

NEW YORK STATE SUCCESS

RESEARCH BRIEF: YOUTH GUIDED CARE

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We would like to give a special thanks to the community & YOUTH POWER! representatives who contributed to this research brief.

## Overview

The purpose of this research brief is to offer some insight about the meaning of youth guided care and provide concrete practice examples for counties involved in the New York State (NYS) Success collaborative. This brief was initiated because NYS Success counties described many innovative activities involving youth guided practice and expressed interest in learning more about youth involvement strategies in their responses to the NYS Success Quarterly Infrastructure Survey.

## Data Sources

To prepare the brief, data were collected and synthesized from a variety of sources:

- **Telephone interviews** were conducted with eight NYS Success community representatives involved with youth programming
- **Document and literature review** was conducted on youth guided care
- **Consultation** was held with YOUTH POWER! (YP!) representatives involved in delivering training and technical assistance throughout the state.

## What is Youth Guided Care?

*“Youth Guided means that young people have the right to be **empowered, educated, and given a decision making role in the care of their own lives as well as the policies and procedures governing care for all youth in the community, state and nation. This includes giving young people a **sustainable** voice and then **listening** to that voice. Youth guided organizations create safe environments that enable young people to gain **self-sustainability** in accordance with the cultures and beliefs with which they identify. Further, a youth guided approach recognizes that there is a continuum of **power** that should be shared with young people based on their understanding and maturity in a **strength based change process**. Youth guided organizations recognize that this process should be **fun and worthwhile**.”***

<http://www.youthmovenational.org/images/downloads/youthguideddefinition.pdf>

## Why is Youth Voice Important?

The active participation of youth in decisions affecting their own lives and care are among the guiding principles for operating effective system of care (Stroul, Blau, & Friedman, 2010). Youth provide a unique perspective for both their own individual care plans, as well as for designing systems operations (e.g. Aarons et al, 2010; Walker, Gowen, & Aue, 2009; Trawick, 2014).

A recent evaluation found that youth receiving mental health services who had access to a youth peer advocate were more satisfied in the domains of access to mental health services, appropriateness of services, participation in services, and overall/global satisfaction. Youth with access to a youth peer advocate were also more informed about psychotropic medication options (Radigan, Wang, Chen, & Xiang, 2014).

