Keystone Partnership Needs Assessment Plan

# Introduction

The Pennsylvania Coalition Against Rape (PCAR), in partnership with the Pennsylvania Coalition Against Domestic Violence (PCADV), the Institute on Disabilities at Temple University (IOD), Disabilities Rights of Pennsylvania (DRP), and the Pennsylvania Statewide Independent Living Council (PASILC) resolve to focus on individuals with complex communication needs recognizing that without access to typical speech, their communication, as well as their as their participation in all aspects of life—education, family, and community -- is severely restricted.

We recognize that, although individuals with complex communication needs are disproportionately to the size of their community, the victims of sexual assault, domestic violence, and stalking, they remain underserved by local rape crisis centers and domestic violence programs.

In the disability community, we recognize that providers address the personal safety concerns of individuals they support within their existing systems and do not generally refer persons with disabilities who are the victim of sexual assault to local domestic or sexual violence programs or agencies. These obstacles are compounded by an overall lack of coordination between sexual assault agencies and domestic violence programs and disability organizations.

We resolve to address the needs of sexual assault, domestic violence, and stalking survivors with complex communication needs on a statewide level.

## Our Project Partners

Pennsylvania Coalition Against Rape

Organized in 1795, the Pennsylvania Coalition Against Rape (PCAR) is the first sexual assault coalition in the country. PCAR is a nonprofit that works at the state and national level, to prevent sexual violence with the mission to eliminate all forms of sexual violence and to advocate for the rights and needs of victims of sexual violence. PCAR provides training and technical assistance to sexual violence advocates and allied professionals statewide and nationally.

Pennsylvania Coalition Against Domestic Violence

Organized in 1976, the Pennsylvania Coalition Against Domestic Violence (PCADV), is the first domestic violence coalition in the country. PCADV is a nonprofit that works at the state and national levels to eliminate domestic violence, secure justice for victims, enhance safety for families and communities, and create lasting systems and social change. PCADV’s mission is to eliminate personal and institutional violence against women through programs providing support and safety to victims, direct services, public information and education, system advocacy, and social change activities.

Pennsylvania Statewide Independent Living Council

Pennsylvania Statewide Independent Living Council (PASILC ) is a nonprofit, cross-disability, consumer-controlled organization dedicated to securing public policies that ensure civil rights for people with disabilities by supporting the independent living philosophy. The PASILC works with Pennsylvania’s eighteen Centers for Independent Living (CILs). CILs are community based, cross-disability, non-profit organizations designed and operated by people with disabilities. CILs are unique because they operate according to a strict philosophy of consumer control, wherein people with all types of disabilities directly govern and staff the organization. They provide peer support, information and referral, individual and system advocacy, and independent living skills training. PASILC supports CILS that work with SV/DV programs.

Institute on Disabilities at Temple University

The Institute on Disabilities (IOD) is one of sixty-seven University Centers for Excellence in Developmental Disabilities Education, Research, and Service. Established in 1973 and located within the College of Education at Temple University, the IOD is a vibrant, diverse organization with more than forty staff members, including persons with disabilities, family members of people with disabilities, and students. For more than twenty years, the IOD has led the Commonwealth’s program under the federal Assistive Technology Act and its amendments (formerly the Technology-Related Assistance for Individuals with Disabilities Act 1988). The IOD is a national leader in leadership development, assistive technology (including but not limited to augmentative and alternative communication), Disability Studies, justice for people with disabilities, and inclusive education.

Disability Rights of Pennsylvania

Disability Rights of Pennsylvania (DRP) is a statewide non-profit corporation designated as the federally-mandated organization to advance and protect the civil rights of adults and children with disabilities. DRP works with people with disabilities, their families, their organizations, and their advocates to ensure their right to live in their communities with the services they need, to receive a full and inclusive education, to live free of discrimination, abuse, and neglect, and to have control and self-determination over their services. DRP advocates to ensure that people with disabilities have equal and unhindered access to employment, transportation, public accommodations, and government services; advocates to enforce their rights to vocational, habilitative, post-secondary educational, health, and other services; and advocates to protect them from abuse and neglect. DRN identifies systemic issues that are important to people with disabilities, and seeks change and reform, through litigation, administrative advocacy, and public education.

## Our Vision

We envision a world in which all people with disabilities, including survivors of domestic violence, sexual assault, or stalking, have equal access to all services that meet their individual needs, regardless of their communication methods.

