Maternal and Child Health Bureau Performance Measures for Discretionary Grant Information System (DGIS) OMB Control No. 0915-0298 - Revision

Attachment E - Public Comments

From: Angela Lindig <<u>angela@ipulidaho.org</u>> Sent: Tuesday, January 25, 2022 3:27 PM To: HRSA Paperwork <<u>paperwork@hrsa.gov</u>> Subject: [EXTERNAL] Maternal and Child Health Bureau (MCHB) Performance Measures for Discretionary Grant Information System (DGIS), OMB No. 0915-0298—Revision.

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I'd like to request a copy of the proposed revisions for the F2F (Family to Family Form 1).

Thank you.

Angela Lindig Executive Director Idaho Parents Unlimited Statewide Parent Training and Information Center Family to Family Health Information Center/Idaho Family Voices IPUL Arts 4619 W. Emerald St., Ste E Boise, ID 83706 208.342.5884 x102 Office 208.696.8016 Cell 208.342.1408 Fax

Idaho Parents Unlimited supports, empowers, educates and advocates to enhance the quality of life for Idahoans with disabilities and their families

Serving Idaho Families with Exceptional Children Since 1985

From: Kira Rodriguez <<u>krodriguez@une.edu</u>>

Sent: Wednesday, January 26, 2022 12:40 PM

To: HRSA Paperwork <<u>paperwork@hrsa.gov</u>>

Subject: [EXTERNAL] Agency Information Collection Activities: Proposed Collection: Public Comment Request; Maternal and Child Health Bureau Performance Measures for Discretionary Grant Information System

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Hello,

I am writing to request a copy of the data collection plans and draft instruments for the Maternal and Child Health Bureau Performance Measures for Discretionary Grant Information System changes published in the Federal Register on 1/21/2022 by the Health Resources and Services Administration (HRSA), Department of Health and Human Services.

Thank you for your time, Kira

Kira Rodriguez (She/Her/Hers) Senior Research Associate Center for Excellence in Public Health University of New England (UNE) 716 Stevens Ave. Portland ME krodriguez@une.edu (907)360-8687

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Sent: Thursday, January 27, 2022 9:34 AM
To: HRSA Paperwork cpaperwork@hrsa.gov>
Cc: James, Cristina <crijames@iu.edu>
Subject: [EXTERNAL] Draft information request

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Information Collection Request Title:

Maternal and Child Health Bureau (MCHB) Performance Measures for Discretionary Grant Information System (DGIS), OMB No. 0915–0298—Revision.

I would like to request a copy of the data collection plans and draft instruments related to these DGIS revisions, please. And any further information that may be relevant to those.

Thank you, Cristy James

Cristina James Data Coordinator Associate Training Director Indiana LEND Department of Pediatrics, Division of Developmental Medicine

Indiana University School of Medicine 1002 Wishard Blvd, Suite 3120 Indianapolis, IN 46202 317-948-5869 crijames@iu.edu Sent: Saturday, January 29, 2022 6:18 AM
To: HRSA Paperwork <<u>paperwork@hrsa.gov</u>>; Augustyn, Marilyn C <<u>augustyn@bu.edu</u>>
Subject: [EXTERNAL] support

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Hello,

I am a T77 PD and am writing to fully support **proposed DGIS form updates** for implementation in calendar year 2023- I only wish it could happen sooner! This move will improve our ability to understand the trainees re gender diversity and also decrease the immense burden of completing these forms. Thank you!

Marilyn Augustyn MD Division Director Developmental and Behavioral Pediatrics Boston Medical Center Boston University School of Medicine

#whitecoatsforblacklives

"Spread love whenever you go. Let no one ever come to you without leaving happier."- Mother Teresa

Join us at the first ever HYBRID <u>Steven J. Parker Memorial Developmental-Behavioral Pediatric Conference:</u> <u>Clinical Problems in Primary Care (Hybrid -2022) | BUSM CME</u> Sent: Monday, February 14, 2022 4:14 PM To: HRSA Paperwork <<u>paperwork@hrsa.gov</u>> Cc: LeMieux, Mary <<u>MLeMieux2@mt.gov</u>> Subject: [EXTERNAL] Maternal and Child Health Bureau Discretionary Grant Information System (DGIS), OMB No. 0915–0298—Revision

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Good afternoon,

I would like a copy of the data collection plans and the draft instruments for the changes to the MDRBD DGIS report. This will help us review the changes with our data/evaluation team. Warmly, Sarabeth

Sarabeth Upson, MPH

Personal Pronouns: She/Her/Hers Perinatal Behavioral Health Initiative Program Officer—Meadowlark Initiative and PRISM for Moms Maternal Depression and Related Behavioral Disorders (MDRBD) Grant Manager Member Services Bureau

PO Box 202951 | 1400 E Broadway 2nd Floor | Helena MT 59620 P: 406.444.0950 C.: 978.460.2203





From: Cari Schmidt <<u>cschmidt3@kumc.edu</u>>
Sent: Tuesday, February 15, 2022 1:33 PM
To: HRSA Paperwork <<u>paperwork@hrsa.gov</u>>
Subject: [EXTERNAL] OMB No. 0915–0298—Revision

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Good afternoon,

Can you please provide copies of the draft instruments for the Maternal and Child Health Bureau Performance Measures for Discretionary Grant Information System?