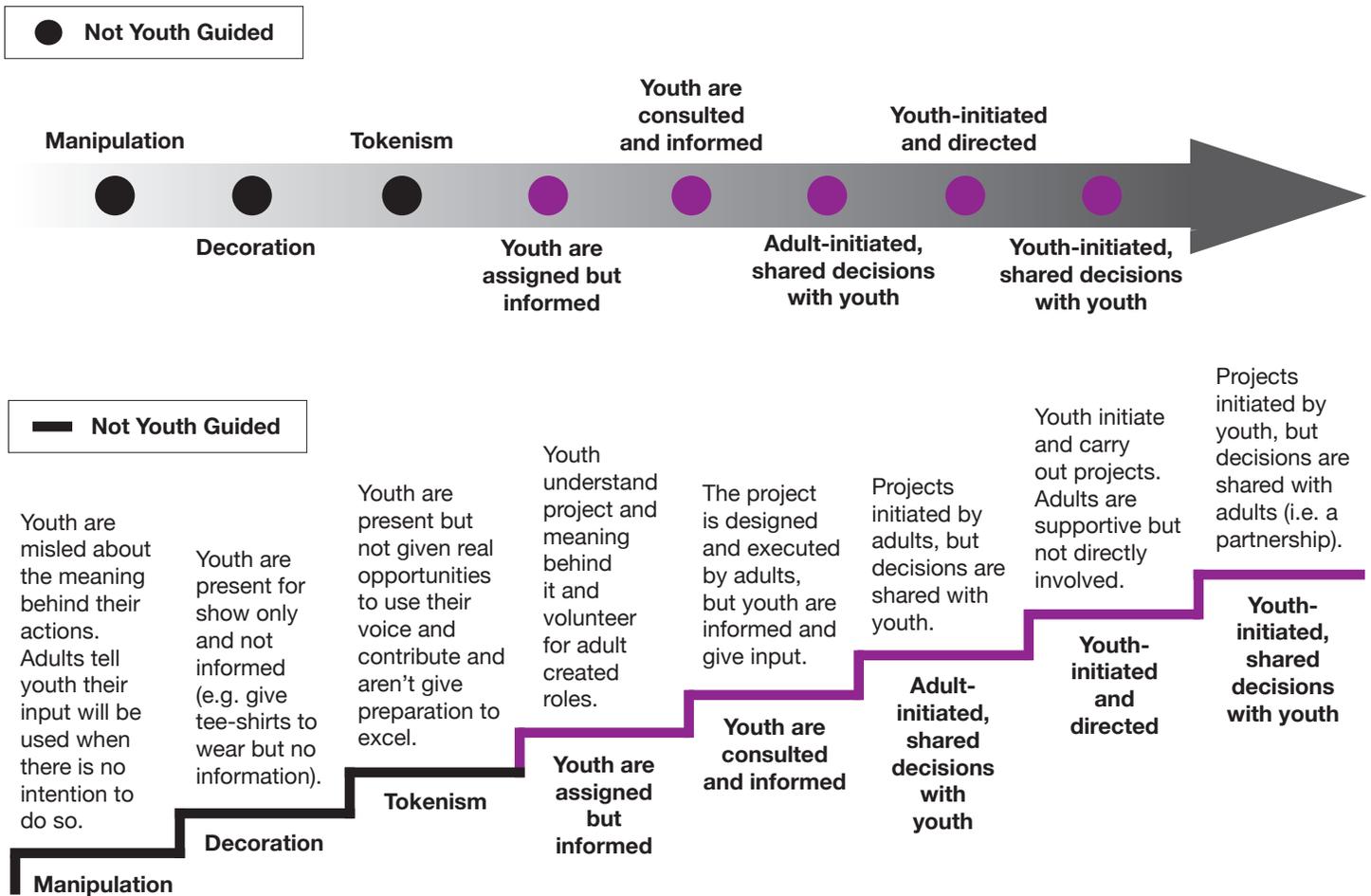
While the research demonstrates the positive effects of youth peer advocates on youth satisfaction and informed choice, there have been few rigorous studies documenting the impact of youth involvement on youth outcomes in the children’s mental health field. Of the published research, several evaluations of programs that include a peer/youth involvement component and serve youth with mental health needs have found positive outcomes in domains including behavior, employment, education, and social functioning (e.g. Butman, 2009; Espinola & Helms, 1996; Geenen, Powers, et al., 2015). However, the particular contribution of youth involvement components to positive outcomes is difficult to discern based on the methodology.

## What Does Youth Guided Care Mean?

Youth involvement can take a variety of forms, but not all types of youth involvement meet the definition of “youth guided.” Many communities find it is a challenge to truly integrate the youth voice into its activities and youth guided practices are often limited. A qualitative assessment of system of care communities revealed that many youth feel excluded from mental health service planning and were unsure of how to increase their involvement. This study also revealed that system of care youth involvement was often limited to youth groups (Gyamfi, Keens-Douglas, et al., 2007).

One useful model that describes various ways in which communities can conceptualize and operationalize youth guided care is Hart’s Ladder (see **Figure 1**).

**FIGURE 1. HART'S LADDER OF CHILD/YOUTH PARTICIPATION**



Modified from Hart, 1992; Darker Grey indicates more youth guided.

To achieve practice that is youth guided, programs should have the goal of moving towards “youth-initiated, shared decisions with adults” (Hart, 1992). However, as the model demonstrates, some aspects of youth involvement that occur within systems and communities do not promote shared power and decision-making. For instance, manipulation, decoration, and tokenism can occur when youth are involved in adult controlled situations and remain powerless, with their contributions “insignificant and underutilized” (TA partnership, 2005). The next three levels of the model demonstrate more advanced youth involvement, where youth have opportunities to learn from adults; however, youth participation still falls short of shared power and decision-making. The final levels of the model are most consistent with youth guided care. These levels vary according to who is initiating/leading

the projects and who is involved in decision-making, but all have strong youth contribution (TA partnership, 2005; Hart, 1992).

