting and creating the PPRs. Given the limited resources that the P&A agencies have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why NDRN and the P&A agencies appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. NDRN and the P&As worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for

Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. Our ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR by ACL started with Fiscal Year 2019. We applaud SAMHSA for working with NDRN and a number of P&As over the last couple of years to incorporate much of the One PPR framework in to this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we support this new version of the PAIMI PPR overall, there are a couple of suggestions that we would propose SAMHSA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing</u> <u>Board, Advisory Council, and Program Staff</u>

We do not believe the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for P&A board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our first suggestion is to change the title to "Gender" rather than "Sex." Second, we believe the choices should be the following four: Male, Female, Nonbinary, and Chose Not To Answer.

Additionally, the "Race" Category is not consistent with the Race options under A. 17 breaking down program staff demographics. We recommend adding "Native Hawaiian/Pacific Islander" and "Unknown" to the list of Races to make it consistent with the list of Races in A. 17. Finally, ethnicity should also consistently have an "Unknown" option as well.

<u>Page 3, Section A, #12 – List of Mental Health Professionals on the</u> Advisory Council

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a)(6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. We suggest that the categories of the PAIMI statute be added to the category. Further, we strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized. At a minimum an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council.

Page 4, Section A, #15 – Governing Board Composition

As the P&A agencies' impact on people with disabilities encompasses more than individuals with psychiatric disabilities, the governing board of a P&A is not limited to individuals or family members of individuals that have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional options should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the ACL perspective and would need to be adjusted to reflect that this is the PAIMI PPR.

	Board
TOTAL Numbers of Members (non-	
duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	

PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary	
Consumers	
PAIMI or PAIR or PABSS Other Eligible	
Secondary Consumers	
Other Members	

We suggest that the PAIMI PPR include the following: PAIMI eligible individuals, Family members of PAIMI eligible individuals, Individuals with other disabilities, Family members of individuals with other disabilities, and Other members.

Page 5, Section B, #2 – Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our preferred suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". We also again believe the choices should be the following four: Male, Female, Non-binary, and Chose Not To Answer

<u>Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI Program Funds</u>

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in a P&A caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program. Thus, we would first suggest dropping this data point.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if you decide to keep the data point, do not just limit the co-occurring disability to I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be

more useful in describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

<u>Section C (Instructions): Complaints/Problems of PAIMI-eligible</u> Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

Page 11, Section C, #5, s - Areas of Alleged Rights Violations

We appreciate the adding back of an education category in the Alleged Rights Violations section, but we are concerned that the language as written in "s" is too restricting and will cause confusion. We suggest that "s" read as follows, "Failure to provide educational services for PAIMI-eligible individuals".

P&As perform advocacy concerning educational services for PAIMI eligible individuals that is beyond just that the educational services the individual is receiving are provided in the least restrictive environment. Ensuring PAIMI eligible individuals have access to transition services is one such example that is beyond services in a least restrictive environment. While, this example could potentially fit into another category under alleged rights violations, it is cleaner and smoother to just modify the description of "s" so that it is broad and encompasses all educational advocacy work of the P&As under the PAIMI program.

Page 12, Section C, #8 – Intervention Strategies

Again, this is another section we appreciate SAMHSA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this is confusing to P&A staff to have different intervention strategies across programs. This is magnified when you consider that the ONE PPR defines Technical Assistance as a non-client

directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for P&A staff. They are tasked to solve issues at the lowest level, and often this includes negotiating with staff to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. Because if they are not, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

- 1. **Self-Advocacy Assistance**: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of their rights; coaching the client in self advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.
- 2. **Limited Advocacy**: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.
- 3. **Administrative Remedies**: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. **Negotiation**: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.
- 5. **Mediation/Alternative Dispute Resolution**: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.

6. **Litigation**: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

<u>Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals</u>

NDRN suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.

Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (nonlitigious and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

Abuse and Neglect Investigation - An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multiplaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these

individuals makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1) programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving the P&A's help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of PAIMI work that is done to ensure that an individual receives community based services so that the individual can **remain** living in the community (like their own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, we suggest "a" read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, these are all contained on 990 filings. P&A management are generally hesitant to post lower level staff salaries and have these common knowledge in the organization. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please be in touch with Eric Buehlmann of my staff at Eric.Buehlmann@ndrn.org or 202-870-2779 if you have any questions about this letter.

Sincerely,

Curt Decker

Executive Director

OKLAHOMA DISABILITY LAW CENTER, INC.