Thank you,

Cari

Cari Schmidt, PhD Director, Center for Research for Infant Birth and Survival Director, Pediatric Research Division Research Professor Department of Pediatrics KU School of Medicine-Wichita 3243 E Murdock, Suite 602 Wichita KS 67208 316-962-7923 From: Upson, Sarabeth <<u>Sarabeth.Upson@mt.gov</u>> Sent: Monday, March 7, 2022 11:55 AM

To: HRSA Paperwork <<u>paperwork@hrsa.gov</u>>

Cc: LeMieux, Mary <<u>MLeMieux2@mt.gov</u>>

Subject: [EXTERNAL] Formal public comment by Montana in regards to Public Comment Request; Maternal and Child Health Bureau Performance Measures for Discretionary Grant Information System Document Citation: 87 FR 3313

Importance: High

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To Whom it may Concern,

Please see Montana's MDRBD Program feedback/public comment in regards to changes to the DGIS form. Sincerely, Sarabeth

Sarabeth Upson, MPH

Personal Pronouns: She/Her/Hers

Perinatal Behavioral Health Initiative Program Officer—Meadowlark Initiative and PRISM for Moms Maternal Depression and Related Behavioral Disorders (MDRBD) Grant Manager

Maternal Depression and Related Benavioral Disorders (MDRBD) Grant Manage Member Services Bureau PO Box 202951 | 1400 E Broadway 2nd Floor | Helena MT 59620

PO Box 202951 | 1400 E Broadway 2rd Floor | Helena MT 59620 P: 406.444.0950 C.: 978.460.2203



MT DGIS Feedback

Our state agrees with removing the following existing forms: Core 1 (Grant Impact), Capacity Building 2 (Technical Assistance), Financial Form 2 (Project Funding Profile), and Financial Form 4 (Project Budget and Expenditures), which are the four forms reported by MDRBD programs. This will reduce some administrative burden on the state program staff.

An issue that has always come up with the DGIS report is having different age ranges for each measure makes the DGIS report more time-consuming to complete. For this patient-level data, we have only ever submitted data on Medicaid patients, which is the data we have access to at our state public health department. Therefore, we agree with changes to Form 5 (now Form 3), which changes the age categories to be consistent across measures, such as matching up with Form 3 (now Form 2).

Given that the administrative burden on enrolled providers is already high when it comes to reporting the quarterly data, we are concerned with requiring more patient-level data in addition to the other data, which will likely lead to sites not wanting to participate in the Meadowlark Initiative care coordination model nor call the PRISM for Moms teleconsultation line.

As it relates to the new Training Form 14, for our state, hand counting the specialty providers for trainings is a large administrative burden and not all provider types fall into the designated categories. We have received inconsistent information from HRSA about how to handle the other provider types, such as just putting them in the "Other" category or adding additional provider type columns to the Form 10 HRSA spreadsheet to accommodate the different provider types. Having written, consistent guidance from HRSA about on how to accurately count provider types would be helpful for future reporting.

We disagree with adding the Leadership, Education, and Advancement in Undergraduate Pathways Training Program Trainee Information Form. Very few states were selected for this program, and our state was not selected, so it does not even apply to most MDRBD states. This data is not currently being tracked by our Department and would need to be added to all training registration forms. This would cause a large administrative burden for any training/conference put on by our program and providers may ask why they now need to report all this additional demographic data when they have not needed to report this data to attend previous training/conferences.

It is helpful to have the clearer, operational definitions for enrolled providers, participating providers, and care coordination. For our state, most providers using the teleconsultation line are participating providers, based on the definition provided in this guidance. Our state decided not to require providers to submit data to HRSA (be an enrolled provider) because we did not want to preclude providers from calling the teleconsultation line when there are already limited resources for providers in our state to adequately treat their patients' mental health needs. There is a very small overlap with enrolled providers who submit data and enrolled providers who call the teleconsultation line. Enrolled providers in our state sign a two-year contract with DPHHS to submit HRSA data while participating providers do not have a contract with DPHHS to submit any HRSA data, but both provider types are allowed to call the teleconsultation line.

From: Clarissa Hoover <<u>choover@familyvoices.org</u>>
Sent: Friday, March 11, 2022 2:34 PM
To: HRSA Paperwork <<u>paperwork@hrsa.gov</u>>
Subject: [EXTERNAL] F2F-1 standard

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I am making a request for further materials relating to "Maternal and Child Health Bureau (MCHB) Performance Measures for Discretionary Grant Information System (DGIS), OMB No. 0915-0298—Revision." I would like copies of any materials related to the proposed revision of Family-to-Family Form 1 (F2F-1).

Thanks, Clarissa

Clarissa Hoover Data and Technology Coordinator 505.221.0248 choover@familyvoices.org



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From: Diana Autin <diana.autin@spanadvocacy.org>
Sent: Tuesday, March 22, 2022 4:21 PM
To: HRSA Paperwork <paperwork@hrsa.gov>
Subject: [EXTERNAL] DGIS OMG No. 0815-0298 Comments on Proposed Changes

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Attached please find our comments on the proposed changes to Maternal and Child Health Bureau Performance Measures for Discretionary Grant Information System (DGIS), OMB No. 0915-0298-Revision. Thank you for the opportunity to provide feedback.



Diana MTK Autin Executive Director Co-Director, FV Leadership in Family Professional Partnerships (LFPP) Co-Director, NE-PACT/Region A Parent TA Center 973-642-8100 x 105; direct line 862-214-2806 35 Halsey Street, Newark, NJ 07102 diana.autin@spanadvocacy.org

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Ensuring a Place at the Table for Every Family

Comments of National PLACE on Proposed Changes to F2F Reporting

Introduction

The National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE) is pleased to provide our comments and recommendations on the US Department of Health and Human Services (HHS) Maternal and Child Health Bureau's proposed changes to the reporting requirements for Family to Family Health Information Centers (F2Fs) (Maternal and Child Health Bureau (MCHB) Performance Measures for Discretionary Grant Information System (DGIS), OMB No. 0915-0298— Revision).