A program has fully adopted a youth guided mindset and philosophy when stakeholders have an accurate understanding and knowledge of what the youth perspective is, and take this into account in everything that they do. In addition, programs can tell they are youth guided when their efforts “bear fruit.” For instance youth will want to be involved, will express passion for the cause, will be comfortable, and will even bring their friends along (YP!, personal communication, 8/2015). YP! offers some additional guidance with the “Dos and Don’ts” of youth guided care (see Appendix A).

## What Are Examples of Youth Guided Practice?

There are many ways in which counties can take steps towards becoming more youth guided. The following table provides some examples describing progress towards youth guided practices, which were obtained from consultation with YP!, the literature, and community interviews.

**TABLE 1. YOUTH GUIDED PRACTICE EXAMPLES**

POLICIES & PROCEDURES
<p><b>Explanation of Roles for all Team Members on Youth Guided Care:</b> During a care planning meeting, there is often a misconception of what youth guided means for team members (e.g. care coordinator, family, youth, and service providers). Youth guided does not mean youth get their way every time; rather, that youth are meaningful and active contributors to their care plan and provide feedback regarding the agency and system.</p>
<p><b>Youth Friendly Policies/Procedures:</b> All materials should be geared toward youth comprehension. All materials should be in straightforward language, avoiding acronyms. Policies should be developed with youth input so that they reflect what youth need to feel safe and involved.</p>
<p><b>Youth Friendly Communication and Outreach:</b> Use social media where youth can have meaningful interactions (e.g. chat functions). Make sure websites are user-friendly. Be flexible and tailor communications to what is best for youth (e.g. text, phone, e-mail, etc.).</p>
LEADERSHIP
<p><b>Youth Coordinators/Facilitators:</b> Having designated staff committed to youth guided care ensures that youth are always in focus. Youth coordinators tend to be most effective when they are young people with lived experience in children’s mental health.</p>
<p><b>Youth Peer Advocates:</b> Youth, as trained, paid staff, can be involved by helping other youth to understand the care process, to educate youth about their options, and to teach them to advocate for themselves. Youth Peer Advocates have lived experiences of receiving mental health or other services.</p>
GROUPS
<p><b>Youth Groups:</b> Groups can be focused on support, specific activities, leadership, education, advocacy, or a combination of these factors. Some groups are specialized for a specific population, for instance youth with juvenile justice involvement or transition-aged youth who are interested in learning workforce skills. The focus of the group should be determined based on youth input.</p>
<p><b>Youth Advisory Councils:</b> Youth meet regularly to discuss and promote changes to improve an organization, based on the youth perspective.</p>
SELF & SYSTEM ADVOCACY
<p><b>Youth Empowerment Trainings:</b> These trainings are designed to prepare youth to engage in self and system advocacy through topics such as leadership and self-esteem.</p>
<p><b>Youth Involvement in Treatment Plan:</b> Youth are present at meetings where their care is discussed and feel empowered to speak their minds. Adults validate and follow-up on youth input.</p>
<p><b>Youth Feedback through Surveys and Focus Groups:</b> Holding periodic youth focus groups and survey administrations provides a mechanism for understanding the youth experience and may be an easier time commitment for youth than an ongoing group.</p>
<p><b>Youth Involvement in Agency Meetings:</b> Youth are present at organizational level meetings, actively participating in discussions about services and agency operations with adult leaders.</p>

## Implementation of Youth Guided Practices: Challenges & Strategies

The following section describes challenges in implementing youth guided programs and practices and strategies to overcome challenges as relayed by counties, YPI, and relevant literature (Ramey, & Rose-Krasnor, 2015; Howe, Batchelor, & Bochynska, 2011; Gyamfi, Keens-Douglas, et al., 2007).

### RECRUITING AND MAINTAINING YOUTH PARTICIPATION

*Challenge: Recruiting sufficient numbers of youth to serve on groups and councils*

