

*We create opportunities for independence for people with disabilities through research, education, and consultation*

---



**Independent Living Research Utilization**

**[www.ilru.org](http://www.ilru.org)**

**IL-NET**

CIL-NET · SILC-NET

# **Approaches to Systems Advocacy on Emerging Issues**

***Presenters:***

**Candace Coleman**

**Michelle Garcia**

**Amber Smock**

**July 12 , 2018**

# Evaluation Survey & Presenter Contact Information

Your feedback on this webinar is important to us. At the end of the presentation you will have the opportunity to complete a brief evaluation survey.

- Candace Coleman – [ccoleman@accessliving.org](mailto:ccoleman@accessliving.org)
- Michelle Garcia – [mgarcia@accessliving.org](mailto:mgarcia@accessliving.org)
- Amber Smock – [asmock@accessliving.org](mailto:asmock@accessliving.org)

## What You Will Learn...

- An understanding of systems advocacy as a CIL core service that builds community and changes lives.
- Elements of a systems advocacy model for emerging issue areas that, when used together, build relationships, strong communities, and successful goal-based community campaigns.
- Effective strategies for recruiting potential leaders and advocates in communities affected by multiple systems of oppression.
- Strategies for keeping your advocates energized, committed, and involved.

# Quick Overview of Access Living Programs

- Based in Chicago since 1980
- About 65 staff
- Three program departments: independent living, advocacy, and civil rights (legal team)
- Advocacy Department has about 10 staff focused on systems advocacy
- Access Living's version of systems advocacy is a hybrid of community organizing and policy work

# Responding to Changing Community Needs

- Over the years, we have had many hard conversations about addressing the needs of people with disabilities experiencing disparities because of race, gender, LGBTQIA\* status, immigration status, and more.
- Our Advocacy Department has developed disability systems advocacy work specifically centering on racial justice and immigrant justice.
- We will focus on emerging systems advocacy issues in these two areas today.

\*Lesbian, Gay, Bisexual, Transgender/Transsexual, Queer, Intersex, Asexual

# Advocacy Work Process at Access Living

- We rely on being able to shift systems advocacy approaches as needed.
- We address about 10-12 issue areas at any given time.
- Weekly Government Affairs staff meetings; includes staff across departments.
- Weekly community organizing staff meetings.
- Six community organizing groups with multiple meetings per month; they also meet monthly in a coalition/workshop meeting called Power to the People.
- Advocacy has to fit with Access Living mission and follow strategic plan goals.

# Identifying Emerging Issues

- Sometimes systems advocacy issues will come up that we haven't addressed before.
- May arise from problems our community members share with us.
- May arise from problems highlighted in the news or by coalition partners.
- Access Living may not have a position on some new issues. These issues are tested through our policy screening tool, which was developed in coordination with a committee of our Board.



## Starting With People

- For Access Living, our systems advocacy is rooted in the real life experiences of our community.
- Powerful change needs people power.
- We intentionally engage in recruitment in communities affected by multiple systems of oppression.
- We are not perfect and have to learn from mistakes as we do our work.
- We remain conscious of always needing to learn new things about people living the disability experience.

# The Story of Our Process

- Our process folds together community organizing and systems advocacy.
- Using both has allowed us to identify emerging issues and solutions from stakeholders.

Racial justice and disability:  
Advance Youth Leadership Power (AYLP)

Immigration and disability:  
Cambiando Vidas

# AYLP

- Established in 2005.
- Current members are mostly younger disabled adults who are also people of color (ages 21-40).
- AYLP started out advocating on disability and education issues.
- Over the years they have transitioned to disability and racial justice topics such as the school-to-prison pipeline.

## Cambiando Vidas

- Means “changing lives” in Spanish.
- Established in 2009.
- Members are primarily Latinx with disabilities.
- Primarily Spanish speaking space.
- Several members are immigrants.
- CV got started organizing on physical access in Latinx neighborhoods of Chicago.

# Recruiting

- We engage in a process of community education about disability in those communities and look for potential leaders/community members.
- AYLP examples: recruited through schools, community events like street fairs, and word of mouth.
- CV example: flyers, recruiting at planned workshops for Latinxs with disabilities, effort to find people on the streets; not always coming into Access Living.

## Dialogue and Discovery

- We facilitate community discussion about problems, and ask people what they think could be solutions.
- These discussions happen within CV and AYLP.
- Discussions also happen at gatherings where CV or AYLP is present with other groups.