5555 East 71 Street, Suite 9100 Tulsa, OK 74136

PHONE: (918) 743-6220 V/TDD/FAX (800) 880-7755 V/TDD/FAX http://www.okdlc.org

January 6, 2020

Summer King SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail - summer.king@samhsa.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection; Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Ms. King:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Oklahoma Disability Law Center, Inc. (ODLC) believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

Yearly, ODLC is required to produce a Program Performance Report (PPR) for the PAIMI program as well as seven other programs administered by the Administration on Disability (AOD), the Social Security Administration (SSA) and the Rehabilitation Services Administration (RSA). These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD)

to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with a number of P&As and NDRN over the last couple of years to incorporate much of the One PPR framework into this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are a couple of suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing</u> <u>Board, Advisory Council, and Program Staff</u>

We believe the choices for the sex demographic question, nor the two answers, appropriately reflect the time in which we live. It is not uncommon for our board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Second, we believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer.

<u>Page 3, Section A, #12 – List of Mental Health Professionals on the Advisory Council</u>

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council that are contained in the PAIMI statute. Section 10805(a) (6) (B) includes other categories like attorneys, providers,

individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

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	Board
TOTAL Numbers of Members (non-	
duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary	
Consumers	
PAIMI or PAIR or PABSS Other Eligible	
Secondary Consumers	
Other Members	

Page 5, Section B, #2 – Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our fist suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second, we also again believe the choices should be the following four: Male, Female, Not Listed, and Chose Not to Answer

<u>Section C (Instructions): Complaints/Problems of PAIMI-eligible</u> Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1 - 5 should match the End Outcomes of group advocacy in Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress.

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Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

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Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between the two PPRs. Because if they are not, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

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would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the change to WebBGas to black out the salary information.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is one big step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. Please feel free to contact me if you have any questions about this letter.

Sincerely,

Melissa Sublett, Executive Director

Oklahoma Disability Law Center, Inc.

918-830-5559

melissa@okdlc.org



The Protection & Advocacy System for South Carolina

January 6, 2020

Ms. Summer King SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 14E57B, Rockville, Maryland 20857

Submitted by e-mail - summer.king@samhsa.hhs.gov.

Re: Agency Information Collection Activities: Proposed Collection: Comment Request 84 Fed. Reg. 59836 (November 6, 2019)

Dear Ms. King:

Thank you for the opportunity to comment on this proposed collection of information regarding the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program. Protection and Advocacy for People with Disabilities, Inc. (P&A) serves as the protection and advocacy system in South Carolina. P&A believes that this iteration of the PAIMI Program Performance Report (PPR) is an excellent opportunity to further the work in standardizing the PPRs that we do for all the programs as well as ensure that the data collected is as clear and useful as possible.

Yearly, P&A is required to produce a Program Performance Report (PPR) for the PAIMI program as well as seven other programs. These PPRs contain a wealth of information, including an evaluation of whether the program has met the goals and priorities developed for the year with input from the community and the individuals that we serve. However, the data requested in each report is not standardized, which requires us to spend a large amount of time drafting and creating the PPRs. Given the limited resources that we have, it would directly benefit people with disabilities if the reports could be standardized so that these resources could instead be used to provide direct services to people with disabilities.

That is why we appreciate the efforts of SAMHSA to consider modeling your updates to the PPR on recommendations from the P&A network. Our national

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association, the National Disability Rights Network (NDRN) and the P&As have worked over the last couple of years with the Administration on Disability (AOD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), Protection and Advocacy for Voter Access (PAVA), Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), and Protection and Advocacy for Assistive Technology (PAAT) PPR reporting processes. The ultimate goal was to produce one PPR that effectively and efficiently documents the work of a particular P&A agency while providing AOD and Congress the information they need to properly evaluate these four P&A programs. This work led to the creation of the One PPR that demonstrates the outcomes of the P&A agencies and gives AOD and Congress the information they need to properly evaluate each individual program. The One PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this concept to ultimately streamline the existing reports.

Use of this One PPR started with Fiscal Year 2019, and we applaud SAMHSA for working with a number of P&As and NDRN over the last couple of years to incorporate much of the One PPR framework in to this new version of the yearly PAIMI PPR. We specifically support the inclusion of a number of important data points that were taken out of the last version of the PAIMI PPR, as well adopting the outcomes from the One PPR to standardize data collection and outcomes across the P&A programs. While we overall support this new version of the PAIMI PPR there are several suggestions that we would propose SAMSHA consider before finalizing the new PAIMI PPR.