*Strategies:*

- **Implement Marketing Strategies that Target a Youth Population:** Marketing is most effective when multiple means are used. Reaching youth through social media provides an effective recruitment device. Consider recruiting through social media sites, such as Twitter, Facebook, Instagram, and YouTube. Other sites to consider are Vine and Google+. Advertising should be placed where youth congregate, such as outreach centers and other youth-friendly spots in the community. Pamphlets and other related documents are less effective strategies. Youth do not want to take them from public places because of the stigma associated with mental health challenges. Also, personally invite youth to participate; they may not make the connection that a group is for them just from viewing an advertisement.
- **Provide Clear Messages:** Ensure that youth want to be members of the group from the onset. Staff should provide information about the group's purpose, expected commitments, procedures, and protocols so youth can make informed choices about joining.
- **Adjust Meeting Times to Accommodate Youth:** Friday evenings and weekends may work best for youth who attend school.
- **Conduct Outreach to Established Youth Programs:** It can be helpful to look to existing groups for recruitment, for example, independent living groups or other groups of youth who meet regularly. In addition, recruitment strategies should include "non-traditional" organizations such as LGBT groups, homeless shelters, and juvenile justice organizations.
- **Provide Additional Support for Youth Reluctant to Participate:** Involving peer advocates to conduct outreach and attend groups may make youth feel more comfortable.

*Challenge: Inconsistent attendance and high turnover*

*Strategies:*

- **Have Realistic Expectations Regarding Attendance and Turnover:** Youth often have a lot going on in their lives, including school, work, and social commitments, in addition to contending with mental health or other challenges. Because of this, regular group attendance can be difficult.
- **Adjust Logistics:** Assure that meeting times and locations are convenient for youth to attend. Youth may be reluctant to attend meetings in locations where they are uncomfortable. Venues like youth centers may make youth more comfortable and encourage attendance.
- **Send Meeting Reminders:** Use texts, e-mails, and phone calls as reminders for group meetings.
- **Solicit Youth Feedback:** Ask youth about what other barriers are preventing them from attending and work to find solutions.
- **Involve Youth in Group Planning Stages:** Attendance will also improve when youth want to attend and see the group as valuable, fun, and worthwhile. By including youth during the planning stages of all youth initiatives, programs can ensure that they are developing the right activities.
- **Ease Transportation Challenges:** Programs can provide bus passes and/or gas cards, as funding allows. Organizations can organize car pools or use agency vehicles, if available. Meetings can be scheduled for times that are convenient for parents to drive youth.
- **Provide Incentives for Participation:** In addition to providing food and gas cards, offering professional development and opportunities to speak at/attend conferences can be appropriate and effective incentives. Providing cash and gift cards for attendance may be more controversial. Some find this to be an effective attendance incentive, while others believe that monetary incentives may lead to decreased intrinsic motivation and meaningful participation. Most do agree however, that in cases where adult attendees are receiving monetary compensation, youth should also be compensated.

## *Challenge: Maintaining Youth Interest (Avoiding Group Apathy and Fatigue)*

### *Strategies:*

- **Provide Ongoing Opportunities for Meaningful Participation:** Youth will stay more interested if the work they are doing is meaningful, and they can see concrete changes resulting from their efforts (e.g. a change in policy). When youth feel empowered and like they are making a difference, they will want to continue meeting.
- **Be Focused and Purposeful:** In some cases coordinators are so focused on recruiting youth and getting the group started, that following the initial meetings where a group name is established, logo is chosen, and statement is drafted, they are at a loss for what to do next. Youth want groups that have a clearly defined purpose and goals. Start off with clear goals and a work plan: clarify roles, expectations, procedures, and protocols. Develop goals in the form of discrete plans rather than only a philosophy.
- **Keep Meetings Exciting:** Mix it up. In addition to traditional meetings, groups can engage in special projects and have guest speakers.

## GROUP COHESION AND FUNCTIONING

## *Challenge: Ensuring Youth Have an Active Voice in Groups and Meetings*

### *Strategies:*

- **Develop “Youth-Friendly” Materials:** One easy first step is to make sure that materials are understandable and avoid using acronyms. Staff should be open to explaining language, so youth can actually participate. Before finalizing, have youth representatives review the materials.
- **Provide Training on Meeting Facilitation:** Staff members should not expect that youth come into groups knowing how to run a meeting. It is important to teach youth how to facilitate group meetings, so they are comfortable in this role. Invite youth leaders from other counties to visit and present or lead a meeting.
- **Involve Youth Leaders:** Another way to make youth more comfortable is to have more than one youth leader per site to prevent isolation, provide support, and foster sharing of ideas.
- **Involve Youth in Planning:** To best support youth autonomy, youth can be in control of planning events and activities.

