Indiana State Department of Health
Division of Maternal and Child Health
Genomics and Newborn Screening Program

Request for Applications (RFA) – Krabbe, Pompe and MPS-I /
Lysosomal Storage Disorders

<table>
<thead>
<tr>
<th>Application Deadline</th>
<th>April 13th, 2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Submit applications via email to:</td>
<td><a href="mailto:MCHBusinessUnit@isdh.IN.gov">MCHBusinessUnit@isdh.IN.gov</a></td>
</tr>
</tbody>
</table>
EXECUTIVE SUMMARY
A key health initiative for Indiana is collaborating with community partners to reduce infant mortality and morbidity rates across the state. The goal of the Genomics and Newborn Screening Program within the Maternal and Child Health Division at the Indiana State Department of Health is to ensure all babies born in Indiana receive timely newborn screens in order to identify potential life threatening conditions early. Prevention and early detection of problems in infants are vital to reduce the magnitude of financial, personal and emotional burdens associated with adverse health outcomes. the Genomics and Newborn Screening Program is seeking community partners able to provide services focused on the confirmation of disease and connection to resources for children 0 through 3 years of age diagnosed with Krabbe, Pompe and MPS-I.

TECHNICAL ASSISTANCE
To ensure fair and equitable consideration to all applicants, questions about the requirements or the application process must be emailed to ISDHNBS@isdh.IN.gov. Applicant questions should be submitted by the designated due date of 3:00 p.m. Eastern Standard Time on March 16th, 2020. All submitted questions will be compiled into a single document, answered, and posted online for all applicants to view by close of business day on March 20th, 2020.
SUMMARY OF TIMELINE

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Posting of Request for Applications</td>
<td>March 6th, 2020</td>
</tr>
<tr>
<td>Deadline to Submit Written Questions</td>
<td>March 16th at 3pm EST</td>
</tr>
<tr>
<td>Response to Written Questions</td>
<td>March 20th at 3pm EST</td>
</tr>
<tr>
<td>Application Due Date</td>
<td>April 13th at 3pm EST</td>
</tr>
<tr>
<td>Length of Project Period</td>
<td>1 year due to current grant cycle alignment.</td>
</tr>
</tbody>
</table>

I. FUNDING OPPORTUNITY DESCRIPTION

The Indiana State Department of Health (ISDH) Genomics and Newborn Screening (GNBS) program announces the availability of funds to satisfy the need for early intervention and follow-up services from a community partner in order to reduce infant morbidity and mortality rates within the state of Indiana. Services included in this opportunity are focused on confirmation of disease and connection to resources for children 0 through 3 years of age diagnosed with Krabbe, Pompe and MPS-I. Services will be for state fiscal year 2021, beginning July 1, 2020 through June 30, 2021.

Applicants, at a minimum, must provide services for the following:

1. Provide services to patients with Indiana residency who screened positive for Krabbe, Pompe and MPS-I and fall within the 0 through 3 year age-range within the state of Indiana including:
   - Ensure early contact to primary care provider (PCP) and families of children with abnormal newborn screening results
   - Confirmatory testing as defined by the Perinatal Genetics and Genomics advisory committee of the Indiana Perinatal Quality Improvement Collaborative.
   - Ensure treatment, intervention services, and management of diagnosed condition.
   - Evaluation and counseling to patients and families, including genetic counseling as appropriate.
   - Other consultations as necessary

2. Address access to care concerns with patients and families (e.g. other care/providers, transportation needs, funding and other available resources).
3. Refer families of children with special care needs to appropriate resources, including Children’s Special Health Care Services, Women with Infants and Children (WIC) clinic, and First Steps (for infants under age 3).

4. Provide appropriate education to patients regarding the proactive effects of prenatal care and family planning, as well as referral to MCH programs as needed.

5. Provide educational presentations to health care professionals, students, and general population. Alert ISDH GNBS of each planned presentation.