# Questions and Discussion

# Supporting Individuals to Stay Involved and Energized on Systems Advocacy



- Different types of communities have different dynamics.
- Food: Control, Choice, Culture, Disability
- Funding for Transportation
- Non-judgmental environment
- One on One's/Personal Check Ups
  - Birthdays, gathering for dinners, support in times of loss
- Supporting members' involvement with other organizations, community meetings
  - Candace joined AYLP members at their community meetings and helped them get the confidence and feel comfortable being in these settings.
  - Michelle has done the same in religious settings.
- Developing roles in meetings and projects
  - Something meaningful and important for the members.
  - Important to look to people's strengths.
  - Members can help each other.



# Caucusing

- AYLP and CV will typically meet, discuss what they have been hearing in the community, and develop their campaigns over time.
- They begin to identify issues, stakeholders, powerbrokers, solutions, demands, and a process of escalation towards achieving what is needed.
- Important: they identify the **SYSTEMIC ISSUE** which is causing problems for individuals.
- This is a typical process for all AL community organizing groups.

## Organizational Buy-in

- Staff summarize new issues in a way that can be easily presented to Access Living management.
- Access Living leadership needs to understand and support what the community organizing groups want to work on.
- Amber works with organizers to communicate emerging topics to executive leadership and the Board.
- If there is no precedent for supporting the emerging topic, Amber coordinates use of the policy screening tool and executive/board approval as needed.

## Cross-Department Updates

- New issue areas are included on the agenda of our weekly Government Affairs meetings.
- The organizers provide updates.
- Staff who work on other approaches (policy, legal, independent living, executive leaders) weigh in and collaborate on tweaks to the advocacy.
- Organizers bring the new suggestions to the grassroots group members for review and action where agreed upon.

## Building Out the Campaigns

- Once gaining approval, we develop the campaign with the community organizing group members and other affected stakeholders.
- Examples of campaigns
  - Stephon Watts response (AYLP)
  - City ID/CityKey (CV)

## About Stephon Watts

- 15 year old black high school student with autism
- Killed by police in his home while in an autistic meltdown.
- Lived in Calumet City, Illinois.
- Family members had been part of Access Living's community for several years.
- His parents asked Access Living's AYLP to try to create systems change so no one else would have to go through this.

# AYLP Response/Approaches

- AYLP members felt that what happened to Stephon could happen to them.
- Finding a possible systemic advocacy solution has been very tricky—not a perfect or smooth process.
- Awareness/Education
  - AYLP members worked to learn more about systems solutions.
  - Community partners needed awareness of the experiences of disabled youth of color in police situations.
- U.S. Department of Justice hearings on Chicago Police Department Patterns and Practice: AYLP participated in public comments, town halls.
- AYLP wanted to see if a state level bill could do something to stop more Stephon Watts situations from happening.

# Challenges for Stephon Watts System Advocacy Solutions

- Developing a bill has been a major cross-disability learning process for AYLP and AL staff.
- AYLP members include both Autistic people and people with lived experience of mental illness, who gave input on solutions they wanted to see.
- Initial discussions with external partners tended to focus on mental health.
- Autistic advocates outside of AYLP have challenged us to be more careful about neuro-divergence concerns.
- A draft bill is in process.
- AYLP currently focusing on educating non-disability stakeholders in the Chicago community.

# Working Towards a Systemic Solution

- AYLP's take: If police presence would escalate someone's crisis or meltdown or put them at risk of harm, it would be better if a non-police emergency response person arrived on site IF appropriate.
- How can we make sure this happens in Illinois for those that want this?
- How can we make sure that coercion is not a factor?
- How can we make sure the law recognizes the difference between a crisis and a meltdown or panic attack?
- Currently, AYLP and Access Living are investigating current or developing models for mobile response units that don't involve police, and do include staff trained to help with de-escalation.



# Working Towards a Systemic Solution, cont'd.



- Options are currently limited in Illinois, and it is complicated because of issues of self-determination and involuntary commitment. Illinois has some existing laws about protections against involuntary commitment.
- The bill is not about Crisis Intervention Training (CIT) because that is slowly rolling out in Illinois, but about a new option for 911.

# Current Status of Stephon Watts System Response

- Discussions with advocates from disability groups who could be affected to fine tune what is needed/possible in Illinois
- Discussions with 911 operators, EMTs, Fraternal Order of Police, AFSCME.
- Planning series of five community discussions on the bill this summer.
- Plan is to hopefully continue shaping bill to something useful and agreed upon by stakeholders for Spring 2019.

