

Attachment A - Comments



HAWAII DISABILITY RIGHTS CENTER

1132 Bishop Street, Suite 2102, Honolulu, Hawaii 96813

Phone/TTY: (808) 949-2922 Toll Free: 1-800-882-1057 Fax: (808) 949-2928

E-mail: info@hawaiidisabilityrights.org Website: www.hawaiidisabilityrights.org

June 6, 2016

Summer King,
SAMHSA Reports Clearance Officer
Room 15E57-B, 5600 Fishers Lane
Rockville, MD 20857

RE: HDRC Comment on PAIMI PPR

Dear Ms. King,

The Hawaii Disability Rights Center, Hawaii's designated protection and advocacy system, appreciates the opportunity to comment on your assessment of the usefulness, format and efficiency of the PAIMI annual program performance report.

While we may have some general issues with the PAIMI PPR, we are specifically concerned with the suggestion by NDRN that it will be improved by modeling the PPR used for the Developmental Disabilities grant.

As you are aware, the Administration on Intellectual and Developmental Disabilities (AIDD) recently approved revision of their PADD annual program performance report. We have found the revised DD PPR, with its convoluted reporting requirements, to be much more difficult to complete, and its design is such that it does not accurately reflect the significant work we have done with the federal funding.

It is our understanding that NDRN is working to improve the revised DD PPR. We hope that over time they will do so and we continue to encourage that effort. However, until that occurs, in the meantime, we would urge SAMHSA to avoid using the PADD PPR as a model until such substantial improvements are made.

Thank you for your consideration.

Very truly yours,

Louis Erteschik, Esq.
Executive Director



HAWAII'S PROTECTION AND ADVOCACY SYSTEM FOR PEOPLE WITH DISABILITIES
HAWAII'S CLIENT ASSISTANCE PROGRAM

CAP

disABILITY LAW CENTER
OF VIRGINIA



Protection & Advocacy for Virginians with Disabilities

1512 Willow Lawn Drive, Suite 100, Richmond, VA 23230
www.dLCV.org

T:800-552-3962
F:804-662-7431

June 6, 2016

Summer King,
SAMHSA Reports Clearance Officer
Room 15E57-B, 5600 Fishers Lane
Rockville, MD 20857

RE: dLCV Comment on PAIMI PPR

Dear Ms. King,

The disAbility Law Center of Virginia (dLCV), Virginia's designated protection and advocacy system, appreciates the opportunity to comment on your assessment of the usefulness, format and efficiency of the PAIMI annual program performance report.

While we find the PAIMI PPR to be cumbersome to complete and not especially useful to our constituents, we do not believe that it will be improved by modeling the PPR used for the Developmental Disabilities grant.

As you are aware, the Administration on Intellectual and Developmental Disabilities (AIDD) recently approved revision of their PADD annual program performance report. Virginia was one of the states to use the PADD PPR in its pilot form. The revised PADD PPR is much more difficult to complete, and more importantly, it is designed such that we are not able to report some of the significant work we have done with federal funding.

In Virginia, we make our PPRs available to the public on our website, we use them as QA tools and as outreach tools. The PADD PPR is un-usable for any of those tasks. The data reporting requirements are so convoluted that we can not have any confidence in the numbers. Further, the data that is collected does not accurately reflect the amazing work that my staff does in critical areas of our operation.

It is our understanding that NDRN is working to improve the revised PADD PPR. dLCV encourages SAMHSA to avoid using the PADD PPR as a report model until substantial improvements are made. In the meantime, any steps that SAMHSA can take to streamline the PAIMI PPR to make it more reader-friendly would be greatly appreciated by our constituents.

Thank you for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read 'Colleen Miller', is written over a horizontal line.

Colleen Miller
Executive Director



Disability Rights

WASHINGTON

Washington's protection and advocacy system

June 6, 2016

Summer King
Statistician
Substance Abuse and Mental Health Services Administration

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

Re: Comments on Proposed Project: Collection of Information on Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program 81 Fed. Reg. 19611 (April 5, 2016)

Dear Ms. King:

I am the Executive Director of Disability Rights Washington (DRW), our PAIMI Coordinator, former Chair of the National Disability Rights Network's (NDRN) Outcomes Committee and a current member of AIDD's Steering Committee for program performance report revisions. In my role as PAIMI Coordinator, I have prepared 25 annual PAIMI Program Performance Reports since coming to DRW in 1990. I also have been responsible for preparing the program performance reports for the Protection and Advocacy for Developmental Disabilities (PADD) program and the Protection and Advocacy for Individual Rights (PAIR) program since their inceptions. While I will be sharing information derived from the work I did in all of these roles, the comments that follow are being submitted on behalf of Disability Rights Washington and not any other entity.