6. Applicants must be willing to work directly with ISDH GNBS leadership and team to ensure compliance to program requirements outlined in the funding opportunity description. Applicants will provide:
   - Reports and documents for all children who screened positive and receive direct and/or telehealth services and consultations. Reports will be sent securely via email to ISDHNBS@isdh.in.gov.
   - Community partner is required to participate in meetings as indicated by ISDH GNBS team (annually at a minimum).
   - Community partner will contact the Newborn Screening Follow-up Care Coordinator via email ISDHNBS@isdh.in.gov regarding any lost to follow-up cases as they occur.
   - Community partner is expected to work alongside ISDH through technology enhancement initiatives including an INSTEP application rebuild.

II. AWARD INFORMATION

AWARD AMOUNT
It is expected that up to $75,000 will be available to fund in FY 2021 for children diagnosed with Krabbe, Pompe and MPS-I ages 0 through 3 years.

III. ELIGIBILITY INFORMATION

ELIGIBLE APPLICANTS
Due to the complexity of healthcare navigation and coordination of services, ISDH GNBS determined that it is the most cost-effective and efficient to limit eligibility to one community
partner. Eligibility for this competitive supplemental funding opportunity is limited to FY 2021 July 1, 2020 to June 30, 2021. ISDH GNBS is providing supplemental funding for this program in order to better address the full range of care and treatment of individuals 0 through 3 years of age who are diagnosed with Krabbe, Pompe, and MPS-I. The selected community partner must possesses the necessary infrastructure in place to immediately implement activities under this supplemental funding announcement. The Community partner must also have a team including (at a minimum) a licensed/board-certified medical geneticist, genetic counselor(s), and social worker/case manager.

IV. APPLICATION AND SUBMISSION INFORMATION

BUDGET AND GRANT APPLICATION SUBMISSION
Applications are due by 03:00 PM (Eastern Standard Time) on April 13th, 2020. Your application must be submitted via email to MCHBusinessUnit@isdh.IN.gov

INSTRUCTIONS FOR BUDGET FORM
Using the Excel template provided, create a budget for Fiscal Year 2021 (July 1, 2020 through June 30, 2021). Budget forms are to be attached as a separate Microsoft Excel workbook. The budget is an estimate of what the project will cost. Include basic business costs and income from patient care or other funding sources depicting ability to maintain daily business practices outside the scope of NBS grant funding project. Be sure to demonstrate that all expenses are directly related to the project and the relationship between budget and project objectives are clear, provide budget narrative inside worksheet if necessary for clarification.

EXAMPLES OF EXPENDITURE ITEMS THAT WILL BE ALLOWED:
Allowable expenditure items are only valid for children with Indiana residency who screened positive for Krabbe, Pompe or MPS-I on their newborn screen.

- Patient visit fees
- Patient transportation (when all other resources are not available)
- Medical supplies/treatment supplies
- In-state staff travel for patient care (if/when necessary) 
  Note: All staff listed in the budget must be included. In-state travel information must include miles, mileage reimbursement rate, and reason for travel. Travel reimbursement may not exceed state rates. Currently,
the in-state travel reimbursement is $0.38 per mile, $32 per day per diem, and $94 plus tax per night of lodging.

- Confirmatory testing fees
- Fees associated with case management, patient communication and outreach services
- Medical courier service
- Other costs associated with providing patient care

EXAMPLES OF EXPENDITURE ITEMS THAT WILL NOT BE ALLOWED:
- Personnel salaries
- Construction of buildings, existing building renovations
- Contributions, gifts, donations
- Entertainment and/or food
- Automobile purchase
- Bad debts and/or interest
- Overhead costs such as internet, electric, utilities, etc.
- Costs for in-hospital patient care
- Fines and penalties
- Accounting expenses
- Contingency funds
- Executive expenses such as car rental and unrelated travel expenses
- Fundraising expenses
- Legal fees
- Legislative lobbying
- Equipment (over $5,000 per unit)
- Dues to societies, organizations, or federations
- Incentives

REQUIRED APPLICATION COMPONENTS/INSTRUCTIONS
Applications cannot exceed 30 pages with one inch margins using Times New Roman 12-point font. Applications must include the following required components:
Section A: Forms A, B-1, B-2, and Budget Worksheet (15 points)
Ensure all of the attached forms are complete and comprehensive. Problems to be addressed are identified and align with the grant opportunity. *Forms A, B-1 and B-2 are not included in the 30 page count.*

- **Form A - Application cover page** – Provided with RFA posting.
- **Form B-1 - Project Description** – Provided with RFA posting.
- **Form B-2 - Facilities** – Provided with RFA posting.
- **Budget Excel template** – Provided with RFA posting.

