

# **UCEDD REPORTING GUIDE**

Guidelines for reporting CHDD affiliated work

# UCEDD REPORTING

It is important to report this information in order to provide our funding sources and supporting agencies with information they can use to help assure continued support in the future.

Information is reported for fiscal years that run from July 1<sup>st</sup> to June 30<sup>th</sup>.  
(i.e. FY2007 = 7/1/2006 to 6/30/2007)



**Projects:**  
on-going major initiatives--  
which may span several  
years--that are likely to  
encompass multiple activities

**Activities:**  
individual events or discrete  
process, pursuits, or functions  
of a project with measurable  
impacts

**Products:**  
materials produced and  
disseminated during activities  
and or affiliated project

**NIRS ONLINE APPLICATION**

National Information Reporting System hosted by  
the Association of University Centers on Disability

Web-based interface where individuals can use a  
login and password to report, update and edit  
information during the fiscal reporting year

UW contact for this system is Richard Masse  
rmasse@u.washington.edu

Project and Product information entered in this  
system is available for public search

**VARIOUS REPORTS**

Administration of Developmental  
Disabilities progress reports for  
UCEDD funding

Maternal and Child Health Bureau  
progress reports for LEND funding

Internal reports used to summarize  
and promote CHDD affiliated work

Internal reports used for program  
evaluation and planning

See guidance and examples provided for more details on projects, activities and products.

## UCEDD REPORTING EXAMPLE A

### PROJECT: PKU Clinical Program

The Phenylketonuria (PKU) Clinic provides diagnosis, assessment, medical nutrition therapy, genetic counseling, and consultation for ongoing dietary management and health supervision, as well as evaluation of treatment outcomes to all children with PKU and their families.

Phenylketonuria is a genetic disorder in which the child is born without the ability to break down the amino acid phenylalanine (phe). This causes higher than normal levels of phe in the blood which can result in damage to the brain and mental retardation.

Currently there is no known cure for PKU. Fortunately, if a child is diagnosed early and the disorder is treated, mental retardation can be prevented. The treatment of PKU requires lifelong management of phe level, regulated through the client's diet. Clinicians at the PKU clinic work with families and clients to ensure that the child is receiving adequate nutrients for normal development while limiting intake of foods high in phe.

The PKU Clinic is made up of a team of trained health care professionals that represent multiple disciplines. Long-term interdisciplinary planning and follow-up services are provided to more than 100 children each year to prevent adverse consequences of this disorder. Clinics are held monthly and have a group format. Patients are organized into sub-clinics by age, and by virtue of this clinic's group format, parents and children develop a strong support network. Focus is not only on medical and dietary health, but independent thinking and self-management skills facilitated by educational curricula in the clinic. As the children near adulthood they are enrolled in the clinic's Adolescent Transition Curriculum, designed to prepare them for PKU management and life management in the Adult Metabolic Program.

Reported 1 project that details overall, ongoing program

### ACTIVITIES:

PKU Clinic  
Adult PKU Clinic – Spokane  
PKU Science Night  
PKU Action Group  
WA State Newborn Screening Review Committee  
National PKU News  
Family to Family Guidelines for PKU Clinic  
Camp Sealth PKU Camp

Reported 8 activities with details on number of clients served, time spent creating material or providing consultation, etc..

### PRODUCTS:

Adults with PKU Diet Manual  
National PKU News  
PKU Clinic Website  
PKU Adolescent Transition Curriculum (online)

Reported 4 products with details on target audience, material type, availability, etc..

## UCEDD REPORTING EXAMPLE B

### PROJECT: Bright Futures in WA State

The mission of this project is to promote the use of a set of nationally published health promotion materials, Bright Futures, by community health providers, child educators, child care providers, and others in Washington state. In collaboration with the Washington State Department of Health, Maternal and Child Health Program, this project works to expand awareness of the Bright Futures health promotion principles and materials, offer training and technical assistance in their use, and offer opportunities for networking.

Bright Futures, initiated by the Maternal and Child Health Bureau (MCHB) over a decade ago, is a philosophy and approach that is dedicated to the principle that every child deserves to be healthy, and that optimal health involves active partnerships among the health professional, child, family, and community. Bright Futures materials are designed to actualize this vision to, promote physical, nutritional and social/emotional health in infants, children and adolescents. The Bright Futures project includes multiple components:

We collaborate with Family Voices in Washington state to serve as one of five state pilot sites for a grant from the Centers for Disease Control awarded to Family Voices, to evaluate the effectiveness of Bright Futures in getting health and wellness messages to families of children with special health care needs.

