

Background:

Enclosed for Committee discussion and possible action are two Executive Summaries:

- Self-Advocate Community Organizing Project Executive Summary
- Partnership with African American Clergy to Support Families Executive Summary

These Executive Summaries were drafted by staff based on previous discussions with the Committee over several meetings and build on successes that TCDD has experienced from past work. The Committee will discuss these and may make recommendations to the Council for funding of future projects.

Both Committees will discuss “Future Public Policy Advocacy Projects” and provide direction to staff to develop a project or projects to further TCDD’s advocacy work by supporting the development of advocates who can effectively address statewide policy issues. Staff will share information regarding:

- possible funding of Policy Fellowships with selected organizations for people who are in graduate school or have recently finished a graduate program; and
- development of advanced level policy-focused symposiums, webinars, or podcasts for advocates interested in working on statewide policy issues.

Public Policy Committee

Agenda Item 9.

Expected Action:

The Public Policy Committee may make recommendations to the Council on “Future Public Policy Advocacy Projects”.

Project Development Committee

Agenda Item 7.

Expected Action:

The Project Development Committee will discuss executive summaries and may make recommendations to the Council.

Council

Agenda Item 8.

Expected Action:

The Council will consider recommendations from the Project Development & Public Policy Committees.

Future Funding Proposal Executive Summary Self-Advocate Community Organizing Project

Background

The Texas Council for Developmental Disabilities invests in advocacy and leadership training for Texans who have developmental disabilities, including individuals with intellectual disabilities, so they can advocate for their right to be fully included in the communities where they live and can exercise control over their own lives. More individuals with intellectual and developmental disabilities (IDD)¹ make decisions about their own lives and work with others to create social change than when the self-advocacy movement began in the 1960's. However, many people still do not recognize and respect people with IDD as equal partners and leaders in driving social change.

In 2011, the Administration on Intellectual and Developmental Disabilities (AIDD) held a series of self-advocacy summits. In these meetings, self-advocates from across the country spoke about the challenges they experienced as self-advocates. The [Envisioning the Future: Allies in Self-Advocacy Final Report](#) (September 2012) summarizes the major challenges that were identified by self-advocates:

- A need for infrastructure, funding, and support by advisors that empower but do not control activities of grassroots groups;
- A lack of general community services and supports (including transportation);
- Difficulties recruiting and developing leaders and engaging current membership in meaningful ways, particularly when trying to expand to rural areas, racial and ethnic minority communities, individuals with limited communication, and autism groups; and
- Perceptions by the general public, service providers, and family members that result in self-advocates continuing to face significant discrimination and feeling that they are not listened to.

Notably, self-advocates from multiple states expressed difficulty finding “consistent, well-trained staff” who will advise but not “try to run” groups, particularly self-advocates with intellectual disabilities. People also shared concerns about top-down approaches that do not support grassroots efforts to grow the self-advocacy movement.

Over the years, TCDD has awarded many grants to self-advocacy organizations to promote leadership and advocacy by self-advocates. In most cases, TCDD awarded these grants through a competitive process, and the grantee received the grant by submitting a multi-year plan outlining how they would meet TCDD's pre-determined goals for the project. While these projects generally had grassroots aspects to them, they tended to reflect priorities and issues identified by TCDD. Additionally, although TCDD always expects that individuals with developmental disabilities and family members of individuals with developmental disabilities will serve in leadership roles in grant projects, it has not been common for the majority of the primary decision-makers for these projects to be individuals with intellectual disabilities.

¹ For purposes of this summary, the term IDD refers to individuals with an intellectual disability who also have functional limitations consistent with the federal definition for “developmental disability”.

In May, 2012, the Executive Director of the Georgia Council on Developmental Disabilities (GCDD) shared information at a TCDD meeting about GCDD's grassroots projects that are creating community inclusion for people with developmental disabilities by supporting local groups to work together on projects that are important to them. GCDD employs and contracts with community organizers to provide support for these projects. The leaders of the GCDD community organizing efforts are not necessarily people with IDD, however people with IDD must be actively involved in the project. TCDD Council members were impressed with the success that this approach has created. This Executive Summary proposes to build on TCDD's past leadership and advocacy efforts to lay the foundation for community-driven projects like those funded in Georgia, with the stipulation that people with intellectual disabilities will be the leaders (ie., key decision-makers) of the TCDD community organizing project.