Section B: Application Narrative (35 points)
Created by applicant and must discuss the following:

- Current services provided by your program for the targeted population. Include the impact of your current services shown through data and community reach.
- Process map of your proposed program’s lysosomal storage disorder follow-up. Begin from the time of notification from the NBS lab and continue through patient diagnosis, treatment, and continued care.
- Ability to reach patients statewide through your individual network, outside networks, other community partners and telehealth solutions.
- Describe your statement of need. Include specific problems or needs to be addressed by this project. Include documentation such as current data, research, local surveys, reports from professional local and national health organizations, and other reliable resources. Please be sure to include a reference page for sources of documentation.

Section C: Proposed SMART Goals and Activities (35 points)
SMART Goals and Activities

Created by applicant and must discuss the following:

- Five SMART goals and defined performance measures to track the progress toward each goal.
- Planned activities including: implementation of follow-up process and how SMART goals will be met.
• Plans to expand or enhance your existing program in order to allow implementation of lysosomal storage disorder follow-up services.
• Description of activities that will be supported with the supplemental grant funds.
• Plans for collaboration and enhancement of the Indiana Perinatal Quality Improvement Collaborative Perinatal Genetics and Genomics Committee.
• Type of data and method of data collection to be shared monthly or as requested by GNBS.
• Describe proposed educational outreach activities

Section D: Staffing Plan and Shortened CVs (5 points)
Include the two content sections below:
• **Staffing Plan:** List the names, roles and contact information of all staff that will work on this project. Indicate who will be the designated newborn screening coordinator. The newborn screening coordinator will be the main point of contact between the community partner, newborn screening laboratory and ISDH. A weekend staffing plan should also be discussed. This should include: who will be the point of contact for the lab and/or ISDH GNBS if the need arises on during a weekend or evening.

• **Staff Credentials:** Demonstrate that staff is both qualified to participate and can adequately manage project requirements and objectives. Submit shortened curriculum vitae (CV) for key staff, highlighting pertinent experience and publications *Note: this will be included in the 30 page count*. Copies of current professional licenses and certifications must be on file at your organization. Copies of current professional licenses and certifications do **not** need to be submitted with the application, only include the license number on the appropriate CV.

Section E: Endorsement (10 points)
• **Endorsements** – Each application must include at least three letters of support from relevant agencies outside of the applicant’s healthcare network. All letters of support should show evidence that the applicant has the necessary staff, equipment, and expertise to perform the timely follow-up of lysosomal storage disorders. Letters of support must demonstrate a commitment to collaboration between applicant agency and other relevant organizations within the proposed follow-up process. A strong partnership among the applicant, other health care agencies, the newborn screening lab, and ISDH is vital to
ensure best outcomes for children screened positive for lysosomal storage disorders. Note: These will not be included in the 30 page count.

V. APPLICATION REVIEW INFORMATION

EVALUATION CRITERIA

All proposals will be reviewed on the quality, clarity, and completeness of the application.

- Section A: Forms A, B-1, B-2, and Budget Worksheet - 15 points
- Section B: Application Narrative - 35 points
- Section C: Proposed Performance Objectives and Goals - 35 points
- Section D: Staffing Plan and Shortened CVs - 5 points
- Section E: Endorsement - 10 points

Discuss the following items within your responses:

- SMART goals contribute to the early detection of conditions and improvement of healthcare for Indiana children ages 0 through 3 years who are diagnosed with Krabbe, Pompe or MPS-1.
- Responsiveness to program objectives for activities for which grant dollars are being made available.
- Identification of target population who experience a disproportionate burden of the health condition and explains the root causes of disparities.
- SMART (Specific, Measurable, Attainable, Relevant, Time-based) objectives, activities, performance targets and outcomes with respect to timelines and resources.
- Evaluation plan and/or data source(s) that will be used to determine the level of success for the project.
- The role that fostering a partnership with ISDH plays in decreasing infant mortality.
- Demonstration of past performance in areas related to programmatic and financial stewardship with program personnel that are qualified for their roles.