National PLACE is a coalition of 70 national, state, and local parent-led, family-serving non-profits who are committed to enhancing the voice and impact of diverse families and family-led organizations at decision-making tables at the individual, program, and systems levels. Our members include federally-funded Parent Centers (US Department of Education), Family to Family Health Information Centers (US DHHS HRSA Maternal and Child Health Bureau), and Statewide Family Networks (US DHHS SAMHSA), as well as National Federation of Families (for Children's Mental Health) and Parent to Parent USA affiliates, among others.

National PLACE supports the comments of Family Voices, home to the TA center for the F2Fs, Leadership in Family Professional Partnerships. National PLACE member SPAN Parent Advocacy Network is a partner with Family Voices in this project, and many National PLACE members are also the Family Voices Affiliate Organization for their state or territory.

Our comments pertain exclusively to the F2F-1 Performance Measure, as this is the only component of DGIS that applies exclusively to the F2Fs who are part of our membership. While we appreciate efforts to reduce the reporting burden of F2Fs, particularly given their low funding amounts, we also believe that it is critical to have data that demonstrates the full reach, scope, and impact of individual F2Fs and the F2F network.

In particular, we are concerned that the proposed changes seem to be taking us farther away from a commitment to the six core outcomes for Children and Youth with Special Health Care Needs (CYSHCN) and their families: early and continuous screening to identify any special needs; access to a medical home to coordinate all needed services; access to community-based services that are easy to use; adequate public and private healthcare financing to pay for all needed care; effective services for the transition to adult healthcare; and partnerships with families at all levels. This step is consistent with earlier actions that also seem to signal an abandonment of the six core outcomes. For example, questions related to the six core outcomes were formerly contained in the national survey of CYSHCN; when that survey was ended, a few of the questions were added to the National Survey of Children's Health, but the data is not as rich as

the data from the previous CYSHCN survey. In the recent draft of the *Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs and Families*, the six core outcomes were not even mentioned as being critical to the blueprint, although they have been "guiding principles" for services to CYSHCN for many years. The current proposed changes in DGIS propose eliminating the collection of any data from the F2Fs about the six core outcomes and the extent to which families are contacting F2Fs with questions and concerns about each of them. This is of great concern to us, especially since there is data on the critical nature of these core outcomes to the lives of CYSHCN and families. It is also of concern because MCHB has not asked the field – families (parents and youth/young adults) or professionals – about our perspective on the continuing value of the six core outcomes as an organizing framework for MCH services to CYSHCN and their families.

We strongly agree with Family Voices' statement that, whether or not MCHB moves ahead with the plan to eliminate all data collection questions related to the six core outcomes, Family Voices recommends that an additional question be added to monitor the emerging issues for CYSHCN. Suggested wording: What other emerging issues, or issues not included here, are important to families you have supported?

We also strongly agree with the concern of Family Voices regarding the removal of the details "family centered, comprehensive, and coordinated system," replaced with "a system of care" in the benchmark data sources. As noted in their comments, "We have seen clearly over the years that some of the biggest challenges families and youth have are around receiving coordinated, comprehensive care that takes into consideration unique family situations. This change reflects changes made between Healthy People 2020 and Healthy People 2030, which in turn reflect changes made to the National Survey of Children's Health. To fully account for these changes, we suggest the possibility of listing additional benchmarks here, such as MICH=19, which focuses on medical home."

In terms of the new questions that are proposed to be added, we join with Family Voices in expecting that the vast majority of F2Fs will report that 100% of their calls involve "assisting families in making informed choices" and "providing information on resources available to CYSHCN." These are at the heart of what F2Fs do across systems. Given that reality, it is unclear exactly what purpose these questions would serve.

Conclusion

As noted by Family Voices in their comments, "in the past, when MCHB was planning to make revisions to the data collection requirements, they consulted with F2Fs and with Family Voices as the TA provider to the F2Fs early and throughout the process. This ensured that the voices of those directly providing the services and implementing the data collection and reporting were able to share our insights, experiences, and expertise at the beginning and throughout the process. That did not happen here, and we believe that the draft revised form would likely have been stronger if it had. MCHB states its belief that individuals who are impacted by its work must be involved in helping to shape that work, which did not happen here. In addition, the process for securing the actual proposed language was burdensome and not timely; despite repeated requests to the entity named in the Federal Register as the person to contact, some F2Fs who requested the draft document received no response, even to this day, the day the comments are due. That does not speak to a true interest in hearing the perspectives of MCHB's investment in family engagement for CYSHCN, the F2Fs."

Thank you for your anticipated serious consideration of our comments and recommendations. We look forward to continued collaboration with MCHB to enhance services to, and outcomes for, CYSHCN and their families. Please contact National PLACE's Executive Director, Diana Autin, at <u>dautin@parentsatthetable.org</u> to discuss our comments and recommendations in greater detail.

From: Lisa Maynes <lmaynes@familyvoices.org> Sent: Tuesday, March 22, 2022 4:03 PM To: HRSA Paperwork <paperwork@hrsa.gov> Cc: Lisa Maynes <lmaynes@familyvoices.org>; Diana Autin <diana.autin@spanadvocacy.org>; Nora Wells <nwells@familyvoices.org>; Clarissa Hoover <choover@familyvoices.org> Subject: [EXTERNAL] DGIS, OMG No. 0915-0298 Comments on Proposed Changes

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Attached please find our comments on the proposed changes to Maternal and Child Health Bureau (MCHB) Performance Measures for Discretionary Grant Information System (DGIS), OMB No. 0915-0298 -Revision.

We appreciate this opportunity to give input.

