

PUBLIC SUBMISSION

As of: 11/18/15 10:10 AM
Received: September 17, 2015
Status: Posted
Posted: September 29, 2015
Tracking No.: 1jz-8l6n-uo1k
Comments Due: November 16, 2015
Submission Type: Web

Docket: CDC-2015-0081

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice through Practice and Implementation Centers and National Partnerships 0920-15BEZ

Comment On: CDC-2015-0081-0002

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice through Practice and Implementation Centers and National Partnerships 0920-15BEZ Federal Register, Volume 80 Issue 178 (Tuesday, September 15, 2015)

Document: CDC-2015-0081-0003

Comment from (name)

Submitter Information

Name: jean publicc

General Comment

state and local facilities, doctors, nurses are adequate and the best place to handle this issue. fat cat bureaucrats at this corrupt agency in Washington DC could care less about this issue. there should be taken care of immediately absolutely no need to expand efforts in this issue or to gouge taxpayers to the maximum for more money to expand. we are doing enough in this regard at this time. no expansion. taxpayers oppose being gouged at a higher level for this agency which has shown itself with its many missteps and accidents to be unaccountable for real health safety. they are careless at this agency. in no way, should there be any expansion at this agency. the employees at this agency are focused on the revolving door to make a killing in salary at the private drug companies and they have shown by endless accidents that they are not focused on real work for America. these efforts belong at the local level where the issue can be identified. the fat cat bureaucrats in corrupt Washington DC don't give a bit of care about America. they are focused on themselves and the salaries they earn. this agency wants to get its hands on as much money as they can get. in fact, I believe a downsizing of this agency and a cut in the budget should take place now in the sum of 50% of the present budget to be cut. this agency sucks and deserves a grade of F minus.

CDC response:

"We received your comment and have forwarded it to the appropriate program. Thank you for your interest."

PUBLIC SUBMISSION

As of: 11/18/15 11:39 AM
Received: September 22, 2015
Status: Posted
Posted: September 29, 2015
Tracking No. 1jz-8l9i-rvib
Comments Due: November 16, 2015
Submission Type: Web

Docket: CDC-2015-0081

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice through Practice and Implementation Centers and National Partnerships 0920-15BEZ

Comment On: CDC-2015-0081-0001

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice through Practice and Implementation Centers and National Partnerships 0920-15BEZ 2015-23088

Document: CDC-2015-0081-0005

Comment from (name)

Submitter Information

Name: sally caldwell

General Comment

Data collection, such as proposed here, has begun to dominate direct services providers' time. A master level clinician can often spend 50%+ of their work week engaged in documentation designed to collect data. This robs the client of precious time with his/her provider and reduces the number of clients providers can serve in one week.

I suggest that focus groups be used to collect data. One provider can set aside time to participate while other providers continue in their direct service to clients. The focus group would generate leanings from its group consult and that would enrich the feedback.

CDC response:

"We received your comment and have forwarded it to the appropriate program. Thank you for your interest."

PUBLIC SUBMISSION

As of: 11/18/15 11:40 AM
Received: October 30, 2015
Status: Posted
Posted: November 02, 2015
Tracking No.: 1jz-8l3-xxwd
Comments Due: November 16, 2015
Submission Type: Web

Docket: CDC-2015-0081

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice through Practice and Implementation Centers and National Partnerships 0920-15BEZ

Comment On: CDC-2015-0081-0001

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice through Practice and Implementation Centers and National Partnerships 0920-15BEZ 2015-23088

Document: CDC-2015-0081-0006

Comment from (name)

Submitter Information

Name: Mariah Mapeso

General Comment

Prenatal exposure to alcohol is a leading preventable cause of birth defect and developmental disabilities. Fetal Alcohol Spectrum Disorders must be stopped. Improving Fetal Alcohol Spectrum Disorders (FASD) prevention and practice through implementation, practice centers, and national partnerships could help combat this birth defect. Expanding FASD training programs and changing perspective from individual training for practicing health care professionals to capitalizing prevention opportunities can impact health care practices at the systems level. The CDC should increase funding to FASD programs and strengthen partnerships to increase prevention and education for women. Through funding, FASD training programs can be expanded and increase awareness on a national level. The Practice and Implementation Centers (PICs) and other national partners collaborating in a discipline-specific workgroups (DSWs) can help identify and increase prevention strategies.