## Our Mission

Leading by example, we will create a sustainable statewide partnership of committed and skilled victim and disability service organizations that respectfully and effectively serve and support individuals with CCN by:

* Continuing to raise awareness and enhance capacity within our own organizations and among our connections
* Developing sustainable relationships between our own agencies to benefit those working at the local level
* Exchanging information and educating our partnerships and their individual networks
* Revisiting organizational philosophies (e.g. mission, vision, values) that influence each partner’s policies and procedures
* Advocating for equal justice
* Promoting cultural and linguistic sensitivity

# Needs Assessment Purpose

The purpose of the Needs Assessment, as described by the Office on Violence on Women is to:

* Provide practical information to our organizations’ capacities to provide training, technical assistance, and support services to survivors of domestic violence, sexual assault, and stalking with CCN and identify ways to improve upon them
* Inform the implementation activities of the Keystone Partnership
* Increase buy-in and support of the Keystone Partnership’s work

## Needs Assessment Goals

The goal of the Needs Assessment is as follows:

Inform the Keystone Partnership’s ability to provide technical assistance and support to each other and our stakeholders by learning about service delivery best practices from individuals with complex communication needs through:

* Identifying components of safe support and services
* Identifying components of welcoming support and services
* Identifying components of accessible support and services
* Identifying aspects of successful support and services

# Methods and Information Sources

## Existing Information

Although crime against people with developmental, and other, disabilities is similar in scope to crime against women, children, and the elderly, their victimization remains largely invisible and unaddressed (Baladerian, Coleman, & Stream, 2013; Sobsey, 1994.) People with cognitive disabilities had the highest rate of violent victimization among all disability types measured in the 2009 to 2013 National Crime Victimization Survey. Among the disability groups included the national survey were hearing, vision, ambulatory, self-care, cognitive, and independent living. With this high rate of victimization, it is important to consider that communication challenges inherent in many disabilities make it difficult for children and adults with disabilities to understand and verbalize incidents of crime and abuse (Knutson & Sullivan, 1993; Sullivan & Knutson, 2000. These challenges are especially problematic when victims attempt to report traumatic episodes, such as rape and domestic violence, to police, and attempt to testify in court (Bryen & Wickman, 2013). Individuals with disabilities who have little or no functional speech face a double vulnerability when reporting victimization (Bryan, Carney, & Frantz, 2005; Davis, 2002).

There are many reasons for this increased vulnerability. Individuals often cannot make themselves heard or are unable to call for help. Because they cannot communicate their intent, they are often perceived as lacking basic receptive language abilities. In some circumstances, family members or care providers believe that the process of disclosing sexual and domestic violence, and the subsequent investigations (provider agency, state, law enforcement) will do more harm than good for the individual. There is also a perception that people with significant speech disabilities are unable to testify in court, either due to competency issues, or to criminal codes about leading the witness and hearsay (Bryan, 2009)because pre-programmed words and phrases on the victim’s Speech Generating Devices can be challenged as hearsay in a court proceeding.

It is important to note that the terms *complex communication needs* (CCN), *significant speech disabilities*, and *limited or not functional speech* (LNFS) are often used interchangeably when referring to an individual with non-typical speech.

Baladerian, N.J., Coleman, T. F. & Stream, J. (2013). A Report on the 2012 National Survey on Abuse of People with Disabilities. Spectrum Institute: CA.  Retrieved October 31, 2016 from disability.abuse.com/survey/survey-report.pdf.

Bryen, D.N (2009). Speaking Up and Speaking Out: Reducing the risk of being a victim of crime and of natural/man-made disasters. Paper presented at the Centre for Augmentative and Alternative Communication, University of Pretoria, Pretoria, South Africa, August 25-26.

Bryen,D.N. & Frantz, B. (2005). End the Silence: Adults who use augmentative communication and their experiences as victims of crim. Augmentative and Alternative Communication, 19, 123-134.

Bryen,D.N. & Wickman, C.H. (2011). Ending the silence of people with little or no functional speech: Testifying in court. Disability Studies Quarterly, 31. Retrieved November 9, 2016 from http://dsq-sds.org/aerticle/view/1711/1759.

Davies, L. (2002). People with mental disabilities and sexual violence. The ARC. (as cited in Bryen & Wickman, 2013).

Knutson, J. F., & Sullivan, P. M. (1993). Communication disorders as a risk factor in abuse. Topics in Language Disorders, 13, 1-14.