Sincerely,

FAMILY

Lisa Maynes, M.Ed **Project Director** 802.324.0686 Imaynes@familyvoices.org OICES

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As the national technical assistance (TA) center for the network of Family-to-Family Health Information Centers (F2Fs), Family Voices appreciates this opportunity to comment on Maternal and Child Health Bureau (MCHB) Performance Measures for Discretionary Grant Information System (DGIS), OMB No. 0915-0298—Revision. As the TA provider for this network, we work with the 59 F2Fs to assist them in understanding and fulfilling their data reporting requirements. As a national network of families and friends of children and youth with special health care needs, this TA role is one of the ways we fulfill our mission of *promoting partnerships with families – including those of cultural, linguistic and geographic diversity – in order to improve healthcare services and policies for children*.

Overall Comments

Our comments pertain specifically to the F2F-1 Performance Measure, as this is the only component of DGIS that applies exclusively to the F2Fs. We appreciate that the proposed changes are viewed as potentially easing the burden on the F2Fs' reporting requirements but seek a balance between this and making sure we are able to adequately report the many ways that the network is able to serve families and children in a way that best serves the MCHB six core outcomes. F2Fs are **family-led centers funded by the Health Resources and Services Administration (HRSA)**. There is one F2F in each state, in the District of Columbia, and in five U.S. territories, and there are three F2Fs serving tribal communities. Each F2F is **staffed by highly-skilled**, **knowledgeable family caregivers and youth who have first-hand experience and understanding of the challenges faced by families of children and youth with special healthcare needs (CYSHCN)**. These uniquely qualified staff provide critical support to families caring for CYSHCN, particularly families of children and youth with complex needs and those from diverse, medically underserved communities.

Proposed Changes to DGIS

Overall Goals of these changes

To best understand and interpret these changes, it is important to understand some background about the goals and intentions of the changes. We know that easier is not always better, and we emphasize the importance of being able to ensure that the excellent work of the network is backed up by data that correlates directly with the desired outcomes for MCHB.

The F2Fs are charged with assisting families to achieve the six core outcomes for CYSHCN, which are:

- Early and continuous screening to identify any special needs
- Access to a medical home to coordinate all needed services
- Access to community-based services that are easy to use
- Adequate public and private healthcare financing to pay for all needed care

- Effective services for the transition to adult healthcare
- Partnerships with families at all levels.

Over the last few years, we are concerned that there appear to be changes that seem to move away from the commitment to the six core outcomes. The questions related to the six core outcomes were formerly contained in the national survey of CYSHCN. When that survey was ended, a few of the questions were added to the National Survey of Children's Health, but the data is not as rich as the data from the previous CYSHCN survey. In the recent draft of the Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs and Families, the six core outcomes were not even mentioned as being critical to the blueprint, although they have been guiding principles for services to CYSHCN for many years. The current proposed changes in DGIS would eliminate the collection of any data from the F2Fs about the six core outcomes and the extent to which families are contacting F2Fs with questions and concerns about each of them. This is of great concern to us, especially since there is data on the critical nature of these core outcomes to the lives of CYSHCN and families. It is also of concern because MCHB has not asked the field – families (parents and youth/young adults) or professionals – about our perspective on the continuing value of the six core outcomes as an organizing framework for MCH services to CYSHCN and their families.

Whether or not MCHB moves ahead with the plan to eliminate all data collection questions related to the six core outcomes, Family Voices recommends that an additional question be added to monitor the emerging issues for CYSHCN. Suggested wording: What other emerging issues, or issues not included here, are important to families you have supported?

F2F 1 Performance Measure

DEFINITION/Numerator: We recommend that parents of CYSHCN be specified in the definition of the numerator as they are in other related statements in the document.

Benchmark Data Sources

We are extremely concerned by the removal of the details "family centered, comprehensive, and coordinated system," replaced with "a system of care". We have seen clearly over the years that some of the biggest challenges families and youth have are around receiving coordinated, comprehensive care that takes into consideration unique family situations. This change reflects changes made between Healthy People 2020 and Healthy People 2030, which in turn reflect changes made to the National Survey of Children's Health. To fully account for these changes, we suggest the possibility of listing additional other benchmarks here, such as Healthy People 2030 MICH-19.

To improve public understanding of this document, we suggest adding a statement to this section that clarifies that these objectives are from Healthy People 2030.

Data Collection Form for F2F 1

A.1. The role of F2Fs is broad and flexible so that F2Fs can be responsive to the most critical unmet needs of families. For example, during the COVID lockdown, F2Fs saw a big jump in the number of families navigating safety-net services for the first time and needing help advocating for services that better met urgent needs of CYSHCN. It is therefore important that the language describing the services of F2Fs be carefully crafted to cover both the needs we most commonly see from families of CYSHCN, and circumstances that we cannot anticipate.

The proposed language implies all services are one to one, as in one individual helping one individual. To be accurate, language should state that F2F services are either one to one or through group training and events. We propose replacing the phrase "one-to-one" throughout with clearer language that more accurately describes the F2F services counted in this section: "individualized assistance and small-group trainings."

The list of examples provided includes items that are ambiguously stated or are not part of the F2F model. We suggest the following clarification: "This includes one-on-one and group education on topics such as systems navigation, advocacy, health insurance, communicating/partnering with your provider, home care, coordination of care; family-to-family matching or mentoring; and transition to adulthood. It does not include large, impersonal webinars or and other activities with minimal personal interaction."

A.1.c The addition of "best estimate" topics of training to this section will add valuable new information without being overly burdensome on F2Fs to report. Our experience and feedback from F2F staff suggest that estimates reported here will be very high for some of these questions. For example, we would not be surprised if 90% of F2Fs report "assisting families in making informed choices" 100% of the time. We still believe that this data will be valuable, but wanted to share this feedback to make sure that the questions will accomplish their intended purpose.

We suggest that asking these questions as Likert scales might be easier for reporting purposes, for example, "Rarely", "Sometimes", "Often", "Usually", "Always".