Community organizing is simply the process of people coming together to address issues that matter to them. It is community organizing when neighbors work together to increase pedestrian and bicycle friendliness or activate block leaders to participate in a Get to Know Your Neighbor Week. A TCDD self-advocate community organizing grant project would support people who have IDD who live in a single community to come together; identify for themselves common issues in their local community; become more informed about possible strategies to address the issue; form a plan; and work together to create the change that they have decided is important.

Individual self-advocates involved in this project may develop different strengths and assume different levels of leadership. However, every leader will be a self-advocate who has IDD, and every self-advocate who chooses to be involved will have access to training, information, and mentoring to exercise their leadership skills and assume meaningful roles. The roles of individuals who are not people with IDD will be limited to providing training, information, and mentoring as contractors, paid staff, or volunteers; and, if necessary, to complete evaluation, reporting, and financial management activities for the grant project.

This proposed local community organizing project will provide opportunities for people with IDD to connect with and develop relationships with peers, neighbors and decision-makers; to be recognized experts, decision-makers, and leaders in their community; and to successfully create change that they have decided will benefit both themselves and others in their community. TCDD will not determine specific local issue to be addressed, but will gain from learning about the issues that are important to people with IDD in a particular community in the state. TCDD will also benefit from building the voice of stakeholders to provide input to Texas legislators, state agencies and other policymakers on disability issues and ways to improve services and supports for people with disabilities. As individuals with IDD gain experience organizing for meetings, presenting issues and negotiating with decision-makers, they will be better prepared to participate in meaningful ways on state advisory committees, councils and boards should they choose to do so in the future.

State Plan Goal

Goal 6: Work with others to double the number of identified leadership development and advocacy training programs that are able to provide culturally appropriate training for people with developmental disabilities without ongoing grant funding from TCDD, by 9/30/2016.

Objective 1: Each year of the plan, provide funding or technical assistance to establish and/or strengthen at least one program for the direct funding of a state self-advocacy organization lead by individuals with disabilities.

Activity 2: At least once every 2 years, offer funding to support individuals with developmental disabilities to work with a state self-advocacy organization to implement a grassroots effort to organize and/or educate members of their community.

Expected Outcome

The Council will fund a local collaboration that is controlled and directed by individuals with intellectual and developmental disabilities and that works to change a program, policy or practice to improve life in their community.

Project Description

A trained community organizer will build and facilitate, but not control the activities of, a community group made up of individuals with intellectual and developmental disabilities living in that community. The group will identify and address issues of common interest. The project will be controlled and directed by self-advocates who have intellectual and developmental disabilities. The project will be implemented in the following manner:

1. A grantee organization and a community will be identified thru a competitive process. The grantee organization will be responsible for managing project funding, ensuring that reporting requirements are followed, and providing support to a Project Advisory Committee. The members of the identified community will control and direct project activities.
2. A Community Organizer will be hired in the identified local community. This person must be someone from the local community. The Community Organizer must be willing to sign a contract to commit to participating for the life of the project.
3. The Community Organizer will receive training about community organizing strategies from the Mid-West Academy or an organization with similar credentials and experience.
4. A Project Advisory Committee (PAC) will be established and will include members from local neighborhood organizations, community action group members, local government decision-makers, systems change advocates, and people who can evaluate the project. The PAC will play a supportive role and will be responsible to assure that TCDD receives: information documenting the project development, roadblocks and successes, and a blueprint for future community group development. The PAC will meet with and support the self-advocate group as requested by the group of self-advocates or as needed to support the project. The PAC will also provide a sounding board and support for Community Organizer, and will be available to role-play with self-advocates. The PAC will have staff support.
5. The Community Organizer will conduct at least 40 one-on-one meetings with self-advocates prior to holding the first meeting, as is expected in traditional community organizing. In these one-on-one meetings, the interviewer and the leader will develop a relationship with each other that will continue — and, it is hoped, deepen — in the future.
6. After the one-on-one meetings are held and commitment is achieved from self-advocates, the first organizing meeting will be held to discuss purpose, systems change, and desired goals.

7. Organizing meetings will continue to be conducted at least twice a month when possible. The Community Organizer will teach the group about community organizing tools: leadership roles, relationship building, negotiation and compromise. Through these meetings and other activities, the self-advocates will build or strengthen their relationships with each other, identify shared perspectives about barriers and opportunities, and prioritize their shared interests. When ready, they will seek expert input on the steps necessary to effect change, narrow their focus, and conduct systems change advocacy. After every meeting or action the group of self-advocates will “evaluate and celebrate.”
8. When the group reaches a point at which they are ready to develop an informed plan on an issue, they will agree on the specific activities and action steps they will engage in to successfully implement the plan; describe their intended outcomes; and identify the resources they will need to make the plan a success. The group of self-advocates will implement their agreed upon action and take full responsibility for negotiation with local decision-makers.
9. The self-advocate group will resolve at least one issue in their community. It is very important that the first action chosen be successful, so that the group continues to be motivated to continue to work together on other issues.