DRW recommends making whatever changes to 81 Fed. Reg. 19611 that are necessary to achieve the result of SAMSHA revising its current program performance report in ways consistent with these comments. DRW recommends SAMSHA engage NDRN and cover the cost to create the necessary infrastructure (database, computer generated reports and reporting platform) for a new program performance report based on the one recently adopted by AIDD for the PADD program. DRW recommends using the second and third attachments of the email delivering these comments as a starting point for a collaboration between SAMSHA and NDRN. We would like the collaboration to result in the creation of a mutually agreeable program performance report for use with the Fiscal Year 2018 report due December 31, 2018. What follows immediately is background regarding the new AIDD Program Performance Report (PPR) and Statement of Goals and Priorities (SGP).

On October 16, 2012 the membership of the National Disability Rights Network, which includes all P&A entities, endorsed by unanimous vote a Model Program Performance Report designed for use with the Protection and Advocacy for Individuals with Mental Illness (PAIMI); Protection and Advocacy for Intellectual and Developmental Disabilities (PADD); and Protection and Advocacy for Individual Rights (PAIR) programs with the intent that it be modified in the future for use with the Protection and Advocacy for Traumatic Brain Injuries (PATBI); Protection and Advocacy for Assistive Technology (PAAT); Protection and Advocacy for Voting Access (PAVA) and Protection and Advocacy for Beneficiaries of Social Security (PABSS) programs. This vote came after extensive

315 - 5th Avenue South · Suite 850 · Seattle, WA 98104
t: 206.324.1521 or 800.562.2702 · tty: 206.957.0728 or 800.905.0209 · f: 206.957.0729
email: info@dr-wa.org · www.disabilityrightswa.org

DRW is a member of the National Disability Rights Network. A substantial portion of the DRW budget is federally funded.

review and input by the P&A network including multiple drafts over a year's time (August 2011 to October 2012).

The idea at the time was to approach our various funders and ask that the Model Performance Report be used as a guide in making revisions to the current at that time program performance reports to improve efficiency and avoid unnecessary duplication while at the same time presenting the work of these programs in the best possible light for the Executive and Legislative branches of government.

Around the same time AIDD made it known that they intended to revise their PADD Program Performance Report (PPR) and Statement of Goals and Priorities (SGP). After consultation with NDRN, AIDD agreed to collaborate with NDRN in the revision of their SGP and PPR using the Model PPR endorsed by NDRN's membership as a starting point for the discussion. AIDD chose some of the members of NDRN's Outcomes Committee (my self-included) and two NDRN staff members to serve on a steering committee which had as its purpose advising AIDD in its effort to revise the PADD PPR SGP. As a result, AIDD revised their PPR SGP mostly along the lines of the Model PPR and conducted a two year pilot program ending on December 31, 2015 when the P&As participating in the pilot program submitted their PADD PPR SGP using the revised format. All P&As will be using the new PADD PPR and SGP for their Fiscal Year 2016 report for the period ending September 30, 2016.

Recently, the Administration for Community Living (ACL), the entity where the PADD P&A program is housed, became the funding agency for three additional P&A programs: PAAT, PATBI and PAVA (see above for acronym meaning). AIDD is now in the process of revising the PPRs for these programs. The AIDD PPR SGP based on the Model PPR is being used as a guide for revisions of the PPRs for these programs. As these programs are smaller and more specialized, it is anticipated their PPRs will be a streamlined version of the AIDD PPR. When this work is complete, four of the seven P&A programs will have program performance reports that are based on the Model PPR endorsed by NDRN's membership on October 16, 2012.

You may hear from P&As opposed to using the Model PPR as a guide to changing the PAIMI Program Performance Report. I have long had some concern that the strains of a complicated and messy implementation would erode support for our goal of having a set of program performance reports that present the value of our work in the best possible light in the most efficient manner possible. However, the AIDD PPR SGP and the overall effort to revise all of PPRs is a work in progress and many of the things that will make it more efficient are not yet fully implemented and some of what will make the overall reporting process better cannot be implemented until we integrate the other reports into a single approach. It is very difficult to make people see the efficiencies of the new system while having to continue the data collection for and preparation of all of the other significantly different program performance reports. Training on the new system for one report while having to continue six other program performance reports is a nightmare but, if we want to make progress, a necessary one.