A.2. The proposed revisions remove four subcategories that were previously reported for this item. **We believe that this change portends a substantial and undesirable change to the F2F model.** Two of the referenced categories - #d.1 (Individualized assistance) and #d.3 (Group training opportunities) - are incredibly important to tally separately. They are not equivalent, they are not interchangeable, and they are both essential to the F2F model. All F2Fs should have the capacity to track this information because they have been required to do so for many years. Individualized assistance is particularly important when families first make contact with the F2F, as they are often in crisis, overwhelmed, and frightened. As families progress from reactive to more proactive circumstances, small-group trainings provide opportunities for them to interact with and learn from other families as well as from trainers. This combination of modalities is central to effective and equitable delivery of the F2F model, and it is important to track that F2Fs are deploying services using both approaches

A.3. [currently mis-numbered as 2, needs correction]

A.3.b The addition of "best estimate" topics of training to this section will add valuable new information without being overly burdensome on F2Fs to report. We suggest a topic to add to this list, "Education and/or one-to-one assistance on working with CYSHCN and their families." Professionals often approach F2Fs seeking help on basic skills relating to CYSHCN. For example, a dentist might have challenges working with children with developmental disabilities or a social worker might be seeking advice specific to helping CYSHCN who are also refugees.

Asking these questions as Likert scales might be easier to consolidate for reporting purposes, for example, "Rarely", "Sometimes", "Often", "Usually", "Always"

B.2.a This is an important clarification. We had previously been interpreting as the count of types represented, not the count of organizations.

B.2.b To improve public accessibility and readability of this document, please use "for example" consistently. This list uses "eg", "e.g." and "ex".

B.2.c This section is confusing and inconsistent in referencing organization qualities and population qualities alternately. A general review of approach would be helpful. In particular, **the first item on the list should say "American Indian or Alaska Native"** for symmetry with the rest of the list and to avoid questions about what exactly makes an organization a "tribal organization".

Conclusion

In the past, when MCHB was planning to make revisions to the data collection requirements, they consulted - early and throughout the process - with F2Fs and with Family Voices as the TA provider to the F2Fs. This ensured that the voices of those directly providing the services and implementing the data collection and reporting were able to share our insights, experiences, and expertise at the beginning and throughout the process. That did not happen here, and we believe that the draft revised form would likely have been stronger if it had. MCHB states its belief that individuals who are impacted by its work must be involved in helping to shape that work, which did not happen here. In addition, the process for securing the actual proposed language was burdensome and not timely; despite repeated requests to the entity named in the Federal Register as the person to contact, some F2Fs who requested the draft document received no response, even to this day, the day the comments are due. That does not speak to a true interest in hearing the perspectives of MCHB's investment in family engagement for CYSHCN, the F2Fs.

Thank you for your anticipated serious consideration of our comments and recommendations. We look forward to continued collaboration with MCHB to enhance services to, and outcomes for, CYSHCN and their families.

Contact for Questions: Lisa Maynes, Co-Project Director LFPP, Family Voices National. <u>lmaynes@familyvoices.org</u> **4** | Page March 22, 2022 From: Owens Shuler, Tara <tara.shuler@dhhs.nc.gov>
Sent: Tuesday, March 22, 2022 7:05 PM
To: HRSA Paperwork <paperwork@hrsa.gov>; Fermin, Martha (HRSA) <mfermin@hrsa.gov>
Subject: [EXTERNAL] Feedback for the DGIS Form 15
Importance: High

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Hello

The NC MDRBD project would like to provide feedback on the DGIS 15 form.

Provider training and consultation

Q: For the definition of "enrolled provider," does this include anyone who has ever enrolled even if it was from a previous fiscal year? Or should this only include those providers who enrolled during the respective fiscal year? For those "participating," should we only count those who have participated in our program for that respective fiscal year?

Suggestion: Add details regarding timeframe for each column

Use of mental health team consultation and referral services (reason for provider contact)

Q. Providers typically call about symptoms or presenting concerns rather than a specific diagnosis. Since this item is based on diagnosis rather than symptoms, should we count the diagnosis(es) that they have at the time of the consultation, the diagnosis(es) that are discussed during the call, OR both? For the diagnosis(es) discussed during the call, this would only apply to consultation calls that involve a psychiatrist.

Number and types of providers trained

Suggestions: -Clarify that each training could be counted in more than one topic category. -It could be helpful to provide an example or two for what constitutes "treatment strategies"

Individuals Served

Q. Is there a specific definition for "treatment?"

Submitted on behalf of our Evaluation team.

Tara Owens Shuler, M.Ed., LCCE, FACCE Branch Head Maternal Health Branch – Women, Infant and Community Wellness Section Division of Public Health – North Carolina Department of Health and Human Services

In office: Mon & Wed; Telework: Tues, Thurs, Fri (office) 919-707-5708 (mobile) 919-214-4518 <u>Tara.shuler@dhhs.nc.gov</u>

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Sent: Tuesday, March 22, 2022 10:42 AM
To: HRSA Paperwork <paperwork@hrsa.gov>
Cc: Garneau, Deborah (RIDOH) <Deborah.Garneau@health.ri.gov>
Subject: [EXTERNAL] RI MomsPRN Public Comment Re Maternal and Child Health Bureau Performance Measures for Discretionary Grant Information System

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Dear HRSA Information Collection Clearance Office,

I hope this finds you well. Attached you find comments regarding <u>proposed modifications and changes to</u> <u>the Discretionary Grant Information System (DGIS) from</u> program staff at the Rhode Island Department of Health (RIDOH) on behalf of the Rhode Island Maternal Psychiatry Resource Network Program (RI MomsPRN).