<u>Page 3, Section A, #11 – Demographic Composition of PAIMI Governing Board, Advisory Council, and Program Staff</u>

We believe there should be choices for the sex demographic question, not the current two answers. This would appropriately reflect the time in which we live. It is likely that board or advisory council members, or staff, to feel constrained by the traditional definitions of female and male. Additionally, the use of the term "sex" connotes a biological definition, while to truly grasp the overall experience of a person, the individual's true identity requires a different term like gender.

Thus, our fist suggestion is to change the title to "Gender" rather than "Sex". Second we believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer.

<u>Page 3, Section A, #12 – List of Mental Health Professionals on the Advisory Council</u>

Only including mental health professionals as choices for individuals that serve on the advisory council ignores the other potential categories of individuals that are allowed to serve on the council and are contained in the PAIMI statute. Section 10805(a) (6) (B) includes other categories like attorneys, providers, individuals receiving or have received mental health services, etc. that are not reflected in this list on Page 3 and should be captured in the PPR somehow.

Should you want to specifically break out the different types of mental health professionals, as referenced in the statute, we are concerned that the list of mental health professionals listed as answers for this question is too narrow for the scope of individuals that may serve on the PAIMI Advisory Council. As SAMHSA's own website shows (https://www.samhsa.gov/workforce) the list of mental health professionals is much broader than the limited list on Page 3. At a minimum an "Other" category needs to be added as an appropriate answer for other types of mental health professionals that may serve on the advisory council. We strongly suggest that Peer Support Specialists should be added as a specifically enumerated choice as this important change in service delivery should be recognized.

Page 4, Section A, #15 – Governing Board Composition

As P&A's impact on people with disabilities encompasses more than individuals with psychiatric disabilities, our governing board is not restricted to individuals or family members of individuals who have received mental health services. We agree that it is important to capture the number of individuals or family members of individuals with disabilities on the governing board, but to properly reflect the governing board's composition, we believe additional answers should be added to this question to reflect other individuals with diverse disabilities and family members of these individuals. For instance, the One PPR contemplates that there is a wider scope of disabilities on a P&A board and could be used as an example for the PAIMI PPR. We have pasted that table down below. We understand that this is written from the perspective of the Administration on Community Living and the One PR and would need to be adjusted to reflect that this is the PAIMI PPR.

	Board
TOTAL Numbers of Members (non-	
duplicative)	
PADD Eligible Primary Consumers	
PADD Eligible Secondary Consumers	
PATBI Eligible Primary Consumers	
PATBI Eligible Secondary Consumers	
AT Users	
PAIMI or PAIR or PABSS Eligible Primary	
Consumers	
PAIMI or PAIR or PABSS Other Eligible	
Secondary Consumers	
Other Members	

Page 5, Section B, #2 – Sex of PAIMI Eligible Individuals Served

As raised in Section A, #11, we believe the use of "sex" does not appropriately reflect the time in which we live nor truly grasp the overall experience of a person. Additionally, the third answer of "unknown/would not disclose" does not appropriately cover that set of individuals.

Like earlier, our first suggestion for this section would be to change the title to "Gender of PAIMI Eligible Individuals Served". Second we also again believe the choices should be the following four: Male, Female, Not Listed, and Chose Not To Answer

<u>Page 6, Section B, #4 - PAIMI-eligible Individuals Served with PAIMI</u> Program Funds

Our concern in this question is in #5 where you ask for the number of individuals with co-occurring mental illness and intellectual and developmental disabilities (I/DD). It is extremely common in our caseload for one individual to identify with more than one disability. Because of this, we do not see the need or importance for collecting this specific data point when it comes to evaluating the program.

However, if you feel this information is important, then limiting it to I/DD does not adequately describe the landscape when it comes to co-occurrence. In fact, as a term of art, co-occurrence typically refers to substance use and mental illness (which is not asked). Additionally, mental illness can, and often does, co-occur with other disabilities such as traumatic brain injury and physical disabilities. We do not see the benefit of restricting this to co-occurrence of mental illness and I/DD. Thus, if the data point is kept, the co-occurring disability should not be limited to just I/DD.

Finally, while the question, if expanded, does potentially yield beneficial information, it feels misplaced in the eligibility section. This question would be more useful in describing the demographics of a program, as co-existence of any other disability is not reflective of the eligibility of that person.