Data, surveys, and other information can help determine if the training programs are educational and helpful. Also, it can help identify what needs to be fixed or what needs to be added into the program. Having the CDC collecting program evaluation information from healthcare practitioners from disciplines targeted by each DSW, health system staff, and cooperative agreement grantees is a great way to gather information and identify improvement. Collecting FASD statistical data nationally can determine if FASD has increase or decrease in the last year. If it has increase, the CDC should improve their methods in prevention or change their approach on FASD programs. If there is a decrease in rate, the CDC could enhance their prevention and education with the same method. The data and surveys should be submitted and

collected on a database or an electronic file. Filing electronically can be easier to collect as well as better being more organized. Paper surveys and data can easily get lost or unable to read the handwriting. Another way to collect information and data are focus groups. Focus groups can provide feedback about the program.

Funding is very important to ensure preventative actions as well as providing programs in FASD. Although the CDC receives funding from grants or from the government, partnerships with other organizations can also provide funding and connections to create awareness across the nation. Also, funding can help the CDC build new faculties for the training programs in high rating areas of FASDs. The CDC should not cut down their funding or budget in order to support FASDs training programs, but instead partner with organizations.

Implementing the improvement of FASDs and collecting training evaluation data from healthcare practitioners and staff can decrease fetal alcohol syndrome across the U.S. by identifying strategies for improvement and through educational programs. CDC partnering with PIC and other national partnerships can help improve and prevent FASD.

CDC response:

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PUBLIC SUBMISSION

As of: 11/18/15 11:40 AM
Received: October 29, 2015
Status: Posted
Posted: November 02, 2015
Tracking No. 1jz-8lyk-lu0m
Comments Due: November 16, 2015
Submission Type: Web

Docket: CDC-2015-0081

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice through Practice and Implementation Centers and National Partnerships 0920-15BEZ

Comment On: CDC-2015-0081-0001

Improving Fetal Alcohol Spectrum Disorders Prevention and Practice through Practice and Implementation Centers and National Partnerships 0920-15BEZ 2015-23088

Document: CDC-2015-0081-0007

Comment from (name)

Submitter Information

Name: Melissa B

General Comment

Even though I support the need of more outlets for prevention of Fetal Alcohol Spectrum Disorders, as well as this proposed Project. I do not agree with the process of information collection. Entirely too much time, money, and resources are being put into the efforts of collecting and analyzing data rather than applying these resources to the real issue at hand. This proposal does not provide enough utility to make it worth the time, money, and effort of collecting and analyzing data.

My first major concern involving this proposal is the time it takes to prepare for, collect, and analyze the data. Before the data collection process can even begin, there is so much required in preparation. The system used for collecting information must be developed, installed, and functioning properly and personnel must be trained to maintain and process the data in addition to responding to the information. This proposal will also take up significant time of respondents who participate in the evaluation as well. They are estimating an average of 4,528 hours each year spent on collecting data rather than spending this time on prevention itself. This does not even include the time it will take verify, validate, and disclose the information!

The next major concern I have with this process is funding. In 2015, the Center for Disease Control and Prevention has budgeted \$132 million dollars to split amongst the following three focus areas: Birth Defects, Developmental Disabilities, and Disability and Health. By using a portion of this allocated cost to conduct the analysis, it reduces the available funds that should

be dedicated to promoting prevention.

Not only would this take quite a bit of time and money, but it would also require personnel and equipment to help manage the process. This is an unnecessary use of resources that could be dedicated to other functions.

In short, every day that is spent focused on data collection and analysis is one more day that a fetus and/or infant will be impacted by Fetal Alcohol Disorders. It is very apparent that Fetal Alcohol Disorders are a problem, so we should focus less on the problem and more on the solution.

CDC response:

"We received your comment and have forwarded it to the appropriate program. Thank you for your interest."