Sobsey, D. (1994). Violence and abuse in the lives of people with disabilities. Baltimore: Paul H. Brooks.

Sullivan, P.M. & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. Child Abuse and Neglect, 24, 1257-1273.

U.S. Department of Justice, Office of Justice Programs, Bureau of Justice Statistics. (2015). Crime Against Persons with Disabilities, 2009 -2013 –Statistical Tables (NCI Publication No. 248676). Retrieved from http://www.bjs.gov/index.cfm?ty=pbdetail&lid=5280.

## New Information

Our Needs Assessment will utilize two well-established research methodologies: interviews and focus groups. The goal of the data collection is learn from individuals with complex communication needs in the best ways to provide safe, welcoming, accessible, and successful supports and services for survivors of domestic violence and sexual assault who have complex communication needs.

The Keystone Partnership will review the information gathered from all groups to develop our Strategic Plan. The goal of the plan is to ensure that each of our agencies will become more valuable resources for individuals with CCN, and will become a model for other organizations within our Commonwealth.

# Overview of Each Method

### FOCUS GROUPSThe Keystone Partnership will primarily use focus groups for gathering information individuals with complex communication needs. Focus groups will be the most efficient way to engage larger groups of individuals in a short time period. Focus groups will help generate a diverse range of ideas and perspectives. If a person cannot participate in the scheduled focus group, they will have the option to participate in an individual interview.

### INTERVIEWS

The Keystone Partnership will interview individuals that cannot participate in a focus group. Interviews can be done in-person, by telephone, or by skype.

### SURVEYS

Surveys will be used to gather information from individuals whose schedules or geography make attending a focus group difficult.

## Description of the Audiences

### Individuals with Complex Communication Needs

Our primary audience will be people with CCNs who access services and supports from disability organizations, specifically those individuals registered with United Cerebral Palsy (UCP) of South Central PA. This organization was selected as a convenience sample because of its close geographical proximity to the team members conducting the focus groups.

People with CCN are vital to the needs assessment process. We believe that people with a disability are the experts of their own experience and have the power to represent their own needs and expectations. It is imperative to ask them directly what their personal experiences are when accessing sexual and domestic violence programs, and receiving supports and services, so that we may make our organizations more welcoming, safe, and accessible.  Because the strategic plan will ultimately influence the way services and supports are provided, it is imperative that we ask the individuals who will be most impacted by our systems changes.

By engaging people with CCN, we hope to gain information about the following (for questions, see pg 31, 33):

* What makes a service provider safe, accessible and welcoming for people with disabilities
* The best methods to inform or alert people with disabilities about accessible sexual assault and domestic violence supports and disability-informed services
* The best practices for serving and supporting people with disabilities (including attitudinal, physical, and programmatic accessibility, staff behavior, knowledge, and skills).
* The best practices for explaining and obtaining informed consent

Table of Method for CCN Engagement

|  |  |  |
| --- | --- | --- |
| Type | Minimum # of sessions | Minimum # of participants |
| Focus Group | 1 groups | 10 participants |
| Survey | 2 list serves  | 15 responses |

Overview of Structure for each Method and Key Roles

#### FOCUS GROUP/INTERVIEW PROCEDURE

Focus groups and interviews will involve a moderated discussion prompted by open-ended questions unique to each audience, based on the goals of that particular group (see pg 31 for all questions).

* An individual from the Keystone Partnership and a identified community partner will conduct the focus groups and interviews
* Each focus group will have a facilitator and a note taker. An additional support/floater will attend as needed
* A trained counselor will be available to provide support at all focus group participants, as needed

INTERVIEW PROCEDURE

Each interview will have a facilitator and note taker.

* Interviews will not have a floater or counselor present, but the facilitator will have experience recognizing symptoms of stress and managing trauma
* Taking into consideration the participant’s potential need for additional emotional support, the facilitator and/or note taker for people with CCN will have training and experience in crisis counseling
* A list of local community resources will be available at all focus groups and interviews, should participants require information about where to obtain support.