<u>Section C (Instructions): Complaints/Problems of PAIMI-eligible</u> Individuals

As mentioned in the introduction, we appreciate the willingness of SAMHSA to consider the outcomes of the One PPR when constructing the outcomes of the new PAIMI PPR so that they more accurately reflect P&A individual and group advocacy. That said, the instructions for this section (abuse section instructions are on page 3) do not reflect these updated outcomes. In particular, both for internal consistency and to provide consistent outcome information, the outcomes of individual advocacy in Section C of Areas 1, 3 and 5 should match the End Outcomes Section 12. The outcomes in Section 12 were specifically developed to provide information for SAMHSA to use in its reporting to Congress. Otherwise after completing charts for abuse, neglect, and rights outcome, P&A staff will then need decide which category in Section 12 it relates to. Ideally, all positive outcomes should easily "fit" into one of the End Outcomes without additional analysis. For efficiency, at the closing of each case, the relevant outcome should be identified so totals for End Outcome can be computergenerated.

Page 12, Section C, #8 - Intervention Strategies

Again, this is another section we appreciate SAMSHA's willingness to harmonize the intervention strategies between the One PPR and the PAIMI PPR to more accurately reflect P&A advocacy, but that did not occur in the way this section is currently written. We noticed that the PAIMI PPR continues to have the "Technical Assistance" option. We believe that this could be confusing to staff to have different intervention strategies across programs. This is magnified when you consider that the One PPR defines Technical Assistance as a non-client directed activity. Cases that would be PAIMI Technical Assistance could easily fall under limited Advocacy and eliminate the confusion.

Additionally, we ask that you add "Negotiation." This is an important strategy for our staff. They are tasked to solve issues at the lowest level, and often this includes negotiating to obtain good outcomes for their clients. Limited Advocacy could describe this strategy, but it seems richer to add the additional category, as it is such a common way that our staff do their work.

Even if the list is the same between the One PPR and the PAIMI PPR, it is critically important that the definitions of these strategies be the same between

the two PPRs. Because if they are not, then the increase in efficiency through harmonized PPRs will be lost. Thus, we have included below the definitions from the One PPR to be used in the instructions on this question.

- 1. **Self-Advocacy Assistance**: Self-advocacy Assistance, formerly referred to as Short Term Assistance, is a level of intervention that can include advice and counseling, brief research, or letter writing to the client to summarize assistance given. Advice and counseling assistance includes informing a client of [the client's] rights; coaching the client in self-advocacy; reviewing information; counseling a client on actions one may take; or assisting the client in preparing letters or documents and/or the dissemination of information and materials related to the disability rights issue raised by the client. It includes providing information sheets and other materials.
- 2. **Limited Advocacy**: Limited Advocacy is a level of intervention that includes the provision of a discrete task to a client or a discrete contact on behalf of a client with a third party. Such activities upon completion require no further or ongoing actions, either formal or informal. Limited Advocacy can include communications by letter, telephone or other means to a third party; preparation of a simple legal document; or assisting a client in the preparation of documents that are submitted by the client pro se to a third party.
- 3. **Administrative Remedies**: An Administrative Remedy is any non-judicial complaint resolution process provided by government agencies, boards, commissions, or other designated adjudicators, exercising decision making authority delegated by statute. Administrative Remedy processes are generally simpler, less formal, and less technical than the judicial process.
- 4. **Negotiation**: Negotiation is a problem-solving process in which two or more people voluntarily discuss their differences and attempt to reach a joint decision on their common concerns.
- 5. **Mediation/Alternative Dispute Resolution**: Mediation is an alternative dispute resolution process using the services of an independent third party to help settle differences or disputes between two or more individuals.
- 6. **Litigation**: Litigation is any lawsuit or other resort to the courts to determine a legal question or matter. Litigation involves many complex legal issues which require not only a knowledge of the law that governs the dispute, but also, the laws governing the procedures to be followed in order to properly litigate a claim. There are rules governing who may file a claim, where it must be filed, when it must be filed, and how to file it.

<u>Page 15, Section C, #11 - 5E - Interventions on behalf of groups of PAIMI-eligible individuals</u>

P&A suggests that the definitions for group advocacy interventions be consistent with those in the One-PPR which again more accurately reflect the work of the P&As. These definitions follow.

Group Advocacy Services: Group advocacy services include work on behalf of groups of people with disabilities pursued through the interventions of systemic litigation, legislative and regulatory advocacy and systemic advocacy (non-litig[ation] and non-legislative). It is concerted action to reform the policies or mode of operations of a system of services such as the disabilities service system or the policies and practices of private actors. Report the intervention strategy (abuse and neglect investigation; systemic litigation; educating policymakers; and other systemic advocacy) used in each case/project. You may select more than one per project.