Through this process, a local issue will be addressed successfully, and self-advocates will develop and improve leadership skills, learn and use strategic thinking to identify a problem and develop a plan of action, and strengthen their relationships with each other as well as with community leaders. Community leaders will have an experience that should result in increasing their understanding of the contributions that individuals with intellectual and developmental disabilities can make to their community.

Proposed Funding Amount

The proposed funding amount is \$100,000 per year, for up to three years to establish the project. Match for the project will come from donated time of the project advisory committee and self-advocates who work together to effect change in a local community. If the group of self-advocates has built their local advocacy skills to a level that can be sustained with the support of a part-time community organizer, they may be eligible for a reduced level of funding for an additional two years to expand on their achievements, develop their organizational capacity, and to support the development of similar efforts in other communities. The ultimate goal is a local self-advocate community change organization that is engaged and self-sustaining.

Other Considerations

TCDD may wish to support the organization selected to provide training on community organizing strategies to come to Texas to provide training directly to the group of self-advocates and possibly to TCDD Council members and staff.

Funding Proposal

Executive Summary

Partnership with African American Clergy to Support Families

Definitions

In this Executive Summary, the use of the words “Clergy” and “Pastor” are based on information provided in Wikipedia.

A **pastor** is usually an ordained leader of a Christian congregation. The word may also refer to a title or a person (e.g., Pastor Smith) or a job title (like Senior Pastor or Worship Pastor).

Clergy is a generic term used to refer to a wide range religious leadership within some religions. Clergy have different functions in different religious traditions, and formal and informal clergy positions may include deacons, priests, bishops, preachers, pastors, and ministers.

Background

Approximately one in four people in the general population experience a mental health condition. Individuals with Intellectual and Developmental Disabilities (IDD) may have a higher risk of mental illness; estimates suggest that approximately 33% of individuals who have IDD also have mental illness. (Co-Occurring Mental Illness and Developmental Disabilities, by Maria Quintero, PhD., and Sarah Flick, MD, *Social Work Today*, 2010, Vol. 10 No. 5 P6). African Americans have rates of behavioral health disorders similar to that of the general population. However, African Americans, with or without IDD, frequently bear a heavier burden of disease, often due to a lack of information and awareness, access to healthcare, or appropriate services. African Americans have among the highest unmet needs for treatment of depression and other mental health disorders, and there continues to be a huge gap between the number of people who need treatment for mental health issues and those who seek treatment. In the African American community, 92 percent of males who have depression and 60 percent of families do not seek mental health treatment nor receive the appropriate support.

Stigma, cultural barriers, socioeconomic barriers, and mistrust of the health system based on past experience of abuse and neglect perpetrated by that system impede recovery and create barriers to seeking support. African American clergy (especially Pastors) are very influential in the lives of their congregants, and congregants are likely to seek their advice when concerns arise. In most black communities clergy are considered gatekeepers and first responders to personal or family crisis. There is less stigma in seeking assistance from clergy who are trusted, known and mostly respected by their congregants, and may frame the problem in spiritual terms that are more comfortable for the congregant/client (Bohnert et al., 2010). It is estimated that 75 percent of African Americans do not use traditional mental health services or providers and rely on pastors/clergy for support for most issues in their lives.

Most individuals will contact clergy without seeking additional formal support; the response by clergy to an individual’s mental health needs may be the deciding factor of whether the person seeks or refrains

from seeking additional formal or information supports. However, most clergy view their knowledge of mental health as limited, and the majority have not received training in mental health issues. It is important that clergy know when to make appropriate referrals to trained mental health professionals. Many studies show that collaboration between faith-based organizations and formal healthcare supports have emerged in the drive to improve access to care.

Four TCDD projects are currently working with faith-based groups to facilitate inclusion and support of people with intellectual and developmental disabilities, including people with mental illness:

- The Arc of Greater Tarrant County (IDD Needs Council of Tarrant County) is partnering with the local faith-based community to facilitate the full inclusion of people with a diagnosis of an intellectual and developmental disability (IDD) into faith communities of their choice.
- Jewish Family Service of Dallas is serving Dallas, Collin, Denton and Rockwall counties and will create a collaborative initiative to share successful community awareness building and inclusion strategies.
- West Central Texas Regional Foundation is working with faith communities in Callahan, Jones and Taylor counties.
- OneStar Foundation is collaborating with Jewish Family Services and the Texas A & M University Center on Disability and Development to create the Austin Interfaith Inclusion Network which serves the Travis County area.