RIDOH staff appreciate the opportunity to provide this feedback in the hope it will help HRSA further refine and optimize DGIS reporting forms specific to grantees of the Screening and Treatment for Maternal Depression and Related Behavioral Disorders (MDRBD) Program. Please reach out if you have any questions.

Best, Jim Beasley Program Manager RI Maternal Psychiatry Resource Network Program (RI MomsPRN) Jim.Beasley@health.ri.gov 401-486-4536



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March 22, 2022

Information Collection Clearance Officer Room 14N136B Health Resources and Services Administration (HRSA) 5600 Fishers Lane, Rockville, MD 20857

Re: Public Comment Request; Maternal and Child Health Bureau Performance Measures for Discretionary Grant Information System

Dear HRSA Information Collection Clearance Officer,

Program staff at the Rhode Island Department of Health (RIDOH) for the Rhode Island Maternal Psychiatry Resource Network Program (RI MomsPRN) respectively submit the following comments regarding proposed modifications and changes to the Discretionary Grant Information System (DGIS) forms. The RI MomsPRN Program is one of seven grantees awarded funding for the Screening and Treatment for Maternal Depression and Related Behavioral Disorders Program (MDRBD) at the Health Resources and Services Administration (HRSA) and has experience submitting numerous DGIS reports in support of work accomplished for this pilot program under the UK3MC32244 grant number. RIDOH staff appreciate the opportunity to provide this feedback in the hope it will help HRSA further refine and optimize DGIS reporting forms specific to MDRBD grantees. Feedback is organized by form through bolded text.

Training Form 14 (Teleconsultation and Training for Mental and Behavioral Health)

With respect to the provider consultation and training table, please know that not all psychiatry access lines use a formal enrollment process for calling providers/practices. The RI MomsPRN teleconsultation line has intentionally opted not to formally enroll any provider or practices in order to streamline the provider experience and remove administrative barriers with calling the line. This strategy has proven to be effective given continued growth in provider calls and sustained provider engagement. As such, it remains difficult for the RI MomsPRN teleconsultation line staff to track and report the number of enrolled providers who may be eligible to call the line. There also continues to be a worry that requiring a formal enrollment process to meet HRSA reporting needs may result in decreased call volume and increased administrative burden to already overtaxed calling providers treating perinatal patients, which should be avoided if at all possible.

It is also important to note that RIDOH continues to define enrollment for HRSA reporting purposes as the subset of RI MomsPRN practices and affiliated providers who opt to participate in 15-month long perinatal behavioral health learning collaborative that includes direct funding support to meet additional HRSA reporting requirements that are difficult to collect through a standard teleconsultation call. While using this subset definition and providing direct practice funding support has been useful with the collection of needed data, it has resulted in some unforeseen difficulties completing other required HRSA reporting in a manner that reflects the overall program reach and service design. For example, RIDOH defines enrolled RI MomsPRN providers from learning collaborative practices as those who manage the behavioral health care of perinatal patients (e.g., prescribers and/or lead behavioral health staff, if they are integrated in a given practices). This definition was selected given the need to field periodic self-efficacy surveys that include clinical care questions. This definition while helpful with fulfilling one HRSA reporting requirement, results in complications with reporting attributed teleconsultation utilization from enrolled practices/providers. This is because the RI MomsPRN teleconsultation line does not restrict who from a practice can

initiate a call. Any staff member, regardless if they prescribe and/or are the lead behavioral health staff or not, can call to the line to initiate support. As a result, there are often are discrepancies with "enrolled provider" counts reported and the affiliated provider utilization figures reported among enrolled practices on some HRSA forms. In addition, practices/providers who are "enrolled" periodically changes with the RI MomsPRN program given the time-limited nature of learning collaboratives and depending on when this occurs in the reporting period, it can result in skewed performance metrics being reported. For example, if a RI MomsPRN learning collaborative starts at the end of a reporting period, underutilization of the line will most likely be reported among enrolled provider is no longer active at a particular practice for any reason for a period of time. Another challenge associated with this subset reporting methodology for enrolled providers/practices is that it does not reflect the overall utilization of the RI MomsPRN teleconsultation line as it is a statewide service. RIDOH has addressed this problem by reporting both the enrolled providers line utilization figures as well as providing context about enrollment cohorts. While being an effective reporting strategy, this approach has been a burden.

Given the variability of enrollment definitions among access programs, time-limited nature of practice partnerships that may result in skewed metrics, challenges monitoring provider attribution at a given practice and discrepancies that may arise between enrollment definition and calling providers, the RI MomsPRN program respectively recommends not pursuing a provider enrollment distinction as a mandatory reporting element in this form. Similarly, HRSA should also not mandate or pursue the required collection of provider counts who are both enrolled and participating (e.g., calling the line). This reporting is particularly hard to enact not just for the reasons detailed previously, but also because of confidentiality protocols between clinical staff fielding the calls and entities compiling de-identified HRSA reports. In order to streamline this reporting in a more feasible and impactful manner, HRSA should instead opt to pursue a least common denominator approach with this reporting and simply require counts of providers who call the line during said reporting period (e.g., just have grantees report the number participating). Optional space and/or columns could be provided in the event a program has a formal enrollment process or uses a more time-limited enrollment definition, but should not be required. By doing this, the most meaningful information will be reported in a manner that reduces administrative burden on both calling providers and teleconsultation staff in a manner that take in account unique service designs implemented at the state level. Additionally, the provider types listed in the form need to be broadened and/or defined further. For example, the RI MomsPRN line accepts calls from OBGYN residents and psychiatric nurse practitioners, among others. Reporting clarification on how those calls should be categorized is welcomed, especially given confusion on whether a psychiatric nurse practitioner should be considered a primary care provider and whether perinatal providers should be classified as primary care providers in general. Furthermore, clarification on how a care coordinator/patient navigator is defined is welcomed as well in light of ongoing support to family visitors, doulas, and social workers by the RI MomsPRN teleconsultation line.