The PPRs for these programs have often asked the same basic questions in different ways and sometimes in different places. When like data is collected in the same way and in the same place the data records will not have to be cluttered with duplicative fields that are needed for one program's report but not another. This will make data entry easier and less confusing. It will also make it easier to modify the database in the future. This is illustrated by a problem we are experiencing right now in terms of updating the database for the AIDD PPR and SGP. We have to add some new fields to accommodate the changes in the PADD PPR SGP but we can't always (especially when a project has multiple funding sources) remove a number of duplicative fields in the data records because they ask for the same information in different ways and are needed for the one or more of the other PPRs.

The answer is not to slow or stop movement toward implementation of Model PPR in all of the P&A programs. That will just leave us indefinitely having to navigate a morass of different reporting requirements full of inefficiencies and confusion.

Here are just some of the benefits of replacing the PAIMI PPR with the Model PAIMI Report:

- The Results Narrative concept gives meaning to the numbers used in documenting accomplishments along introduced in the Model PPR provides a holistic, integrated approach to presenting the work of P&As in a way that with narrative that tell the stories of the people we help.
- The use of end and other outcome performance measurements in a way that can be aggregated across P&As provide a much more meaningful tool for understanding the accomplishments of the program than the output measures currently in use in the PAIMI and other program performance reports.
- Duplicative and incongruent reporting is eliminated. Information common to all seven reports will only have to be entered once in a central location.
- A P&A's ability to use a single database with all 7 programs will be easier and less expensive when the Model PPR is fully implemented.
- A P&A's ability to develop or share accurate training materials on how to enter and aggregate data for reporting will be easier and less expense when the Model PPR is fully implemented.

DRW thanks you for consideration of these comments.

Sincerely,

Mark Stroh, Executive Director
Disability Rights Washington

From: Mark Stroh [<mailto:mstroh@dr-wa.org>]

Sent: Monday, June 06, 2016 12:47 PM

To: King, Summer (SAMHSA/OPPI)

Subject: Comments on Proposed Project: Collection of Information on Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program 81 Fed. Reg. 19611 (April 5, 2016)

Ms. King:

Here is one further comment on the Collection of Information on Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program 81 Fed. Reg. 19611 (April 5, 2016). DRW would like the language in blue be added after the current language indicated in black:

“These annual PAIMI Program Performance Reports (PPR) to the Secretary must include the following information: • The number of (PAIMI-eligible) individuals with mental illness served; • A description of the types of activities undertaken; • A description of the types of facilities providing care or treatment to which such activities are undertaken; • A description of the manner in which the activities are initiated; • A description of the accomplishments resulting from such activities; • A description of systems to protect and advocate the rights of individuals with mental illness supported with payments from PAIMI Program allotments; • A description of activities conducted by States to protect and advocate such rights; • A description of mechanisms established by residential facilities for individuals with mental illness to protect such rights; and, • A description of the coordination among such systems, activities and mechanisms; • Specification of the number of public and nonprofit P&A systems established with PAIMI Program allotments; • Recommendations for activities and services to improve the protection and advocacy of the rights of individuals with mental illness and a description of the need for such activities and services that were not met by the State P&A systems established under the PAIMI Act due to resource or annual program priority limitations. It is not required that the information listed above for inclusion in the program performance report be siloed into different sections that align with each of the above bullets . A holistic, integrated approach to the organization and presentation of information in the PAIMI program performance report is permissible.”

Mark Stroh

Executive Director

Disability Rights Washington

315 5th Avenue S, Suite 850 | Seattle, WA 98104

voice: 206.324.1521 or 800.562.2702 | fax: 206.957.0729

www.disabilityrightswa.org | www.rootedinrights.org | www.donatetodrw.org

Disability Rights Washington (DRW) is a private non-profit organization that protects the rights of people with disabilities statewide. Our mission is to advance the dignity, equality, and self-determination of people with disabilities. We work to pursue justice on matters related to human and legal rights.

The contents of this message and any attachment(s) may contain confidential or privileged information. Any disclosure, copying, distribution, or unauthorized use of the contents of this message is prohibited and doing so may destroy the confidential nature of the communication. If you have received this message by mistake, please do not review, disclose, copy, or distribute the email. Instead, please notify us immediately by replying to this message or phoning us.