# Questions and Discussion

## Cambiando Vidas and the City ID/CityKey

- CV has ongoing discussions about the needs of people with disabilities who are immigrants.
- CV was concerned that people with disabilities who are not documented could not access basic city services.
- In a series of community discussions with Chicago area immigration and homeless groups, they discovered that lack of documentation affected a lot of different groups.
- The City Treasurer's office proposed that perhaps a city ID card (like in San Francisco) could benefit these groups.

# Building Disability Activism on the City ID/CityKey

- Awareness/Education
  - Community partners needed awareness about why the City ID was needed by people with disabilities.
  - CV members also worked to learn what a City ID was and figure out what the program needed to be disability friendly.
- Participation in public comment/community workshops.
- Coalition work to pass a city ordinance to establish the City ID program...now called the CityKey.

## What is the CityKey?

- The CityKey is an optional, valid, government-issued photo identification card for all Chicago residents regardless of a resident's housing status, criminal record, immigration status, or gender identity.
- The CityKey will serve as a three-in-one card that will not only be a valid, government-issued ID card, but also serve as a library and transit card. Additional benefits including partnering with cultural institutions, local businesses, and sports teams will be announced over the next several months.

## Intersectionality and the CityKey

- Turns out that the CityKey is needed by many kinds of people.
- Many homeless people have no documentation.
- CityKey also important to LGBTQ advocates; important to have nonbinary option, use chosen name.
- Many very poor people who have fallen out of contact with “the system” need an ID to access assistance.
- People from many countries, who are not documented, need an ID to access assistance.

## Challenges for the CityKey Campaign

- Fighting public war of image: in the Chicago City Council, there was a fracture between communities of color over the CityKey proposal. This rift is still healing.
- Since the CityKey is new, it has not yet been audited by the Chicago Office of the Inspector General, as to its effectiveness and cost.
- Lingering distrust in immigrant community regarding “official” documents.



# Emerging Issues and Organizational Impact

Now let's look at how the systems advocacy work on emerging issues has a ripple effect on the organization. What have we learned?

# The 360 View: Parallel Internal Work at Access Living

- As AYLP and CV have worked on their campaign, there has been a parallel process of support among staff at Access Living.
- Updating colleagues on status of campaigns and whether approaches need to be shifted.
- Problem solving issues of communication with community partners.
- Ensuring internal accountability such as reporting and mission alignment.
- Engaging partners and donors.

# Encouraging Investment in Emerging Issues

- When an organization commits to addressing an emerging issue area, it can attract new donors. Donors like to see that an organization is doing new things that meet a community's needs.
- Some donors are particularly interested in serving specific communities.
- Some donors are developing emerging areas of philanthropy themselves.
- Donors that have invested in racial or immigration justice are just learning about investing in those areas as they overlap with disability.
- Communication w/ donors is key.

## Getting the Right Staff on Board

- Diversity in CIL staff is important; will attract diverse people to get involved in different ways.
- If we have a diverse team, at least one of us will be a peer to consumers, community, donors.
- We also need to feel our colleagues will back us up/keep us safe as possible.
- When staff have diverse viewpoints, we have richer expertise from which to shape the work.

# Organizational Planning

- Ensure year round effort to secure grants and donations.
- Create staff benchmarks that are clear and reasonable.
  - Measure activities (meetings, trainings, actions, recruiting) and outcomes (progress on issues, indications of strengthened community, individual leader growth).
- Support staff in use of vacation time and sick time.
- Have a backup plan.
- Empower staff in professional and leadership development.
- Strive for creating inclusive, welcoming space.
- Show appreciation and celebrate all the victories.
- Publicize successes; engage the public.

## Advocacy is a CORE Service, not Extra

- In Access Living's view, we as a CIL are supposed to be welcoming, developing sense of belonging, developing safe feelings.
- This is an ongoing learning process, and sometimes we do it well and other times less well.
- We think our process of engaging PEOPLE with systems advocacy pays off.
- CILs can help systems advocacy be authentic and support people to be ready to work with us over the long term.

# Final Questions and Evaluation Survey

Any final questions?

Directly following the webinar, you will see a short evaluation survey to complete on your screen. We appreciate your feedback!

[https://usu.co1.qualtrics.com/jfe/form/SV\\_8AoubhFTBMbWLCI](https://usu.co1.qualtrics.com/jfe/form/SV_8AoubhFTBMbWLCI)

## CIL-NET Attribution

This project is supported by grant number 90ILTA0001 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.