We coordinate with existing Washington state health promotion programs to ensure their consideration and use of Bright Futures in products they develop. Examples include CHILD Profile, Adolescent Health Fact Sheets, and Well Child Exam forms from the state Department of Social and Health Services.

We work with the Department of Health and the Office of the Superintendent of Public Instruction to prepare training programs for school nurses on mental health promotion and use of Bright Futures mental health materials.

We coordinate a federally funded project to evaluate the impact of using Bright Futures materials in Head Start, Early Head Start, Early Childhood Education and Assistance Program, and other child care programs in Washington state.

We promote use of Bright Futures in curriculum and student training within higher education and advanced training programs at the University of Washington. Programs include the schools of Nursing, Public Health, and Medicine, and MCHB-funded training programs.

Additional activities include producing a quarterly electronic newsletter, Bright Ideas for Washington state Bright Futures, and maintaining an electronic listserv to increase awareness of Bright Futures projects and promote sharing of ideas.

### ACTIVITIES:

Bright Futures Foster Care Training  
Bright Futures Mental Health for School Nurses  
Bright Futures Website Development  
Infant and Early Childhood Conference

### PRODUCTS:

Bright Futures Guidebook for Early Childhood Care and Education  
Bright Futures in Mental Health: Foster Care Training Manual  
Bright Ideas Newsletter for Washington State Bright Futures

Reported 1 project that details overall, ongoing program

Reported 4 activities with details on number of clients served, time spent creating material or providing consultation, etc..

Reported 3 products with details on target audience, material type, availability, etc..

## UCEDD REPORTING EXAMPLE C

### PROJECT:

#### Alaska Consultation Clinics and Technical Assistance

The purpose of the Alaska Consultation Clinics is to provide technical assistance to the Alaska Maternal Child Health Program and Providence Alaska Medical Center, continuing education for health care professionals, and consultative clinical services for children with neurodevelopmental disabilities and other special health care needs. These services aim to increase and improve clinical services for children with special health care needs in Alaska.

The faculty work with the developmental pediatrician for the state of Alaska, public health staff, and interdisciplinary providers in each community to provide technical assistance regarding systems that serve children with special health care needs and offer in-service education to local health care providers.

Consultation clinics are held in partnership with Alaska Title V programs in Fairbanks, Juneau and other locations. The clinics, which are organized locally and held at public health departments, serve over 100 children each year. Local public health, school and private practice professionals participate in clinics and receive consultation regarding complex diagnostic and treatment issues of clients in their community. At Providence Alaska Medical Center in Anchorage, specialty clinics are conducted for children with neurodevelopmental disabilities, specifically cerebral palsy and spina bifida.

Consultation clinics also provide in-service education, including walking rounds with local physicians and family practice residents in a pediatrics rotation, clinical teaching for medical and nursing students and education sessions with families.

Reported 1 project that details overall, ongoing program

### ACTIVITIES:

Alaska Outreach Clinic - Providence Alaska Medical Center  
Alaska Outreach Clinic - Children's Hospital  
Alaska Consultation - Providence Alaska Medical Center

Reported 3 activities with details on number of people served, time spent providing consultation, etc..

### PRODUCTS:

Reported 0 products because work does not result in this type of material

## PROJECT GUIDELINES

### OVERVIEW OF PROJECT REPORTING GUIDELINES FOR NIRS ONLINE APPLICATION

The Projects dataset is intended to capture general information each fiscal year on all the major initiatives of the UCEDDs and LENDs. Centers should record data on all projects, not just those primarily funded by ADD or MCH.

The Projects dataset is intended to record information on on-going major initiatives--which may span several years--that are likely to encompass multiple activities. In contrast, the Activities dataset is intended to record information on individual, time-limited events (often measurable in hours) with a more targeted purpose. NIRS is designed so that projects in the Projects dataset may be linked to a number of measurable activities.

Project-level reporting can further be distinguished from activity-level reporting in that project reporting focuses more on the project's purpose or infrastructure than the impact of their activities (e.g., number of students trained).