Additionally, people sending email to DRW have a reasonable expectation of privacy. However, DRW does not use encryption, and all email coming to DRW is routed through a third party internet service provider (ISP) before it reaches DRW. Although it is unlikely that an ISP will intercept and review a message, it is a possibility, especially if a message is incorrectly addressed and "bounced back" to the sender.

From: Mark Stroh

Sent: Monday, June 06, 2016 8:49 AM

To: 'summer.king@samhsa.hhs.gov' <summer.king@samhsa.hhs.gov>

Subject: Comments on Proposed Project: Collection of Information on Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program 81 Fed. Reg. 19611 (April 5, 2016)

Dear Ms. King:

The three attachments constitute Disability Rights Washington's comments on Proposed Project: Collection of Information on Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program 81 Fed. Reg. 19611 (April 5, 2016). Thank you for this opportunity.

Mark Stroh

Executive Director

Disability Rights Washington

315 5th Avenue S, Suite 850 | Seattle, WA 98104

voice: 206.324.1521 or 800.562.2702 | fax: 206.957.0729

www.disabilityrightswa.org | www.rootedinrights.org | www.donatetodrw.org

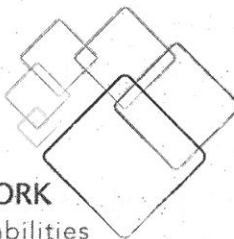
Disability Rights Washington (DRW) is a private non-profit organization that protects the rights of people with disabilities statewide. Our mission is to advance the dignity, equality, and self-determination of people with disabilities. We work to pursue justice on matters related to human and legal rights.

The contents of this message and any attachment(s) may contain confidential or privileged information. Any disclosure, copying, distribution, or unauthorized use of the contents of this message is prohibited and doing so may destroy the confidential nature of the communication. If you have received this message by mistake, please do not review, disclose, copy, or distribute the email. Instead, please notify us immediately by replying to this message or phoning us.

Additionally, people sending email to DRW have a reasonable expectation of privacy. However, DRW does not use encryption, and all email coming to DRW is routed through a third party internet service provider (ISP) before it reaches DRW. Although it is unlikely that an ISP will intercept and review a message, it is a possibility, especially if a message is incorrectly addressed and "bounced back" to the sender.

NATIONAL
DISABILITY RIGHTS

NETWORK



Protection & Advocacy for Individuals with Disabilities

June 6, 2016

Summer King
Statistician
Substance Abuse and Mental Health Services Administration

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

**Re: Comments on Proposed Project: Collection of Information on
Protection and Advocacy for Individuals with Mental Illness (PAIMI)
Program 81 Fed. Reg. 19611 (April 5, 2016)**

Dear Ms. King:

Thank you for the opportunity to comment on this proposed extension of 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 proposed extension is an excellent opportunity to further the work in standardizing the Program Performance Reports 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 8 different 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.

NDRN and the P&A agencies have just completed our work with the Administration on Intellectual and Developmental Disabilities (AIDD) to streamline the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) PPR reporting process. Our ultimate goal was to produce a document that effectively and efficiently documents the work of a particular P&A agency while providing AIDD and Congress the information they need to properly

evaluate the PADD program. This work on the PADD PPR ultimately led to the creation of a PPR that demonstrates the work of the P&A agencies and gives AIDD and Congress the information they need to properly evaluate each individual program. The PPR itself was designed with the idea that all P&A programs, including the PAIMI program, can use this PPR to streamline the existing eight separate reports.

Use of this PADD PPR started in September of Fiscal Year 2016. We believe that SAMHSA should follow AIDD's lead and work with NDRN and the P&As to use much of this model PPR as the framework for the yearly PAIMI PPR. Attached is a copy of this model PPR for your information and consideration.

In addition to the use of this model PPR to reduce the burden of data collection on the P&As, NDRN believes that the continued use of the electronic data collection system created a couple years ago has increased the effectiveness of the data reporting. Rather than having to file paper versions of the report, the creation of a standardized electronic format has streamlined the collection of and delivery of the PAIMI PPR. It is imperative that SAMHSA continue to financially support the upkeep of this electronic database so that it can remain available for use in completing the PAIMI PPR.

Again, we appreciate the opportunity to comment on this collection of information, and continue to believe that SAMHSA should work with NDRN and the P&As using the model PADD PPR as a basis to create a more streamlined data collection process that would be adopted by SAMHSA for the PAIMI PPR. Please feel free to be in touch with Eric Buehlmann of my staff at Eric.Buehlmann@ndrn.org or 202-408-9514 if you have any questions about this letter.

Sincerely,



Curt Decker
Executive Director