At the beginning of each focus group and interview, the following will be explained (pg 28)

* Consent and voluntary participation in the focus group or interview
* The purpose of the focus group/interview
* Participants will be informed that they are called upon as experts to assist us in our work
* Confidentiality and exceptions to confidentiality
* Individuals have the opportunity to speak with an on-site counselor or receive a list of local community resources during, or immediately following, the focus group/interview if they require emotional support

#### ROLES OF THOSE CONDUCTING FOCUS GROUPS AND INTERVIEWS

The following is a list of the individual roles within the focus groups and interviews and a description of each role. All individuals filling these roles will be members of the Keystone Partnership and will understand:

* The grant and the needs assessment process
* Their role and expectations
* Specific requirements of the role
* How to manage special circumstances; safety, confidentiality, reporting requirements, and accommodations

Facilitator

A Keystone Partnership member with experience working with individuals with CCN will facilitate the focus group comprised of people with CCN. The facilitator will:

* Welcome participants and introduce the moderator of the meeting
* Review general housekeeping details
* Address safety and confidentiality issues using the script created by the Keystone Partnership, prior to asking the pre-determined questions and prompts. (See Appendices xx-xx for all facilitation scripts)
* Keep the discussion focused on the questions and intervene quickly in cases of possible disagreements or personal disclosures (See pg 40 for all questions.)
* Ensure that participants feel safe and comfortable in the environment and inform participants that they can leave at any time
* Keep track of time
* Participate in a debriefing session with the floater, led by the note taker, following each focus group to jointly identify themes, significant comments, and new information related to the goals of the needs assessment.

Note Taker

The Project Manager will be the note taker at all focus groups and interviews. The note taker will:

* Objectively and efficiently take notes on the discussion Not participate in the discussion, and will remain in an area of the room that is least distracting to participants
* Document main themes of discussion, excluding any identifying information except the organization name and type of group (for example, “Staff from XXX said…”)
* Ensure that all written notes are kept in a safe and confidential place
* Transcribe all notes into “note summaries,” which will be provided to Keystone Partnership team members

Floater (For focus groups only)

The primary responsibilities of the floater are to ensure that the facilitator and note taker have what they need to facilitate the meeting, and to attend to any comfort and safety requests of participants. The Floater will:

* Assist with food (if applicable) and room set-up and ensure that focus group participants feel safe and comfortable
* Escort any individual who requests access to the counselor or their personal care attendant out of the room
* Assist with keeping track of time when available

SA or DV or Victim Service counselor

A SA and/or DV counselor will be available to provide emotional support during or immediately following focus groups for individuals with CCN, The counselor will:

* Be in a separate, private, accessible space to ensure confidentiality and safety
* Have completed 40 hours of training as a domestic violence or sexual assault counselor/advocate and have experience working with people with disabilities, specifically those with CCN
* Have a list of local resources available for participants

SURVEY PROCEDURE

* Surveys will be conducted through Survey Monkey software, (see pg 35) and accessed by a clickable link emailed to participants
* The email will include an introduction to the project, and explains the process (see pg 33).
* Surveys will be voluntary and anonymous, unless a participant wishes to be contacted for an interview or to provide further information
* Questions will be multiple choice, Likert scale, and open ended

# Recruitment Plan

## Recruitment Methods

The following is an explanation of the methods we will use to recruit participants for each group and a description of the individuals who will act as primary recruiters for each group.

 In-person recruitment is the preferred recruitment method for survivors and people with disabilities due to inherent safety risks. However, because our groups are already identified, we will use email to correspond.

### For People with Complex Communication Needs

*In-person recruitment*

Participants in focus groups of people with disabilities will be recruited through in-person conversations, or print, facilitated by a service provider and a project partner from DRP. (pg 23). The recruitment materials will include an RSVP form (pg 25) with a list all accommodation options that invitees will be instructed to complete and return to the recruiter. The recruiter will be directed to provide the option of an interview or focus group to the potential participants. They will also be informed by members of the collaborative on the scope of our project and how to mitigate risks to confidentiality and safety to the individuals by learning Dynamics of sexual assault and domestic violence.

*Email Recruitment*

Participants of the CCN survey will be recruited via email list serves that are maintained by Temple University. The Keystone Partnership does not know the membership of these lists and will not be directly emailing list serve memberships.

