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REQUEST FOR PROPOSALS

Request for Proposal (RFP) from the WITH Foundation (WITH), the American Academy of Developmental Medicine and Dentistry (AADMD) and Ability Central

Enhancing the Resources, Programmatic Efforts, and/or Advocacy regarding Supported Decision-making for Adults with Intellectual and Developmental Disabilities who use Augmentative and Alternative Communication (AAC).

SUBMISSION DEADLINE

September 4, 2019

(11:59 p.m. PDT)

EXECUTIVE SUMMARY

Background

The WITH Foundation (WITH), the American Academy of Developmental Medicine and Dentistry (AADMD) and Ability Central are partnering in an effort to foster the development of additional resources, programmatic models, and/or advocacy related to Supported Decision-making* for adults with intellectual and developmental disabilities (I/DD) who use augmentative and alternative communication (AAC)*. This RFP is intended to promote innovation in the use of supported decision-making within healthcare settings and beyond. The geographic areas of focus are self-selected by the proposing organization/collaborative partners but must be within the United States. As a result of this RFP, it is anticipated that at least 4 grant awards will be made - at least two (2) of the grants awarded will be to nonprofits located in California and at least two (2) will also be to nonprofits located outside of California.

WITH is a private foundation that promotes comprehensive and accessible healthcare for adults with developmental disabilities. The mission of AADMD is to improve the quality, outcomes and value of healthcare for individuals with developmental disabilities and their circle of support. Ability Central makes grants to improve communication and information access for people with disabilities.

WITH, AADMD, and Ability Central embrace person-centered innovations and culturally competent care*; We want to see people with intellectual and developmental disabilities, their advocates, healthcare providers, and others smoothly navigate in today's complex world.

RFP for Supported-Decision-making—New Funding Opportunity

This is an invitation for collaborative proposals which focus on the development of additional resources, programmatic models, and/or advocacy related to Supported Decision-Making (SDM) for adults with intellectual and developmental disabilities who use Augmentative and Alternative Communication (AAC). Proposals should use one of the following approaches:

- Educational materials and/or Process Development: Develop additional educational resources and/or process information related to SDM
- Place-based Implementation: Supports place-based implementation of SDM models, i.e. projects that support the implementation of supported

decision-making within a specific healthcare institution or system, community organization, etc.)

- Advocacy: Supports local, regional, or national advocacy related to SDM

A secondary goal of this RFP is to foster new partnerships or significantly enhance existing partnerships between disability organizations, advocates, community organizations, and healthcare providers.

Supported Decision-Making (SDM)* allows people to obtain guidance and support without relinquishing their legal right to make personal choices about their lives. Using supported decision-making, a person with a disability selects a person or a team of trusted people to help understand, make, and communicate their decisions. The individual may rely heavily on their supporters when making choices, but the final decision ultimately remains within their control. Supported decision-making is a very flexible process; as the person gains experience, the areas in which they seek support and the people who they choose to support them may change.

Within healthcare settings, where supported decision-making strategies are used, the issue of informed consent needs to be considered. The four tenets of informed consent should be addressed in a proposal's approach are:

- Does the individual understand the treatment that is being proposed and the reason for the treatment?
- Does the individual understand the risks and benefits of accepting the proposed treatment?
- Does the individual understand the risks and benefits of rejecting the proposed treatment?
- Has the individual had the opportunity to ask questions and receive answers about the proposed treatment in a manner that is understood by the individual?

Families, advocates, and providers sometimes face challenges in understanding the personal rights afforded to adults with developmental disabilities as well as how best to support individuals with I/DD in communication strategies that allow the individual's desires to be known during the supported decision-making process.

Proposal Elements Required

Proposals should specifically address the needs of adults with intellectual and developmental disabilities who use augmentative and alternative communication (AAC).

Proposals should also address one of the following focus areas:

- Educational materials and/or Process Development: Develop additional educational resources and/or process information related to SDM;
- Place-based Implementation: Supports place-based implementation of SDM models, i.e. projects that support the implementation of supported decision-making within a specific healthcare institution or system, community organization, etc.);
- Advocacy: Supports local, regional, or national advocacy related to SDM;

This RFP encourages the development of new partnerships between community, healthcare, disability, and/or UCEDD, and LEND programs. If the proposed project includes organizations that have an established/existing partnership(s), the proposed project should include significant and new efforts undertaken by the partnership and/or new partners joining the existing collaborative efforts.

Applicants are asked to self-select their geographical area of focus (which must be within the United States). In the event that a collaborative proposal is submitted, a lead organization must be selected (by the applicant) for the proposed project. The lead organization is responsible for executing MOUs between themselves and the collaborating organizations. Copies of the MOUs must be provided in the “Letters of Support” section of the application process.

