SUPPORTING STRONG AND SUSTAINABLE PEER ADVOCACY NETWORKS

Table of Contents

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Peer Advocacy Networks

WHAT IS A PEER ADVOCACY NETWORK?

A peer-advocacy network is a set of self-advocacy groups designed and operated primarily by and for people with intellectual and developmental disabilities (I/DD). Peer-advocacy networks work together to promote equality in opportunities, self-determination, civic rights, community living, and independence for people with I/DD. A slogan used to communicate the idea that no plan or policy should be decided without the full and direct participation of members of the I/DD population is, "Nothing About Us, Without Us!"[1] In the United States, there are more than 1200 local self-advocacy groups[2].

FEATURES LEADING TO STRONG AND SUSTAINABLE PEER ADVOCACY NETWORKS:

Outreach

Effective peer-advocacy outreach starts by identifying underserved groups, convincing members of these groups to participate, and creating strategies for redressing gaps in services. Persuading members of these groups can be challenging because it requires careful planning to support collaboration. Finally, devising strategies for redressing gaps in services may mean changing Federal, state, or local policy, which is rarely easy. Finding effective statewide processes include developing outreach committees; gathering, analyzing, and sharing findings with the state peer-advocacy network, self-advocates and other stakeholders.[3]

Person-Centered Advocacy

Person-centered self-advocacy, in general, can be understood as "a set of organized actions aimed at influencing public policies, societal attitudes, and socio-political processes that enable and empower the marginalized to speak for themselves"[4]. Compared to the traditional approaches to advocacy that seek to achieve policy change on behalf of marginalized groups, person-centered advocacy pursues social transformation by encouraging civic-motivated people to negotiate for their rights as a means to obtain their basic needs. Person-centered self-advocacy for people with I/DD starts with listening to individuals to understand what factors are essential to them for living full and independent lives. Barriers to achieving a "best life" are then identified so that strategic plans for self- advocacy can be made.

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[1] https://autisticadvocacy.org/wp-content/uploads/2015/02/CurriculumForSelfAdvocates_r7.pdf
[2] https://www.selfadvocacyinfo.org/self-advocacy/
[3] https://ncil.org/effective-statewide-outreach-one-states-collaborative-approach-for-cils-and-the-silc/

[4] https://pubs.iied.org/sites/default/files/pdfs/migrate/G01974.pdf

OUTREACH

Peer Advocacy Networks

WHY IS OUTREACH IMPORTANT?

Peer networks empower self-advocates to define their needs, set personal goals and objectives, and learn how to advocate for the services and resources they need to live full and independent lives. There is emerging evidence that people with I/DD from racial, ethnic, and linguistic minorities experience disparities in service access, and life quality[5]. Self-advocacy peer networks can provide a space for people with I/DD to share their experiences and support one another to work towards systemic change[6]. To include a diversity of voices, it is critical for peer advocacy networks to establish ongoing efforts to locate and encourage new membership.

What does outreach look like?

Many different outreach approaches can work to build the membership of people with I/DD in self-advocacy groups. Some states have multiple statewide self-advocacy organizations, while others focus more on regional approaches. Some outreach efforts promote broad cross-disability organizing, while others focus more narrowly on subgroups or particular issues. Many approaches to outreach are largely driven by funding streams at the local, state, or national level[7].

Promising Approaches to Outreach

- Community of Practice on Cultural and Linguistic Competence in Developmental Disabilities (CoP): The goals of this federally funded effort are to identify disparities and address gaps in racial, cultural and linguistic competence. Ten states are participating in this five-year program. The CoP developed a framework to be used by systems and organizations to reflect and address disparities in availability, accessibility, acceptability, quality and utilization of supports and services for people with I/DD across multiple domains including health, housing, employment, transportation and more.
- The Munroe-Meyer Institute of the University of Nebraska Medical Center State Disability Leadership Seminar Series: This was a series of community training seminars held across the state of Nebraska involving disability leaders from a variety of provider partners to encourage leadership, advocacy skills, and the best outcomes for individuals with disabilities and their families. Session topics included developing advocacy plans and building and supporting state and local coalitions with the goal of improving services and systems for individuals with disabilities.
- American Association of People with Disabilities: AAPD is a national cross-disability civil rights organization that works to increase the political and economic power of people with disabilities. Outreach examples in AAPD's initiatives include summer internship programs, disability mentoring days, get out the vote actions, and a campaign to stop bullying.
- The Voice of Reason (VOR): is a national, grassroots, nonprofit 501(c)(3) organization that is unique in its mission to advocate for high quality care and human rights for all people with (I/DD).