## Recruitment Process

CCN Focus Groups

Recruitment for the CCN focus group will occur in person by a recruiter, identified by the project partners, who will use our recruitment letter script as a guide

The Recruiter will:

* Explain the purpose of the focus group/interview and the overall goal of the project
* Alert the invitee of any reasons that confidentiality cannot be maintained, such as mandatory reporting (See Confidentiality)
* Review the recruitment materials, including the RSVP form and Frequently Asked Questions (pg 40)
* For all activities with people served: Discuss what incentives they will receive
* Review the date, time, and location of the interview or focus group
* Review accommodation options (See RSVP form for a complete list: pg 25)
* Discuss the use of a known communication partner with the participant. Offer the option of an interview if the person will be utilizing a known communication partner as an accommodation, however the individual can choose to still participate in the focus group (see pg 39)
* Identify risks to confidentiality and safety of an individual. Take steps to mitigate risk by offering an interview or identifying them as not appropriate for this focus group.
* Confirm whether the individual is willing to participate
* Offer an individual interview for those who do not want to participate in a focus group. If the invitee prefers an individual interview, the recruiter will direct that individual to the Project Manager
* Answer any additional questions
* Have a list of supports and service in the event someone discloses abuse.

All recruiters will contact the Project Manager by email. The recruiters will submit the RSVP form email responses to the Project manager within 7 calendar days.

CCN Email Survey

Recruitment for the CCN email survey will occur through IOD list serves. The Keystone Partnership does not have access to the membership of these list serves. An email explaining the project and asking for participation will go out to identify lists.

The email will inform them:

* Of the purpose of the survey and the overall goal of the project
* Of any reasons that confidentiality cannot be maintained, such as mandatory reporting (See Confidentiality)
* Of the anonymity of this survey
* Of the anonymous recording of their comments in writing
* Of their voluntary participation.
* Not to share any identifying information, such as name, age, where they live, where work, or other such information.
* There is no requirement to answer all the questions--Just answer the questions they are comfortable answering
* The survey can be stopped at any time
* That by clicking on the survey you give your consent to participate.
* Of project contact information.

Recruitment Tools

Recruiters will utilize the following tools during recruitment. The recruiter will read aloud all documents for anyone needing assistance.

Frequently Asked Questions Sheet

The FAQ sheet will answer general questions about the focus groups/interviews (Appendix X). This sheet will be provided to all participants during the recruitment process. For people with CCN, sexual assault survivors and domestic violence survivors, the instructions will indicate that individuals can return FAQ sheet.

Meeting Reminder Emails

We will offer to provide participants of focus groups with an email meeting reminder, unless other accommodations have been requested. This will mitigate safety concerns.

Inclement weather

The recruitment email will include an option to be notified if a focus group or interview has been canceled due to inclement weather. We will provide a toll-free phone number with an extension for individuals to call if they prefer not to provide their contact information for cancellation notifications.

Incentives

We will provide light refreshments during all focus groups for people with CCN. The support person will make accommodations for any food/drink restrictions and requirements as needed.

During the check-in process prior to each focus group/ interview, each individual participant and support person will receive a gift card. Individuals will be informed during recruitment, and before each focus group/interview, that a gift card will be provided to them. Participants can choose how they would like to receive their card.

The note taker will count the number of participants in attendance and the number of gift cards distributed and keep a record for potential grant auditing requirements. The facilitator will reconcile and confirm in writing that this number is correct.

Recruitment Training

Any individual who does not belong to the Keystone Partnership who directly recruits for focus groups on behalf of our project will participate in mandatory recruitment training.  Recruitment training will occur prior to any recruitment activity and will be delivered in-person or by conference call. The training will last approximately one hour and will be conducted by the Project Manager and another project partner.  Recruiters may be project members, leadership, or staff from specific programs being engaged.

Recruiters for each group participating in the Needs Assessment will be trained on the following information:

* An overview of the grant and Needs Assessment process
* Participant requirements
* Instructions for discussing issues of safety, confidentiality, reporting requirements, and accessibility with possible participants
* Recruitment RSVP Form
* Instructions to identify risks to participant and how to offer alternatives to the individual
* Instructions for recruiting the minimum/maximum number of participants for focus groups and for keeping track of the limited number for each group

For additional questions or concerns the name and contact information of a Keystone Partnership member will be provided.

Confidentiality

The following information outlines the specific considerations made to preserve confidentiality:

Focus Groups

Personally identifying information will only be collected during the RSVP process; individuals will be asked for their first name and contact information to connect them with their accommodations and to provide optional meeting reminders. The project assistant will keep a list of any individuals who request accommodations.  The assistant will bring this information to each focus group/interview as needed, and the information will be destroyed within a week of the focus group’s conclusion.

Only the number of focus group participants will be utilized for the needs assessment report. No personal information obtained from the RSVP forms will be aggregated or shared.