Abuse and Neglect Investigation - An investigation is a systematic and thorough examination of information, records, evidence and circumstances surrounding an allegation of abuse and neglect. Investigations are distinct from advocacy and require a significant allocation of time and resources including such activities as interviewing witnesses, gathering evidence and generating a written report, which may or may not be made public.

Systemic Litigation - Systemic litigation is a concerted action to reform the policies or mode of operations of a system of services. It attempts to address a systemic issue raised by many individuals, through class action litigation, multiplaintiff litigation, or in some cases individual litigation when the relief sought has the potential of affecting many people with disabilities.

Educating Policy Makers- A critical strategy used to achieve systems change. Policy-makers may include individuals in both the executive and legislative branches of government who make or interpret policies (legislation, regulations, rules or practices) that impact the lives of people with disabilities. Our advocacy efforts might be directed at the local, state, or federal level. Educating these individual makes them aware of how their actions may impact people with disabilities. Information reported should only include work done in accordance with the limit on federal funding.

Other Systemic Advocacy - Other Systems Advocacy refers to concerted action by the P&A agency to promote and effectuate changes in the policies, rules, and laws that impact groups of people with disabilities, and to remove the barriers that prevent or impede them from leading full, productive lives in the community that does fit elsewhere in the form. Systems advocacy typically addresses the establishment, support, improvement, or expansion of (1)

programs that provide services or benefits to persons with disabilities, and (2) the legal rights, protections, and entitlements of persons with disabilities; and may involve opposition to efforts to weaken, reduce or eliminate existing services or rights.

Monitoring - Includes activities in which a P&A evaluates compliance issues and quality of service by providers of services, supports and other assistance. Monitoring may involve using the a P&A's access authority to visit and in other ways seek information from institutional or community settings including public and private facilities where people with disabilities live, work and go to school by a) conducting face-to-face interviews with individuals with disabilities in those settings; b) conducting at least one face-to-face interview with a staff member in those settings; 3) observing and evaluating the physical conditions of the setting; and 4) accessing and reviewing records, when appropriate, in accordance with applicable federal and state law.

Page 15, Section C, #12 - End Outcomes of P&A Activities

The phrasing in "a" implies that the individual is receiving our help to move from a segregated setting to a community based setting to achieve integration and independence. However, there is plenty of our PAIMI work that is done to ensure that an individual receives community based services so that the individual can **remain** living in the community (like the individual's own home) and be integrated and independent. Thus, we believe that "a" should specifically reference maintaining already existing community integration. So, for example, "a" could read as this:

PAIMI-eligible individuals who are provided with appropriate community-based services resulting in, or maintaining, community integration and independence;

Page 21 - Section G #1 - PAIMI Personnel

We are unclear as to how important it is for SAMHSA to know the salaries for P&A's individual PAIMI staff. While we understand that it is beneficial to understand the higher salaries, these are all contained on our 990 filings. We are generally hesitant to post lower level staff salaries and have these common knowledge in the organization. It seems as though aggregate salary information would accomplish the needs of SAMHSA, while also maintaining the integrity of the lower level data. We do applaud the recent change to WebBGAS as to limit access to identifiable salary information.

Page 2, Item 10 Commissioner/Director of State Mental Health Agency

We recognize one unique aspect of the PAIMI PPR that would warrant an additional notation in the form. 42 U.S. Code Section 10805 (7) requires P&As to provide a copy of their annual PPR to the head of their state mental health agency. For that reason the name and contact information of the individual is included on page 2 of the form. As a helpful reminder of this requirement, the statute was cited in the PPR form as late as the FY16 PPR. It does not appear in the WebBGAS form. It would be helpful if this were again noted, at least in a footnote.

Again, we appreciate the opportunity to comment on this collection of information, and believe this new PPR is a significant step to a streamlined data collection process that will provide the necessary data to show the effectiveness of the PAIMI program to SAMSHA and Congress. If you have any questions about this letter I may be reached at zoellner@pandasc.org and 843 763 8571 Extension 305. I have been with P&A in South Carolina for over 25 years and as managing attorney have been closely involved with preparation of our PPRs. I served as a SAMHSA consultant for 15 P&A monitoring visits and as a PPR reviewer in Washington DC in the years that process was used.

Sincerely,

David H. Zoellner Managing Attorney