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[5] Tawara Goode, "A Resource Guide to Respond to Disparities in Intellectual and Developmental Disabilities: Services and Supports," (Washington, D.C.: Georgetown University National Center for Cultural Competence, Center for Child and Human Development, 2019)
[6] Advocating Change Together: https://www.selfadvocacy.org/about-act/
[7] Washington, D.C.: Georgetown University National Center for Cultural Competence, Center for Child and Human Development: https://www.nccdd.org/images/Public_Policy/Public_Policy_Topics/Full_Self-Advocacy_Summit_Report.pdf

VOR is the only national advocacy organization focused on residential choice and family decision-making. Individuals, families, professionals and organizations support VOR through annual membership dues and additional contributions.

PERSON-CENTERED ENGAGEMENT
Peer Advocacy Networks

WHY IS PERSON-CENTERED ENGAGEMENT IMPORTANT?

Person-centered peer networks understand that self-advocates with I/DD have the ability and the right to make informed decisions about issues that affect their lives. Peer advocate networks can use the lived experiences of self-advocates to establish a shared understanding about what it means to be person-centered. Person-centered engagement can determine the necessary accommodations and supports that self-advocates need to participate forcefully in meetings, conferences, task forces, boards, and other forums that focus on issues and policies that are important to them ("Nothing about us without us" principle)[8]. Person-centered engagement respects the desires of people with I/DD, including, for example, how they prefer to be identified. In most circumstances, it is appropriate to refer to an individual as a "person with I/DD". However, some people with I/DD prefer identity-first language[9], such as "autistic person." Person-centered engagement also entails respecting people's self-identified pronouns for gender identity.[10]

HOW CAN PEER-NETWORKS BENEFIT FROM PERSON-CENTERED ENGAGEMENT?

Peer networks are more effective when they employ person-centered engagement for this reason: we all learn better, trust more, and gravitate to the shared experiences of a group of trusted peers. Peer-networks provide a place for groups of self-advocates to test their thinking and share ideas, to ask questions with supportive colleagues who can help move an issue forward.

Through person-centered engagement, peer networks can directly align their advocacy, events, and strategic planning, to clearly reflect the core values of their members; this includes an emphasis on the strengths, capabilities, and preferences of each group. The main benefit of using person-centered engagement ensures that the views of members are heard, honored, and valued[11]. Self-advocacy groups that use person-centered engagement organize the information obtained to actualize person-centered outcomes[12].

PROMISING PRACTICES

- **National Youth Leadership Network (NYLN):** This self-advocacy group prioritizes people with I/DD coming together to create and share inspirational written and video content. The NYLN is dedicated to countering isolation and building community by supporting youth with disabilities and encouraging them to reach their full potential.
- **Autistic Self Advocacy Network (ASAN):** This nonprofit organization is run by and for autistic people. ASAN is a national grassroots disability rights organization for the autistic community, advocating for systems change, advancing civil rights, and ensuring that the voices of autistic

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[8] American Association on Intellectual and Developmental Disabilities: https://www.aaidd.org/news-policy/policy/position-statements/advocacy
[9] Autistic Self Advocacy Network: https://autisticadvocacy.org/about-asan/identity-first-language/
[10] National Institutes of Health: https://www.edi.nih.gov/blog/communities/what-are-gender-pronouns-why-do-they-matter
[11] https://ncapps.acl.gov/docs/NCAPPS_Principles_NationalEnvironmentalScan%20191202.pdf
[12] The ARC – Self-Advocacy and Leadership: https://thearc.org/position-statements/self-advocacy/

people are heard in policy debates. ASAN's members and supporters include autistic adults and youth, cross-disability advocates, and non-autistic family members, professionals, educators, and friends.

- The Peer Support and Self-Advocacy group at The Independence Center: Provides cross-disability peer-lead support groups, facilitated workshops, advocacy coaching, and individual mentoring.
- The Association of Persons with Severe Handicaps (TASH): This organization works to advance inclusive communities through advocacy, research, professional development, policy, and information and resources for parents, families and self-advocates. The TASH membership includes a diverse array of individuals and perspectives, including researchers, professionals, direct service workers, family members and people with disabilities.

RESOURES TO SUPPORT SUSTAINABILITY

Peer Advocacy Networks

WHY IS SUSTAINABLE SUPPORT FOR PEER ADVOCACY IMPORTANT?