A common element to all projects that are reported in this dataset is that they are the entry point for funding and other resources. The types of information collected in the Projects dataset include:

- \* Who to contact
- \* Funding dates, types, sources, amounts
- \* Core functions
- \* Areas of emphasis
- \* Types of action
- \* Target audiences
- \* Unserved and underserved populations
- \* Collaboration with other agencies
- \* Consumer participation
- \* Geographic scope
- \* General description

Note: A project record should be created prior to creating any activity records that will be affiliated with it.

## PROJECT REPORTING FAQs

**Q. Who should report projects?**

A. In general, since projects can include the work of many staff, reporting should be overseen by Program Directors, Clinic Directors, Principle Investigators, etc.... Actual entry into the NIRS application can be performed by a designee, but the aforementioned staff should be involved to assure accurate descriptions of projects.

**Q. Do reported projects have to be funded directly by UCEDD or LEND funding?**

A. No. The funding source can be detailed in the NIRS application to be certain that proper funding sources are noted for projects. In general, all projects that are completed in affiliation with CHDD programs or staff should be reported. Staff that split time between the CHDD and another department may work on projects that are clearly separate from work they do at the CHDD. In this scenario, that work would most likely not be included. These gray areas can be discussed internally as needed.

**Q. Do we need to report fiscal information on projects?**

A. No. Currently fiscal information is tracked in the central CHDD office outside of the NIRS application. This system will continue to be used, but this may change in the future if reporting directly into NIRS is determined to be a viable option.

**Q. Who can see project information in the NIRS database?**

A. Project information can be seen by CHDD staff with a login and password. Selected information is also available for public search via the AUCD website. This tool provides the public and other centers a way to see what type of work is being accomplished. Fiscal information is not displayed via the public search tool.

**Q. How is project information used?**

A. Project information reported will be used in various ways. It will be used for progress reports to assure future financial support from federal grants. It will also be used to provide accurate and up to date information for internal publications and the CHDD website to promote the CHDD and work being done by affiliated staff.

## ACTIVITY GUIDELINES

### OVERVIEW OF ACTIVITY REPORTING GUIDELINES FOR NIRS ONLINE APPLICATION

Data collected in the Activities Dataset is intended to be linked to particular projects identified in the Projects dataset. Activities are the individual events or discrete process, pursuits, or functions of a project, and are often clearly measurable. In contrast, the Projects Dataset is intended to record information on on-going initiatives that may encompass multiple activities.

Activity-level reporting can further be distinguished from project-level reporting in that activity records focus more on impact (e.g., number of students trained) of the work than on the infrastructure of any project. NIRS allows Centers to manage information on the activities performed for each project. All the data collected in the Activities Dataset is linked to particular projects identified in the Projects Dataset.

Descriptive information about each activity is collected in the Activities dataset including:

- \* The core function that best describes the activity
- \* The type of activity
- \* The area of emphasis the activity addresses
- \* Numbers, types, and demographics of activity participants
- \* Collaborators on the activity
- \* Projects the activities are affiliated with
- \* Duration and dates of activity

Note: If an Activity Record is to be linked to a Project Record, the Project Record must be created prior to creating Activity Record.

## ACTIVITY REPORTING FAQs

**Q. Who should report activities?**

A. Activities can include the work of many staff or of individuals. Therefore, coordination of reporting should be handled appropriately. Activity reporting allows users to report the amount of time taken to perform the work. If an activity involves the work of multiple staff, then the time should reflect that. Activities will tend to detail work of specific individuals involved with a project.

**Q. Do reported activities have to be affiliated with a project?**

A. No. In general, most activities will be affiliated with a project, but sometimes staff do work or consultations that are in support of outside projects. In this case, the users should choose the 'No Affiliated Project' option in the appropriate section. Basically, we want to try and capture all work done through staff affiliation with the CHDD.

**Q. If I perform an activity more than once, do I have to report it more than once?**

A. No. However, the time spent and the people served during all the occurrences of the activity being reported should reflect your actual work. For example, if you perform a training seminar covering the same material four times a year, then you can report one activity that reflects time spent and the audience reached.

**Q. I do work for a project that provides many services, how do I report that?**

A. Activities can only have one designated core function so if you are performing tasks that cover multiple core functions then you should report multiple activities. For example, if you do work under a project that includes training professionals and creating education material for families, then you should report those as two activities. If you are unclear on how something should be reported, you can work with Richard Masse and other staff to determine what to do.