Focus group participants will be asked to withhold any identifying information about themselves or staff.  If identifying information is disclosed, it will be removed from notes and transcripts. All RSVPs will be destroyed no later than one week following each focus group.

Focus group participants will be asked to keep any information discussed or shared during the focus group confidential.  Participants will also be asked not to discuss what is said in the group with other group participants after the session concludes.

Survey

Survey information cannot be tracked back to a particular participant and will report at the aggregate. The Keystone Partnership will not have access to identifying participant information or membership of the list serves. The Keystone Partnership will also not have access to participants email addresses. Participants are reminded that it is not necessary to provide any personally identifying information in the survey.

Final Report

The final needs assessment report will identify trends, barriers and strengths correlating to each organization’s statements summarized in the needs assessment process.

The Project Manager and assistant will retain information gathered through the needs assessment process on password protected computers that only they can access. Team members will be provided with summaries of focus groups by the Project Manager.  Summaries will identify themes, patterns, and issues that emerge from focus groups. Drafts of the needs assessment report will be stored using password protected software that only members of the Keystone Partnership team can access.

The report will not be shared with anyone outside the project until it has been reviewed and approved by Keystone Partnership members, with Vera Institute on Justice, and the Office on Violence Against Women.

All notes, records, and recordings related to the needs assessment will be destroyed after the strategic plan has been approved by the Office on Violence Against Women and members of the Keystone Partnership.

Consent Process

The Keystone Partnership will use a passive consent process for all focus groups, interviews, and surveys. Passive consent provides greater confidentiality for participants because it does not require documentation of consent. This process will be outlined in the facilitator’s introduction prior to a focus group or interview.

Focus group and Interviews

A script will be read before each survey explaining passive consent. Participants will be informed that, by choosing to stay and complete the survey, they are giving their consent to participate. Participants of focus groups, interviews and surveys will agree to:

* Participate in a focus group, interview or survey
* The anonymous recording of their comments in writing
* The anonymous use of their comments in the needs assessment report
* The anonymous use of their comments to develop the Keystone Partnership’s strategic plan and implementation process.

Focus groups with individuals with CCN will be informed that, should they choose to leave the focus group, will not need to return their gift card.

Surveys

The survey email will discuss consent and inform participants that: Before you start the survey we would like to remind you that:

* You are participating because you want to.
* You do not need to share any identifying information, such as your name, age, where you live, where you work, or other such information.
* You don’t have to answer all the questions. Just answer the questions you are comfortable answering.
* You can stop the survey any time you want to.
* By clicking on the survey you give your consent to participate.

Accessibility Considerations

The Keystone Partnership is committed to providing fully reasonable accessible focus groups, surveys, and interviews for all participants throughout the needs assessment process. We will ensure accessibility to the best of our ability.

Recruitment

We will announce the availability of accommodations, upon request, while recruiting for the needs assessment, and while conducting interviews, surveys, and training.

Recruiters and facilitators will be instructed to attend to the particular needs of any participant each audience and speak in a manner that is accessible to all participants.

Accommodation
Reasonable accommodation will be provided to those participating in focus groups, interviews, and surveys. The RSVP form for focus groups and interviews will include a checklist of available accommodations. The Project Manager will be responsible for overseeing requested accommodations.

All Keystone Partnership members, focus group, and interview participants will be asked to refrain from wear perfume or scented lotions.

All print materials and needs assessment tools will be written in plain language. Acronyms will not be used. All print materials will be written in 14 pt. using a sans-serif font. In addition, the font color and background color will be compatible with screen readers.

Participant’s Personal Care Attendants (PCAs) and family will remain outside room during focus groups or interviews. PCAs and family may wait outside of the room for the participant. A member of the collaborative team will be available for any participant who needs assistance. Alternative PCAs will be made available upon request.

Certified speech/language and tactile-sign interpreters will be provided upon request. Foreign language translators will also be provided upon request.

If the individual requires the assistance of their known communication partner during the focus group or interview, we will accommodate this request.

Focus groups and interviews will be conducted when it is most convenient for people with disabilities who must rely on alternative transportation services or who lack accessible transportation.

Physical Site
All focus groups and interview locations will be accessible. Focus groups and interviews will take place in a space that is commonly used or recommended by the participants or organizations supporting our focus group members, with the assumption being that, because their familiarity and prior use of the space, proper accommodations will have been made for accessibility.