> *Sustainability is key to continuing the work of self-advocacy in every community. Ensuring the sustainability of a peer advocacy network allows for the important work of peer advocates to continue, grow, and have greater impact on policy, programs and the day to day lives of individuals. In this section we outline key features of a sustainable peer advocacy network.*

Many variables contribute to a sustainable peer advocacy network, including but not limited to:

- **Funding** – Peer advocacy networks need stable funding to maintain operations, grow their networks and participate in advocacy efforts.
- **Leadership** – Strong leaders are critical to advocacy efforts, building membership of peer advocacy organizations and ensuring the financial stability of an organization.
- **Infrastructure** – Peer advocacy networks take different and structures which impact the different organizations' sustainability. Some networks join larger regional networks and share resources; others partner with and receive support from their state Developmental Disability Councils; while others are standalone 501(c)3 nonprofits.

WHAT RESOURCES ARE AVAILABLE TO SUPPORT THE SUSTAINABILITY OF PEER ADVOCACY NETWORKS?

The table below outlines tips, strategies and relevant resources peer advocacy networks may consider sustaining their networks through funding, leadership development and infrastructure.

	Tips and Strategies	Resources and Links
Funding	- Diversity Peer Advocacy Network Funding - Public funds (state and federal) - Grants - Fees for goods and services - Donations/fundraising - Establish Funding Strategies - Implement safeguards - Dividing responsibility around handling money - Financial audits	Sustainability Planning for Self-Advocacy Networks Funding Advocacy: A toolkit to Assist State Self-Advocacy Networks Increase Financial Independence:
Leadership Development	- Promote Leadership through training and tools - Strengthen peer advocacy skills of your network through training and resources	Vermont Leadership Series for self-advocates and families Self-Advocacy Start-up Toolkit by Self Advocates Becoming Empowered:

		Self-Advocacy Leadership Manual by the Illinois Self-Advocacy Alliance Self-Advocacy Online - an online resource to learn more about self-advocacy, find self-advocacy groups and view stories from self-advocates:
Infrastructure	• Form partnerships with other groups with shared goals and missions • Partner with state Developmental Disability Councils	Illinois Self Advocacy Alliance – formed by a network of self-advocacy groups: Green Mountain Self-Advocates includes more than 20 local peer support groups across the state of Vermont:

PROMISING PRACTICES

Colorado Cross-Disability Coalition - https://www.ccdconline.org

The Colorado Cross-Disability Coalition (CCDC) is a cross disability coalition dedicated to advocating for social justice for people with all types of disabilities. To accomplish its goals the CCDC provides leadership development, conducts grassroots organizing, supports individual and systemic advocacy, litigation, education, and voter engagement. The group's advocacy efforts and accomplishment include forcing the continuation of de-institutionalization programs, promoting consumer directed care, and promoting Medicaid Buy-in programs allowing people with disabilities to have paid employment and remain eligible for the supports they need to continue living in their communities. . CCDC receives financial support in the form of:

- Program fees and settlement revenues
- Foundation contributions
- Event Sponsorships and donations
- Corporate and individual contributions
- In-kind donation.

DEVELOPMENTAL DISABILITY COUNCILS
Peer Advocacy Networks

HOW CAN STATE DEVELOPMENTAL DISABILITY COUNCILS SUPPORT PEER ADVOCACY NETWORKS?

Developmental Disabilities (DD) Councils are federally funded networks made up of voluntary and governor appointed members dedicated to creating programs and advocating for policy that empower people with developmental disabilities to participate as equal members in our communities[13]. DD Councils are present in every state and a are a strong resource for supporting and promoting self-advocacy networks in their states and communities. DD Councils are mandated to support self-advocacy with:

- *Direct funding of a State self-advocacy organization led by individuals with disabilities;*
- *Opportunities for leadership development and training; and*
- *Cross-disability and culturally diverse leadership coalitions.*

While all DD Councils share these supports, agencies provide these resources and supports in a variety of ways. Several examples of DD Council approaches to support peer self-advocacy groups are included below. [14]

EXAMPLES OF DD COUNCIL SUPPORT

Green Mountain Self Advocates (Vermont) & The Vermont DD Council

The Green Mountain Self-Advocates (GMSA) is made up of 23 plus self-advocacy organizations. The Vermont DD Council prioritizes supporting and building its self-advocacy network in a variety of ways including:

- **Funding:** The Council provides GMSA $60,000 each year to ensure each local group receives technical assistance and training and strengthens its board with capacities such as strategic planning and basic financial oversight.
- **Contracts:** The Council partners with GMSA to train and recruit for Vermont's Leadership Series and to participate in the Vermont Community of Practice (CoP) for Cultural and Linguistic Competence.
- **Securing additional funding**: The Council supported GSMA in securing funding to train public health providers in disability awareness to improve the overall delivery of the public health programs and to support the sustainability of GSMA.
- **Advocacy**: The Council lends its policy expertise to collaboration with the GSMA around advocacy efforts[15].