**Q. How is activity information used?**

A. Activity information reported will be used in various ways. It will be used for progress reports to assure future financial support from federal grants. Information reported on activities provide detailed measurable impacts and this detail can in turn be used to demonstrate the number and types of people affected by our staff's work.

## PRODUCT GUIDELINES

### OVERVIEW OF PRODUCT REPORTING GUIDELINES FOR NIRS ONLINE APPLICATION

The Products Dataset is intended to capture information on various materials produced and disseminated by network. NIRS allows Centers to manage information on the products they develop and/or disseminate. The products may be linked to specific activities and trainees.

Products may include:

- \* Refereed journal articles
- \* Non-refereed publications
- \* Books
- \* Book chapters
- \* Audio/Visual Materials, Software, Web Portals/Sites
- \* Educational Modules
- \* Doctoral Dissertations and Master's Theses
- \* Periodicals
- \* Public awareness materials

Product records are intended to capture information on the title, author, date of publication, publisher, and the fiscal year in which it is being reported. The records also have fields for providing a brief description, indicating alternative formats, ordering, and cost information. The basic descriptive information provided when creating a new product record may be edited at any time.

The Products dataset links with the Activity dataset to capture product dissemination information. To capture dissemination information in NIRS, first an activity record must be created and then a new or existing product must be linked through the Information Dissemination core function option. After a product is linked to an Activity record, dissemination data entry fields will appear in the Product record.

Note: Dissemination data entry fields do not display in Product records that are not linked to an Activity record.

Once the Product and Activity records are linked, the dissemination data entry fields may be accessed for editing or updating through either the Product or Activity records.

## PRODUCT REPORTING FAQs

**Q. Who should report products?**

A. Products can include the work of many staff, individuals or collaborations with outside entities. Therefore, coordination of reporting should be handled appropriately. Please see the notes below on reporting of publications, books and book chapters.

**Q. Do reported products have to be affiliated with a project or activity?**

A. No. Products like publications and book edits will usually not be affiliated with a specific project or activity. However, when a product is linked to an activity in NIRS, the user will have the ability to report dissemination numbers. It is important to note that the link between an activity and a product can only be made if the activity is designated as Development/Dissemination of Information for its core function.

**Q. Do I have to know the dissemination number of a product to report it?**

A. No, but when this is known, it is good to report.

**Q. We already report publications, books, etc to Carolyn Hamby at the beginning of each year, do we need to report these to NIRS?**

A. No. The system in place that staff use to report publications and books will remain the same. Once that list is compiled in the early spring, it will be imported into the NIRS application.

**Q. How is Product information used?**

A. Product information reported will be used in various ways. It will be used for progress reports to assure future financial support from federal grants. Information reported on products will also be available for public search via the AUCD website.

## GENERAL REPORTING FAQs

**Q. How do I get access to the NIRS online application?**

A. Access to the NIRS application can be granted by contacting Richard Masse at [rmasse@u.washington.edu](mailto:rmasse@u.washington.edu). Once a user has access, supplemental documents, training and support will be available.

**Q. How often do I have to report?**

A. Progress reports that depend on this information are generally due in June each year. Ideally, staff will report information as it occurs over the year to avoid complications that come from trying to remember what work has been done during the prior 12 months. Notices from the CHDD central office will be provided during the year via e-mail to assist in reminding staff to report. Year to year staff will be able to easily copy and transfer information from one fiscal year to the next for those projects, activities and products that carry over. In these cases, we just need to be sure the details (numbers, audience type) accurately reflect what occurred.

**Q. I report to other systems and we have other databases with this information, can't we use those?**

A. Ideally we want all the information to be input into the NIRS application. However, when existing systems can be used to retrieve information on work being done, we will do so. For example, most of our clinics at the CHDD use databases for patient scheduling and to detail clinic visits. These systems can be used to provide numbers on patients for the activities of "clients being seen" by individual staff. If similar systems exist that you feel can be used to retrieve data, please inform Richard Masse.

**Q. Do I have to actually report or can someone else do it for me?**

A. In general, the staff doing the work should be involved at some level to assure accurate reporting. However, the method of reporting is really up to each program within CHDD to determine. Some programs designate a few staff to compile and enter information, while other individuals just do it themselves.

**Q. I have more questions, who do I contact?**

A. If you have more questions, or need assistance, contact Richard Masse at [rmasse@u.washington.edu](mailto:rmasse@u.washington.edu).