Additional elements to address in the proposals include:

- a. Self-Advocates*: All project plans must include partnering with Self-Advocates throughout the grant period. Input and participation from Self-Advocates is required. For the purpose of this RFP, self-advocacy is defined as “an adult with an intellectual and/or developmental disability advocating for themselves about the rights and responsibilities in their life, their community”. Strong proposals would include self-advocates being involved in the design process of the proposed project and/or serving as paid staff (or advisors) for the project.
- b. Cultural competency*: Cultural competency should also be emphasized throughout the planning and implementation process to ensure the incorporation of best practices. This would include ethnic, cultural, linguistic and other ways of understanding and communicating important information to one another.

- c. Target population: The target population to benefit from this funding opportunity is adults with I/DD who are 18+ years old who use Augmentative and Alternative Communication (AAC) -- and the organizations that serve this population.
- d. Target audiences: The target audiences can include, but are not limited to 1) self- advocates/advocates; 2) family members/guardians; 3) physicians and dentists (including students and residents); 4) nurses and nurse practitioners; 5) physician assistants; 6) medical assistants; 7) allied health professionals; 8) social workers/case managers; 9) front desk, clerical, and clinical staff; 10) administrators; and 11) other relevant individuals who provide caregiving and/or decision-making authority.

Suggested Applicants

- 1. University Centers for Excellence in Developmental Disabilities (UCEDD)
- 2. Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs
- 3. Other Not-for-Profits 501(c)(3) - Healthcare, Community, and Disability organizations.

Budget

A detailed budget will be required. Specifications are outlined in project budget section.

Award of Grant

Grants of up to \$100,000 (each) for 1-year period will be awarded. Please read the information provided on the following pages before submitting your proposal. Additional information will be posted on the foundation's website at withfoundation.org.

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A. OVERVIEW

The WITH Foundation (WITH), the American Academy of Developmental Medicine and Dentistry (AADMD) and Ability Central are partnering to support the development of additional resources, programmatic models, and/or advocacy related to Supported Decision-making for adults with intellectual and developmental disabilities who use augmentative and alternative communication (AAC) over a one (1) year period.

This RFP is intended to promote innovation in the use of supported decision-making within healthcare settings and beyond. This RFP also seeks to encourage the development of new partnerships between community, healthcare, disability, and/or UCEDD, and LEND programs. If the proposed project includes organizations that have an established/existing partnership(s) than the proposed project should include significant and new efforts undertaken by the partnership and/or new partners joining the existing collaborative efforts.

The geographic areas of focus for this RFP are self-selected by the proposing organization/collaborative partners but must be within the United States. As a result of this RFP, it is anticipated that at least 4 grant awards will be made - at least two (2) of the grants awarded will be to nonprofits located in California and at least two (2) will also be to nonprofits located outside of California. Each grant award will be up to \$100,000.

B. PROGRAM DESCRIPTION

A program's goals and objectives should also address one of the following areas:

- Educational materials and/or Process Development: Develop additional educational resources and/or process information related to SDM;
- Place-based Implementation: Supports place-based implementation of SDM models, i.e. projects that support the implementation of supported decision-making within a specific healthcare institution or system, community organization, etc.);
- Advocacy: Supports local, regional, or national advocacy related to SDM;

For Educational materials and/or Process Development —proposals must include learning goals and objectives. An approximate time commitment for learners in terms of hours should be included. If similar materials already exist, information on if/how these materials would be enhanced (when compared to similar version) should be included. An in-depth description of the design components listed here should be included:

- Educational Materials – videos, webinars, articles, textbooks, online training, podcasts, electronic applications, etc.) Of note—the timeline for the creation of these materials must be realistically achievable in a 12 month project term.
- Development Methodologies – utilizing evidence-based practices and input from self-advocates for working with I/DD populations, having adults with I/DD co-develop the materials and/or process

For Place-based Implementation - proposals must include information on the SDM model being used (and whether or where the model has been implemented before), demographics of the IDD population receiving services at the location(s), information on the projected number of individuals who use augmentative and alternative communication (AAC) who would participate in the implementation project, and information on the assessment of implementation project – (participant and provider surveys , evaluations, etc.)

For advocacy - proposals should include information on the target audience for the advocacy efforts, information on the geographic reach of the advocacy efforts, information on the need of the targeted advocacy effort(s) and insight in how self-advocates are involved in the design and implementation of the advocacy efforts.

The four tenets of informed consent should be addressed in a proposal. The four tenets are: 1) Does the individual understand the treatment that is being proposed and the reason for the treatment? 2) Does the individual understand the risks and benefits of accepting the proposed treatment? 3) Does the individual understand the risks and benefits of rejecting the proposed treatment? 4) Has the individual had the opportunity to ask questions and receive answers about the proposed treatment in a manner that is understood by the individual?