Although these projects are reaching out to diverse communities and faith-based groups across Texas, they have not successfully reached African American clergy. However, TCDD staff have worked closely with the Austin Area African American Behavioral Health Network (4ABHN), a professional network for African American mental health professionals supported by the Hogg Foundation, to address this issue more successfully. Various activities have occurred thus far:

- The Hogg Foundation sponsored specialized clergy tracks at the 2012 and 2013 Central Texas African American Family Support Conferences. Led by practitioners dually-licensed in theology and mental health and by pastors, the tracks attracted more than 125 clergy and resulted in a commitment by many of the attendees to continue to work together. The Hogg Foundation also hosted a 2-day conference entitled “Spiritual Crossroads: Faith, Mental Health and the African American Community,” at the Southwestern Baptist Theological Seminary for nearly 350 consumers and family members, faith leaders, mental health advocates, policy makers from around the state.
- Dr. King Davis, University of Texas School of Social Work, the Health and Human Services Commission’s Center for Elimination of Disproportionality and Disparity, the Hogg Foundation, and Texas State Representative Garnet Coleman provided significant assistance to TCDD, Austin Travis County Integral Care, Helpful Interventions, and community members in the Houston area to establish the Gulf Coast of Texas African American Family Support Conference.
- The 4ABHN and a group of clergy have formed a vision of how clergy, properly trained and supported, may meet the needs of African Americans who may not be receiving services and supports for their needs related to IDD or Mental Illness.

Activities are proposed below to complement and enhance current efforts to support African American clergy in the central Texas area.

TCDD State Plan Goal

Goal 5: Demonstrate how to prevent unnecessary admissions to State Supported Living Centers (SSLC) by supporting community organizations in at least 1 HHS Region to increase their capacity to provide community-based services that support people with developmental disabilities to improve and maintain their health and to have access as needed to necessary healthcare, behavior supports, and/or respite, by 9/30/2016.

Objective 2: Provide funding to enable at least 10 organizations working in the target region(s) to implement plans that will increase their capacity to provide healthcare services, behavior supports, and/or respite to support people with developmental disabilities living in the community by 9/30/2016.

Activity 3: Provide support to non-medical community leaders (such as ministers) & service providers (such as speech pathologists) to collaborate with others to support the full inclusion of people with developmental disabilities and to support people with developmental disabilities to gain access to necessary healthcare services, behavior supports, and/or respite.

Expected Outcome

African American clergy in central Texas will increase their understanding of how to encourage and support members of their communities who have disabilities to gain access to necessary services and supports and to be fully included in their communities.

Project Description

TCDD staff will continue to work in collaboration with state agencies, community organizations, legislative offices, clergy, and other community members to reach the expected outcome. TCDD, the Hogg Foundation, the HHSC Center for Disproportionality and Disparities and others will collaborate with 4ABHN to develop a workplan that may include the following activities: It is expected that TCDD funds will be used to support to the following activities:

- Funding for a fellowship at one of the 4ABHN member organizations to coordinate various activities of 4ABHN and include additional organizations in that group;
- Speakers, trainers, purchase or distribution of materials, necessary travel, and other items as needed to support the work of 4ABHN;
- Evaluation(s) of the results of 4ABHN activities as appropriate;
- The sponsoring organization will receive, account for and disperse TCDD funds, assure timely progress towards activities on an approved plan, and comply with various reporting requirements.

It is expected that organizations currently participating in 4ABHN will jointly select an organization to serve as fiscal agent for TCDD funds. In that manner, the organization will be able to maintain a supportive relationship with African American clergy and show evidence of cultural competency.

Proposed Funding Amount

TCDD will provide funding up to \$75,000 per year including support for a fellowship. The selected entity will be responsible for contributing match to the project, in the amount of 25% of the total project costs for activities that are not in federal poverty areas and 10% for total project costs for activities that are in federal poverty areas.

Proposed Duration

TCDD funding will be available for up to five years.

Other Considerations

Note: There is some disagreement among developmental disability advocates about mental illness meeting the federal definition of “developmental disability.” Federal guidance provided in the past clearly indicated that if there is evidence that the mental illness first became evident prior to the individual’s 22 birthday, and results in at least three functional limitations as required by the federal definition of developmental disabilities, whether on an ongoing basis or episodically, that individual can be considered to have a developmental disability for purposes of the DD Act.