With respect to the "use of program teleconsultation and care coordination support services" section of the form, please know that it is difficult for the RI MomsPRN program to fully report teleconsultation only and care coordination support only figures. This is due to a current database structure that tracks specific call outcomes (e.g., various referrals offered as well as medication consultations completed) in a non-mutually exclusive, encounter-based manner. In addition, the clinical teleconsultations currently tracked are limited to medication consultations. HRSA should provide clarification on what "teleconsultation" specifically entails and by what level of provider this encompasses for planning purposes. It is also important to note that nearly all teleconsultation calls involve some level of care coordination support, which makes this proposed only distinction not a particularly informative measure in addition to being administratively difficult to report. As such, RI MomsPRN Program recommends the removal of the "only" distinction from the type of contact table. In addition, the specific mental health and substance use conditions listed in part b should be informed by technical assistance networks such as the Lifeline for Moms Network before being finalized. While the RI MomsPRN teleconsultation line does collect a good number of the proposed conditions, clarification will be need for polysubstance use, disruptive, impulse-control, conduct disorders as well as co-occurring mental and substance use disorders before they should be required to be reported. There are significant call intake processes and database modifications, especially for the poly and co-occurring measures, that would need to be enacted to report these measures and having clear definitions from HRSA well in advance will be needed before any data collection and reporting should be required. There should also be more robust discussion on the substance use disorder conditions listed as well as considerable advisement on how best to obtain and collect suicidality or self-harm data, which often can be difficult to collect uniformly. Finally, reporting the number of referrals given in section c also needs further clarification from HRSA. Currently, the RI MomsPRN program tracks referrals given in a non-mutually exclusive encounter-based manner by specific referral categories. This allows the tracking of multiple referrals that may be provided during a single call/performance period for any given patient. This methodology was informed by fellow peer access programs. The RI MomsPRN program first suggests that HRSA define this measure not as the number of referrals provided, but rather as the number of referrals services/supports that could be offered. Reporting the former results in a subset measure being reported that is only reflective of varied patient need in given time period, while reporting the latter (e.g., count of directory services) provides a better depiction of the totality of referral service/support that could be offered to any calling provider. If this level of referral detail is needed, RI MomsPRN program staff request that a simple composite count of all referral encounters by any category suffice. Any further refinement or attempt at de-duplicated referral categories or patient counts would require a significant modification to existing database and would be a challenge for any access program using an encounter-based data collection approach.

Regarding the training proposed reporting, please know that tracking of provider type is incredibly difficult and presents a significant administrative burden. Most of the RI MomsPRN provider trainings occur during time-constrained standing practice meetings and/or are organized by various outside entities that are offered virtually, which often have a call-in number and/or registration/invite systems that are managed by external entities. As a result, it is incredibly difficult to collect information about provider type either before, during, or after any time-limited training session. This is due to a variety of reasons, including organizational email spam filters, providers calling into a virtual training, and/or joining slightly late or being in a conference room, where group virtual chat functionality is not present for all members. This becomes even harder, when RI MomsPRN clinical staff are part of training session being offered by local external entities in which attendance tracking abilities is incredibly limited or beyond the control of the program. The RI MomsPRN program has

found no easy and/or time efficient manner to collect provider type information for virtual trainings. This reporting becomes exponentially burdensome when HRSA requires de-duplication of training counts by provider type, which it has done in the past among enrolled providers. The level of coordination and documentation needed to achieve this reporting specificity far exceeds the administrative burden figures highlighted in the DGIS public comment form by many times. As such, the RI MomsPRN program strongly recommends that provider type information no longer be mandated to be reported for program training, especially among those states not using a Project ECHO or ECHO-like training model. Rather, a less administratively burdensome approach should be enacted. A potential more feasible reporting approach would be tracking the number of training sessions offered at the practice-level by type (e.g., number of training sessions at a pediatric practice, family medicine practice, OBGYN practice) and providing overall attendance counts, when available. It is much more feasible to note the practice type and overall attendance count of each session than the specific role of everyone in attendance of a virtual training for reasons noted previously. The worry with this level of proposed reporting is that it will result in clinical staff adding more cumbersome training registration requirements, surveys, or administrative requests on extremely busy and overtaxed providers, which will lead to less time for clinical training, hamper the training experience, and result in reduced follow-up training requests.

It is also important to note that most RI MomsPRN provider trainings are comprehensive in nature in that they often address mental or behavioral health conditions, medication, screening/assessment, and treatment strategies all at once. They are designed to meet the comprehensive needs and interest of extremely busy providers in a just-in-time format. Rhode Island providers treating perinatal patients often do not have the ability to attend multiple ongoing training sessions given other training requirements or sessions organized by their practice or various external entities. When reviewing the proposed topics covered by training and number of trainings per topic reporting as currently outlined in this draft form, it seems that this reporting is most feasible for those using a Project ECHO or ECHO-like training approach, which is not easily replicated or collected by states such as Rhode Island using other training modalities. The level of stratification being requested in this form should be feasible and meaningful for all states regardless of the training approach used to meet the unique provider training needs within their state. Unfortunately, what is proposed achieves neither, especially in states like Rhode Island that take a comprehensive just-in-time training approach. If this level of specificity must be collected, they should be check-box only and without attributed counts. This will allow states that offer comprehensive training sessions from reporting duplicative counts across many categories. Using this approach will also ease the administrative burden placed on clinical and evaluation staff, which require a level of coordination and follow-up that often greatly exceeds the administrative burden calculations as detailed in the DGIS form to collect only a subset of this information currently, mostly relating to depression training.