REVIEW AND SELECTION PROCESS

Applications are reviewed by ISDH agency staff according to the evaluation criteria listed above. If multiple applications are received for this funding opportunity, the highest scored applicant will be awarded.
VI. ADMINISTRATION INFORMATION

AWARD NOTICES
You will receive a letter from ISDH GNBS program via email that describes the general results of the review of your application, including the score that your application received.
If you are approved for funding, you will receive an additional notice through email, the Notice of Award, signed by ISDH Grants Management Officer. The Notice of Award is the sole obligating document that allows you to receive state funding for work on the grant project.
If you are not funded, you will receive notification from ISDH GNBS.

ADMINISTRATIVE POLICY REQUIREMENTS

- If you are awarded you must comply with all terms and conditions of the grant contract.
- Depending on the scope of work within your proposed project, ISDH GNBS may negotiate additional terms and conditions with you prior to grant award. These may include:
  - Actions required to be in compliance with confidentiality and participant protection/human subjects requirements
  - Requirements relating to additional data collection and reporting
  - Requirements to amend proposed project approach
  - Revised budget
- If you are awarded you will be held accountable for the information provided in the application relating to performance targets. ISDH GNBS program officials will consider your progress in meeting goals and objectives, as well as your failures and strategies for overcoming them, when making an annual recommendation to continue the grant and the amount of any continuation award. Failure to meet stated goals and objectives may result in withholding opportunity for continuation awards.
- Grant funds cannot be used to supplant current funding of existing activities.
VII. AGENCY CONTACTS

For questions about application process contact:
Eden Bezy
Indiana State Department of Health
Director of Maternal and Child Health
2 Meridian St
Indianapolis, IN 46204
317-233-1252
EBezy@isdh.IN.gov

For questions about grants management contact:
Michael Mendyk
Indiana State Department of Health
Director of Grants and Contracts
2 Meridian St
Indianapolis, IN 46204
317-234-6874
MMendyk@isdh.IN.gov
VIII. DEFINITIONS

- **Client/patient**: A recipient of services that are supported by program expenses funded in whole or in part by ISDH GNBS dollars
- **INSTEP**: Indiana Newborn Screening Tracking and Education Program (INSTEP) is a web-based application developed by the Indiana State Department of Health Newborn Screening (NBS) Program in order to help ensure that all children in Indiana receive the best care related to newborn screening.
- **IPQIC**: Indiana Perinatal Quality Improvement Committee
- **ISDH**: Indiana State Department of Health
- **GNBS**: Genomics and Newborn Screening program within the Indiana State Department of Health
- **NBS (newborn screening) supported services**:  
  - Direct medical and dental care: family planning, prenatal care, child health (infant, child adolescent), women’s health  
  - Enabling services: prenatal care coordination, family care coordination.
- **PGG sub-committee**: IPQIC Perinatal Genetics and Genomics sub-committee
- **Program expense**: Any expense included in the budget to be funded by NBS (supplies, space costs, etc.)
- **SMART goals**: SMART is an acronym for **Specific, Measurable, Attainable, Relevant, and Time-based**. SMART goals take each of these into account. Example of a SMART goal:  
  - **Specific**: Detailed  
  - **Measurable**: Metrics are provided and tracked  
  - **Attainable**: Reasonable and realistic  
  - **Relevant**: Pertains to activities outlined in this grant application packet  
  - **Time-based**: Includes specific timeframes
- **Supplant**: Replacing funding of a recipient’s existing program with funds from a federal grant.
- **Telehealth**: the provision of healthcare remotely by means of telecommunications technology.
FORM A