## *Challenge: Defining the Adult Role While Empowering Youth*

### *Strategies:*

- **Establish Clear Role Definitions:** The adult’s primary role should be to ensure youth safety and to provide support. Adults can aid with paperwork, negotiating bureaucracy, and problem solving. In groups and councils that have both youth and adult members, youth should be considered and treated as equal partners. Adults need to be patient with youth and believe that youth can achieve their goals. Youth should lead the way, with adults responding to youth.
- **Utilize Appropriate Facilitators:** Programs may consider utilizing trained facilitators that youth can relate to (e.g. younger staff, same-culture staff, or those with lived experience). If appropriate staff are not available or interested, an alternative option would be to have youth leaders, such as YP!, coordinate and facilitate youth groups.

## *Challenge: A Lack of Group Cohesion*

### *Strategies:*

- **Alternate Activities:** When groups consist of youth from diverse populations with differing interests, providing alternate activities that cater to different groups can elicit a sense of inclusion for all members.
- **Emphasize What Youth Have in Common:** In addition, introducing activities, such as “What Helps What Harms” or having youth share their story may build cohesion by showing youth they can be different, but still share common experiences and ideas.
- **Branding:** One practical way to create cohesion is to foster a sense of belongingness by having youth create group logos and providing clothing, such as t-shirts with group logos. Conducting fundraising activities also promotes the team dynamic.

## CREATING YOUTH GUIDED INFRASTRUCTURE

## *Challenge: Insufficient Funding or Losing Funding When a Grant Ends*

### *Strategies:*

- **Seek a Variety of Funding Streams:** Youth guided practice is not exclusively beneficial to children’s mental health; many other domains can also benefit (e.g. juvenile justice and education). Counties can

incorporate youth guided care initiatives in funding applications across a broad spectrum of agencies. In one county, stakeholders approached administrators about using left-over funds from a program that had ended to support a youth initiative.

- **Create Dual Roles for Staff:** For cost savings, available staff such as the SPOA coordinator can also act as a coordinator for youth initiatives.
- **Provide Consistent Funding for a Youth Coordinator:** Plans for sustaining the youth coordinator should occur from the onset of the project. Different county agencies can contribute funds for the position, which would lessen the financial burden on a single agency.

### *Challenge: Lack of an Understanding of Meaningful Youth Involvement*

#### *Strategies:*

- **Assess Program's use of Youth Guided Practices:** Programs should continually self-assess how youth guided they are with surveys and focus groups of care coordinators, service providers, peer supports, families, and youth (See Resources Section for assessment resources).
- **Ensure the Youth are Involved in Multiple Organizational Domains:** This would include: youth control over their service plans and active participation in meetings, including decision-making processes (e.g. youth on committees and boards).
- **Provide Cross-agency with Training:** Training should be offered on youth guided practice to assure agreement across service sectors. The training should be offered annually to accommodate new staff and agency turnover.
- **Consult with Youth Centered Networks:** There are a number of organizations promoting youth voice such

## *Conclusion*

Youth guided care is a central component of the system of care approach. As presented in this research brief, youth guided care can be challenging to implement, but creative solutions and strategies can be leveraged to address challenges. Youth guided care can pay great dividends in terms of improving the lives of youth and enhancing system functioning.

## *Resources*

### **What Helps What Harms**

<http://www.youthmovenational.org/what-helps-what-harms.html>

What Helps What Harms is a resource created by Youth MOVE National where youth describe aspects of their care and services that helped them and harmed them. It is a good tool to understand where youth are coming from and for youth to bond over shared experience; it is also helpful to identify necessary system changes.

### **Youth Guided Assessments**

<http://www.pathwaysrtc.pdx.edu/pdf/pbCompleteSurveyPacket.pdf>

The Youth Efficacy/Empowerment Scale: Mental Health and the Youth Participation in Planning Scale are concise, easy to administer surveys to assess youth guided practices. These surveys can be administered to youth (in part or by entire scale) to determine if youth feel involved and comfortable with their care and if they feel empowered to be advocates. These scales also assess if youth feel their participation is meaningful. These surveys are free to use. If you would like to administer them, simply e-mail the address on the first page of the pdf for permission.