Hawaii Self-Advocacy Advisory Committee & HI State Council on DD

The Hawaii Self Advocacy Advisory Committee (SAAC) is supported by the Hawaii State Council on DD through appropriated funds to support SAAC statewide advocacy efforts through education and training, opportunities to develop leadership skills, and to network with other self-advocacy organizations across the country. Funding from the DD Council provides support for a dedicated staff coordinator position as well as operating expenses. With support of the Hawaii DD Council, SAAC has:

- Grown to 200 members statewide in four years
- Received 501(c)3 status
- Established monthly meetings, leadership development, and train-the-trainer events
- Moved self-advocates out of paid supported day health facilities and created self-support groups[16]

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[13] https://www.nacdd.org/about/
[14] https://nacdd.org/wp-content/uploads/2017/08/Understanding-Advocacy-through-the-DD-Council-Lens.pdf
[15] https://myemail.constantcontact.com/MARCH-FIELD-NOTES-2020-IS-HERE-.html?soid=1119021574758&aid=i931FAoVwSY

[16] https://hiddcouncil.org/areas-of-emphasis/

RESOURCES
Peer Advocacy Networks

TOOLS AND RESOURCES TO SUPPORT PEER ADVOCACY NETWORKS

Outreach
- Community of Practice on Cultural and Linguistic Competence in Developmental Disabilities (CoP)
- University of Nebraska Medical Center| State Disability Leadership Seminar Series: This seminar was a series of community trainings held across the state of Nebraska involving disability leaders from a variety of provider partners to encourage leadership, advocacy skills, and the best outcomes for individuals with disabilities and their families.

Funding Resources
- Sustainability Planning for Self-Advocacy Networks: https://www.selfadvocacyinfo.org/wp-content/uploads/2020/10/October-22-2020-Presentation-Funding-For-State-Self-Advocacy-Groups.pdf
- Funding Advocacy: A toolkit to Assist State Self-Advocacy Networks Increase Financial Independence: https://www.selfadvocacyinfo.org/wp-content/uploads/2020/08/Funding-Advocacy-a-Tool-Kit-to-Assist-State-Self-Advocacy-Networks-Increase-Financial-Independence.pdf

Leadership and Advocacy Resources
- Vermont Leadership Series for self-advocates and families: https://gmsavt.org/events/vermont-leadership-series
- Self-Advocacy Start-up Toolkit by Self Advocates Becoming Empowered: https://www.selfadvocacyinfo.org/resource/self-advocacy-start-up-toolkit-more-power-more-control-over-our-lives/
- Self-Advocacy Online: http://selfadvocacyonline.org/learning/

Sustainability
- The Independent Living Research Utilization: Creates opportunities for independence for people with disabilities through research, education, and consultation.
- List of Centers for Independent Living and State Plan for Independent Living by State: These programs are based on the belief that all people can live with dignity, make their own choices, and participate fully in society.
- Administration for Community Living: Resources, research, and information to advance independence, integration, and inclusion for older adults and people with I/DD throughout life.
- Self-Advocacy Resource and Technical Assistance Center (SARTAC): This resource center is funded as a Project of National Significance by the Administration on Intellectual and Developmental Disabilities under the Administration on Disabilities. It operates through grant from the Administration for Community Living.
- Self-Advocacy Online: Offers plain language web-based access to find local and national self-advocacy groups, provides health, employment, direct care workforce, and advocacy resources.
- Self-Advocates Becoming Empowered (SABE): Is a national self-advocacy organization for people with I/DD. The board of SABE is comprised of regional representatives and members from every state in the US.

Example Self-Advocacy Networks

- Illinois Self Advocacy Alliance
- Green Mountain Self-Advocates
- Colorado Cross-Disability Coalition

General Resources

- American Association of People with Disabilities: AAPD is a national cross-disability civil rights organization that works to increase the political and economic power of people with disabilities.
- The Voice of Reason (VOR): is a national, grassroots, nonprofit 501(c)(3) organization that is unique in its mission to advocate for high quality care and human rights for all people with (I/DD).