LYSOSOMAL STORAGE DISORDER
GRANT APPLICATION
FY 2021

Title of Project:
______________________________________________________________________________

Federal ID Number: __________ Medicaid Provider Number: __________

Legal Agency/ Organization Name:
______________________________________________________________________________

Address: Street ________________________________          City ________________________________
            Phone ________________________________          Fax ________________________________

Project Director (Printed) ________________________________          Title ________________________________          Email ________________________________

Project Director Signature* ________________________________          Date ________________________________

Agency CEO or Official Custodian of Funds ________________________________          Title ________________________________          Email ________________________________

Agency CEO/Custodian of Funds Signature* ________________________________          Date ________________________________

Date registered with Secretary of State: ___________________________________
   (Applicants must be registered with the Secretary of State to be considered for funding)
## FORM B-1

### FY 2021

**Project Description**

<table>
<thead>
<tr>
<th>Project Name:</th>
<th>Project Number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td>City, State, Zip</td>
</tr>
<tr>
<td>Telephone Number:</td>
<td>Fax Number:</td>
</tr>
<tr>
<td>Counties Served:</td>
<td></td>
</tr>
<tr>
<td>Type of Organization:</td>
<td>State □</td>
</tr>
</tbody>
</table>

**Requested Funds:** $_________________  (Amount should reflect total for FY 2021)

**Sponsoring Agency:**

Summarize identified needs to be addressed by this project.

Summarize proposed performance objectives and goals.
<table>
<thead>
<tr>
<th>NBS Project Name:</th>
<th>Project Number:</th>
<th># Clinic Sites</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinic Site Address:</td>
<td>Clinic Schedule (days &amp; times):</td>
<td>NBS Budget for Site:</td>
</tr>
<tr>
<td>Counties Served:</td>
<td>Services Provided in NBS Budget for site:</td>
<td></td>
</tr>
<tr>
<td>Target Population and estimated number to be served with NBS funds:</td>
<td>Other services provided at site (non-NBS):</td>
<td></td>
</tr>
<tr>
<td>Clinic Site Address:</td>
<td>Clinic Schedule (days &amp; times):</td>
<td>NBS Budget for Site:</td>
</tr>
<tr>
<td>Counties Served:</td>
<td>Services Provided in NBS Budget for site:</td>
<td></td>
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</tr>
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<tr>
<td>Counties Served:</td>
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<td>Target Population and estimated number to be served with NBS funds:</td>
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<tr>
<td>Target Population and estimated number to be served with NBS funds:</td>
<td>Other services provided at site (non-NBS):</td>
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</tr>
<tr>
<td>Clinic Site Address:</td>
<td>Clinic Schedule (days &amp; times):</td>
<td>NBS Budget for Site:</td>
</tr>
<tr>
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</tr>
<tr>
<td>Counties Served:</td>
<td>Services Provided in NBS Budget for site:</td>
<td></td>
</tr>
<tr>
<td>Target Population and estimated number to be served with NBS funds:</td>
<td>Other services provided at site (non-NBS):</td>
<td></td>
</tr>
</tbody>
</table>
### Account Codes

#### 111.000 Physicians
- Clinical Geneticist
- Family Practice Physician
- General Family Physician
- Genetic Fellow
- Medical Geneticist
- OB/GYN
- Other Physician
- Neonatologist
- Pediatrician
- Resident/ Intern

#### 111.200 Other Service Providers
- Audiologist
- Child Development Specialist
- Community Educator
- Community Health Worker
- Family Planning Counselor
- Genetic Counselor (M.S.)
- Health Educator/ Teacher
- Outreach Worker
- Physical Therapist
- Physician Assistant
- Psychologist
- Psychometrist
- Speech Pathologist
- Occupational Therapist

#### 111.350 Care Coordination
- Licensed Clinical Social Worker (L.C.S.W.)
- Licensed Social Worker (L.S.W.)
- Registered Dietician
- Social Worker (M.S.W.)
- Social Worker (B.S.W.)
- Registered Nurse
- Physician