C. PROGRAM DETAILS

Eligible Organizations

UCEDD and/or LEND programs and other Not-for-Profits 501(c)(3) - Healthcare, Community and/or Disability not-for-profits are eligible to apply. Proposals submitted as a collaborative project or partnerships among multiple entities are welcome. The role of each entity must be clearly defined in the proposal. In the event that a collaborative project is submitted, a lead organization must be selected (by the applicant) for the proposed project. The lead organization is responsible for executing MOUs between

themselves and the collaborating organizations. Copies of the MOUs must be provided in the “Letters of Support” section of the application process.

Grant Period

The 1-year grant period is expected to begin by March 1, 2020.

Reporting Requirements

The reporting requirements and deadlines will be clearly stated in the grant agreement. The final report must be submitted via the online grant management portal and will include a financial accounting and narrative summary describing the outcomes of the grant-funded activities.

D. INSTRUCTIONS FOR GRANT PROPOSALS

Completed proposals must be submitted online at withfoundation.org. A federal tax identification number must be entered to begin the online submission process. To begin the submission process go to the grant management portal account sign in page which can found under the “Grant Information” tab then select “Login”. Once you have logged-in or created your account, the RFP application can be accessed by clicking on the “Apply” button in the blue text box on the left of the page. Then proceed by putting required information in the designated field(s). An explanation and space parameters will be defined within fields.

E. PROJECT BUDGET

- Submit a detailed 1-page budget. The total proposed budget may not exceed the maximum award amount of \$100,000 total for the grant period.
- Project Budget Narrative
- Budgets should include, but are not limited to, the following line items along with a budget narrative:
 - Personnel
 - Meetings and Events
 - Travel
 - Supplies and Equipment
 - Administrative Support/Indirect Costs (not to exceed 20% of project budget)
 - Other

- The budget should have a column that shows the cost of the total project budget by line item and a column for the amount requested from the foundation by line item with corresponding totals at the bottom of each column.

F. DEADLINES AND SUBMISSION PROCESS

- **Proposal Deadline:** Proposals must be submitted online by **September 4, 2019** by *11:59 p.m. PDT*.
- **Submission Process:** All proposals must be submitted online via the foundation's grant management portal at: withfoundation.org
- **Notifications and Release of Funds:** Notice of awards will be announced and released prior to *March 1, 2020*. The release of funds will be made contingent upon receipt of the signed grant agreement.

Applicants will receive email notification within three working days that their proposal was received and is complete. For inquiries about the RFP and assistance with the online submission process, please contact WITH Foundation staff at info@withfoundation.org.

Questions and answers that may be relevant will be posted on the WITH Foundation's website. Check the website for updated information.

Technical Assistance Call

A conference call will be held on **Thursday, August 8, 2019 at 2pm ET/11am PDT** to answer any questions pertaining to the project design and/or the application. Call in information follows:

Phone Number: **866-317-5076**
No Passcode Required

The call will not be recorded. However, a summary of the Q&As discussed during the call will be provided on the WITH Foundation website at: withfoundation.org/current-grant-cycle/. The Q&A summary will be available online by *August 13, 2019*.

*Glossary of terms

Culturally Competent care: is defined as care that respects diversity in the patient population and cultural factors that can affect health and healthcare, such as language, communication styles, beliefs, attitudes, and behaviors. Further, it includes other marginalized population groups who may be ethnically and racially similar to a provider but who are at risk for stigmatization or discrimination, are different in other identities, or have differences in healthcare needs that result in health disparities. (Agency for Healthcare Research and Quality, Evidence-based Practice Center Systematic Review Protocol, “Improving Cultural Competence to Reduce Health Disparities for Priority Populations”).

Self-Advocacy: means speaking up for yourself about the rights and responsibilities in your life. Refer to this link for further explanation provided by The ARC New Mexico:
www.arcnm.org/how-we-help/self-advocacy/.

Supported Decision-Making: gives people with disabilities the help they need to make choices about their own lives. These choices could be about where to live, what to do during the day, how to spend money, or when to see a doctor or have a procedure. Everyone needs support to make decisions. People with disabilities may need more or different kinds of supports (austisticadvocacy.org).

Augmentative and alternative communication (AAC) includes all of the ways we share our ideas and feelings without talking.

There are two main types of AAC: (1) unaided systems and (2) aided systems.

- (1) *Unaided Systems*: You do not need anything but your own body, e.g. using gestures, body language, facial expressions, and sign language.
- (2) *Aided Systems*: Uses some sort of tool or device, ranging from pen and paper or pointing to letters, words, or pictures on a board (basic aided systems) to selecting letters or pictures on a computer screen that speaks for you (high-tech aided system).

Most people who use AAC use a combination of AAC types to communicate.

<https://www.asha.org/public/speech/disorders/AAC/>