### **Resources compiled by YOUTH POWER!**

<http://www.nyssuccess.org/resources/youth-family/resources-for-youth-families-youth-and-family>

The NYS Success website has links to several valuable resources compiled by YOUTH POWER!, including guides on youth-appropriate language as well as a Youth SOC Toolkit, which provides many tools for planning and conducting youth groups and/or meetings.

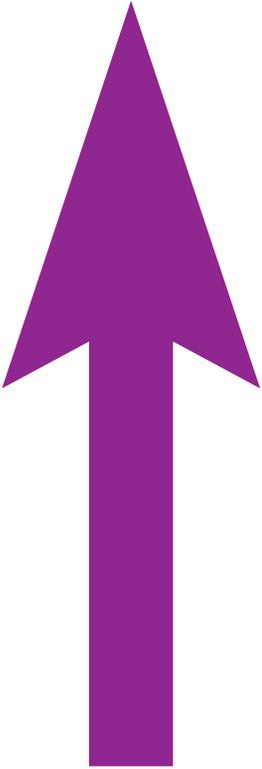
### **Additional Youth guided resources can be found at:**

<http://www.tapartnership.org/content/youthInvolvement/>

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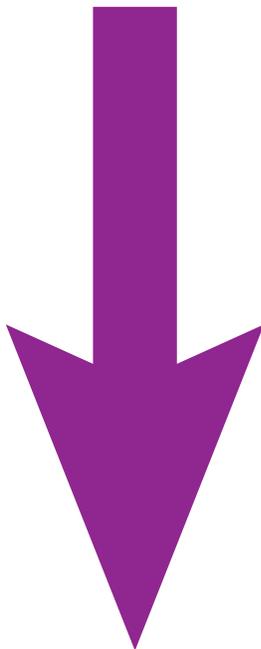
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*Appendix A: The Do's and Don'ts of Youth Guided Care  
Developed by YOUTH POWER!*



## Do's

- **DO** understand that Youth Guided Care (YGC) is not the same things as youth involvement.
- **DO** have more than one youth present during planning for YGC, meetings, events, panels, etc.
- **DO** provide youth with training.
- **DO** allow youth to conduct trainings for staff on YGC.
- **DO** allow youth use their lived experience to help themselves, peers, and staff.
- **DO** give youth time to reflect on and process what is happening and why they are acting that way when they are struggling – give them time to use their coping skills, and to think about how they can handle the situation, instead of just jumping to a punishment or decision for them.
- **DO** train staff on how to be truly culturally and linguistically competent.
- **DO** hire staff/workers with passion. Change the culture – allow youth to help in hiring processes and to hire peer advocates.
- **DO** understand youth culture as a whole.
- **DO** – when setting up a Youth Advisory Council – make sure there is a line of communication between the Council and decision makers (e.g. the Board of Directors).
- **DO** make sure staff feel empowered about youth guided care to create an environment to empower others – make sure all staff are on board and understand the “What’s” and “Why’s” of YGC.



## Don'ts

- **DON'T** address adults instead of youth (e.g. thanking staff for bringing youth without thanking youth for being there; telling staff to make sure “their youth” are “being behaved and respectful” during an event – be sure to address youth themselves).
- **DON'T** create a setting that limits the opportunity for choice and expression (this is a natural and vital part of the developmental process).
- **DON'T** allow funding/politics to keep you from moving towards YGC.
- **DON'T** get discouraged about the time and effort it takes to truly become Youth Guided – we know it does not happen overnight.
- **DON'T** forget to ask youth to help you to become more Youth Guided.
- **DON'T** get offensive/defensive when youth voices their opinion about services.
- **DON'T** underestimate the power youth voice holds.
- **DON'T** be afraid of change – or it will never happen.
- **DON'T** judge youth on a diagnosis and their “chart”.
- **DON'T** only involve youth in the small decisions (tokenism); use their voices to make bigger changes.

## About the Center for Human Services Research

The Center for Human Services Research (CHSR) is a research department within the School of Social Welfare at the University at Albany. CHSR has over 20 years of experience conducting evaluation research, designing information systems and informing program and policy development for a broad range of agencies serving vulnerable populations. CHSR studies cover a wide range of topics including children and family services, education, early childhood development, health behavior and services, youth development, and juvenile justice.

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