#### 111.400 Nurses
- Clinic Coordinator
- Community Health Nurse
- Family Planning Nurse Practitioner
- Family Practice Nurse Practitioner
- Licensed Midwife
- Licensed Practical Nurse
- Other Nurse
- Other Nurse Practitioner
- Obstetric Nurse Practitioner
- Pediatric Nurse Practitioner
- Registered Nurse
- School Nurse Practitioner
- OB/GYN Nurse Practitioner
<table>
<thead>
<tr>
<th>111.600 Social Service Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caseworker</td>
</tr>
<tr>
<td>Licensed Clinical Social Worker(L.C.S.W.)</td>
</tr>
<tr>
<td>Licensed Social Worker (L.S.W.)</td>
</tr>
<tr>
<td>Counselor (M.S.)</td>
</tr>
<tr>
<td>Social Worker (B.S.W.)</td>
</tr>
<tr>
<td>Social Worker (M.S.W.)</td>
</tr>
<tr>
<td>Counselor</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>111.700 Nutritionists/ Dietitians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietitian (R.D. Eligible)</td>
</tr>
<tr>
<td>Registered Dietitian</td>
</tr>
<tr>
<td>Nutritionist (Master’s Degree)</td>
</tr>
<tr>
<td>Nutrition Educator</td>
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</tbody>
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<table>
<thead>
<tr>
<th>111.800 Medical/ Dental Project Director</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental Director</td>
</tr>
<tr>
<td>Medical Director</td>
</tr>
<tr>
<td>Project Director</td>
</tr>
</tbody>
</table>

| 111.825 Project Coordinator                                       |

<table>
<thead>
<tr>
<th>111.850 Other Administration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accountant/ Finance/ Bookkeeper</td>
</tr>
<tr>
<td>Data Entry Clerk</td>
</tr>
<tr>
<td>Nurse Aid</td>
</tr>
<tr>
<td>Administrator/ General Manager</td>
</tr>
<tr>
<td>Evaluator</td>
</tr>
<tr>
<td>Other Administration</td>
</tr>
<tr>
<td>Clinic Aide</td>
</tr>
<tr>
<td>Laboratory Assistant</td>
</tr>
<tr>
<td>Programmer/ Systems Analyst</td>
</tr>
<tr>
<td>Clinic Coordinator (Administration)</td>
</tr>
<tr>
<td>Laboratory Technician</td>
</tr>
<tr>
<td>Secretary/ Clerk/ Medical Record</td>
</tr>
<tr>
<td>Communications Coordinator</td>
</tr>
<tr>
<td>Maintenance/ Housekeeping</td>
</tr>
<tr>
<td>Genetic Associate/ Assistant</td>
</tr>
</tbody>
</table>

| 115.000 Fringe Benefits                                           |

<table>
<thead>
<tr>
<th>200.000 Contractual Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance and Bonding (insurance premiums for fire, theft, liability, fidelity)</td>
</tr>
<tr>
<td>Equipment Leases</td>
</tr>
<tr>
<td>Licensing</td>
</tr>
<tr>
<td>Maintenance Agreements</td>
</tr>
</tbody>
</table>
bonds, etc.; malpractice insurance premiums cannot be paid with grant funds)

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>200.700 Travel</td>
<td>Conference Registrations In-State Staff Travel</td>
</tr>
<tr>
<td>200.800 Rental and Utilities</td>
<td>Janitorial Services Utilities Rental of Space</td>
</tr>
<tr>
<td>200.850 Communications</td>
<td>Postage (including UPS) Publications Subscriptions</td>
</tr>
<tr>
<td></td>
<td>Printing Costs Reports Telephone</td>
</tr>
<tr>
<td>200.900 Other Expenditures</td>
<td>Approved items not otherwise classified above</td>
</tr>
</tbody>
</table>

Consultants

*Individuals* not directly employed by your organization, but with whom you want to contract to perform services under this grant. (If you are contracting with an *organization* for services, you should list the organization under 200.00 Contractual Services.)