With respect to the individuals served aspect of the form, the RI MomsPRN program would like to re-iterate some previous comments highlighted above. It is remains difficult to report referral only and treatment only patient level counts, the only distinction reporting is not particularly meaningful given that most calls involve resource/referral, more clarification about what treatment means specifically is needed, and there is a hardship in general with adding de-duplication programing in an encounter-based database. The RI MomsPRN program also continues to echo feedback along with other perinatal access programs about the ongoing difficulty of a teleconsultation program readily collecting and reporting practice-level screening data from electronic health records for depression, anxiety, and substance use screening among perinatal patients. Rhode Island has been fortunate to identify a learning collaborative model to facilitate this data collection on a time-limited basis from

select practices, but it remains a challenge to obtain this information from new prenatal care practices and to sustain data reporting after a cohort collaboration ends. As a result, HRSA should consider making this screening-level measure optional for MDRBD grantees similar to PMHCA grantees and if that cannot be done, provide enhanced funding to support this data extraction and reporting which is no small feat. Obtaining practice-level screening data, inclusive of patient zip code, requires intensive ongoing collaboration with prenatal practices, who often have less practice infrastructure and supports for population health reporting and quality improvement interventions compared to their professional peers, such as pediatricians and family physicians. In addition, the work to obtain and analyze this data is often beyond the scope of clinicians who staff a psychiatry access line as it requires unique evaluation and data collection abilities, ongoing quality assurance, as well as direct practice funding. Rhode Island has been fortunate to collaborate with another non-clinical entity for this reporting and quality improvement services, but this approach may not be readily available to all access programs. Finally, please note that depending on the specific modality used to obtain practicelevel screening data, the numerator and denominator time frame may not fully align with the federal fiscal year. This has been the case in Rhode Island because practice-level screening data is not readily collected within any state-level databases. As such, the RI MomsPRN program has opted to use a practice learning collaborative model to collect this information. Since the timeframes of these learning collaborative vary, flexibility with reporting timeframes should continue to be allowed with space provided to explain needed methodology reporting context. RI MomsPRN has been most appreciative with this reporting flexibility and urges the continuation going forward.

Other Forms Feedback

New Core 1 Health Equity Form: RIDOH welcomes the revisions of the Core 1 Health Equity form, but wanted to clarify that specific health equity goals and objectives being pursued may be overarching and aligned with organizational equity aims. As such, progress toward achieving them may be hard to quantify and/or specify from a programmatic-level. That being said, RI MomsPRN is joining other perinatal access programs through the Lifeline for Moms Network in defining a health equity framework specific to perinatal access programs.

WMH 1 & WMH 2 Forms: Similar to feedback offered to Training Form 14, RIDOH staff wanted to note that it remains difficult to specify/stratify training counts specific to pregnancy and postpartum care given that most training is specific to the perinatal period. As a result, grantees whose focus spans the entirety of the perinatal period like MDRBD grantees would benefit from additional reporting instruction on how best to fill out these forms and whether to include training counts only in the new Training Form 14 or in these forms as well.

WMH 4 Form: RIDOH wanted to re-iterate the challenges associated with collecting information relating to the Tier 4 measure about the percentage of women who screened positive for depression who receive a referral for services. Even when using a practice learning collaborative model that includes practice funding, the RI MomsPRN program has found it particularly hard to obtain this level of data from practices treating perinatal patients, even when accounting for a 15-month long collaboration. The RI MomsPRN program has found that it can take up to two years to enact needed electronic medical record modifications and reporting protocols before one can obtain treatment/referral information and when it is provided more immediately, more often than not it involves manual tracking. A more feasible measure to collect that is equally informative is the number of perinatal patients screening positive for maternal depression. This measure has been more readily available/reportable among a variety of practices participating in program learning collaboratives. As such, HRSA should consider changing this tier 4 measure accordingly and

continue to allow optional reporting given reporting difficulty. Finally, RI MomsPRN staff also encourage HRSA to add significance about depression during pregnancy in addition to retaining the new text about postpartum depression in the significance section.

Attachment C New Form 2, Form 3, and Form 5: Given a programmatic focus on the perinatal period, RI MomsPRN staff request that the pregnant women (all ages) target population rows listed in the above forms be broadened to perinatal women (all ages). MDRBD grantees seek to help providers who treat pregnant and postpartum patients access needed mental health and behavioral health services, care, and treatment. As such, it is a significant reporting burden to further stratify program reach/impacts just among pregnant patients and then among postpartum patients over a particular age range along with associated patient demographics, especially when support provided may span the entire perinatal period for any patient of a calling provider during a given reporting period. RIDOH also does not think including postpartum counts in the "non-pregnant women (age 22 and over) grouping" is a meaningful aggregation given the unique clinical needs of postpartum patients that differ from non-pregnant, non-postpartum women age 22 plus. Given the unique health status and challenges associated with the entirety of the perinatal period (pregnancy through one year postpartum) and the need to provide unique tailored clinical care during this time, HRSA should broaden the pregnancy women stratification to the perinatal period (up to one-year postpartum). This will be an impactful distinction to note across all MCH grantees, especially as states seek to enact policies to extend and/or enhance postpartum health coverage options, access to postpartum health care services, and improve postpartum care coordination supports.

Conclusion

RIDOH staff appreciate the opportunity to provide this feedback on behalf of the RI MomsPRN Program. If you have any questions regarding these comments, please feel free to contact Jim Beasley, RI MomsPRN Program Manager, at Jim.Beasley@health.ri.gov. Sincerely,

Jim Beasley

Jim Beasley, MPA RI MomsPRN Program Manager Rhode Island Department of Health State of Rhode Island