Any meeting space unfamiliar to the Partners will be visited prior to any meetings to ensure accessibility.
Surveys, Interviews, and Focus Groups
Survey, interview, and focus group questions have been written using plain (non-abstract) language to ensure accessibility for individuals with cognitive disabilities. Questions were developed with disability service agency employees who have expertise adapting language to meet the needs of people with disabilities.

Safety Considerations

Physical and psychological safety is a primary consideration of The Keystone Partnership. This partnership is comprised of The Pennsylvania Coalition Against Rape (PCAR), the Pennsylvania Coalition Against Domestic Violence (PCADV), the Institute on Disabilities at Temple University (IOD), the Disability Rights Pennsylvania (DRP), and the Pennsylvania Statewide Independent Living Council (PASILC). Each member of the Keystone Partnership represents the unique needs of his or her specific stakeholder group.

Acknowledging that safety may be defined differently for each individual, every effort will be made to ensure the safety of all participants in the needs assessment activities process, including focus groups, one-on-one interviews, and surveys. The Keystone Partnership will make every effort to develop and utilize tools and processes to maximize the safety of all involved.

Each focus group and interview will have a facilitator and note taker. The note taker is responsible for capturing themes only. No identifying information will be tied to individual responses. Any transcribed materials will be destroyed 30 days after the responses are transcribed.

 Keystone Partnership

Considerations for Participants of Interviews or Focus Groups

During recruitment and at the beginning of each focus group or interview participants will be informed that:

* Questions are designed to elicit information that supports members in reaching the goals the project
* To minimize disclosures, questions are not intended to gather personal experiences related to violence, abuse, or neglect.
* If applicable, considerations about mandated reporting confidentiality exceptions will be shared.
* Participants may choose to discontinue a focus group or interview at any time.
* Participants are not required to answer any question with which they are not comfortable
* Individual interviews are available for anyone who prefers to participate outside of a group setting.
* We will explain our mission to focus group participants and to those that participate in interviews and surveys.
* All focus group/interview printed or signed materials will refrain from language regarding the intersection of domestic and/or sexual violence and disabilities.
* An advocate will be available at focus groups to provided emotional support during or immediately following the session if the discussion is triggering to and/or if a participant appears likely to disclose
	+ The support person will be available in a private, accessible space to ensure confidentiality and safety
	+ Participants will be informed of the availability and location of the support person, and can request an escort to that location
* A list of list local resources and national hotlines related to domestic violence, sexual assault, and disability services will be available upon request.
* Keystone Partnership members will inform the known communication partners and PCAs that the focus group/interview is designed for individuals with CCN. However, if the participant requests that the known communication partner or the PCA speak on their behalf, the PCA will be permitted to do so with the understanding that PCA’s are solely present to assist in communication, and not to actively participate in the discussion.
* No outside observers will be present in any of the needs assessment activities
* Identifying information will only be used to provide participants with their requested accommodations. All other identifying information will be destroyed after the session concludes.

Considerations for Survey Participants

The survey is designed to minimize risk to the participant by:

* Utilizing questions that are designed to elicit information that supports partnership members in reaching the goals of their mission
* Minimizing disclosures, as questions are not intended to gather personal experiences related to violence, abuse, or neglect
* Reminding participants that they may choose to discontinue a focus group or interview at any time
* Informing participants they are not required to answer any question with which they are not comfortable
* Ensuring that the Keystone Partnership does not have personally identifying information of the participant

Locations of groups/interviews

Focus group and interview sites will be selected based on safety and proximity to public transportation. In most cases, sites will be selected in locations where participants already have an established routine to avoid calling attention to the group. Focus groups for People with CCN will meet on site at a provider organization or at an alternate site that better meets the needs of the participants.

Work Plan

|  |  |
| --- | --- |
| **Activity** | **Timeframe** |
| Collaboration building/Charter development | Jan. 2014 - Dec. 2015 |
| Narrowing the Focus/Defining our Scope | Dec. 2015 – Feb. 2016 |
| Needs Assessment Plan Development | Feb. 2016 - Jan. 2017 |
| Conducting our Needs Assessment | Jan. 2017-Mar. 2017 |
| Create Needs Assessment Report | Apr. 2017- May 2017 |
| Strategic Plan Development | May 2017 – Jun. 2017 |
| Implementation | Jun. 2017- October 2017 |

RSVP FORM

Focus Group RSVP

Please complete this form. All the information that you provide on this form is confidential and will be destroyed within a week of the focus group’s conclusion.  Please return completed forms to your recruiter.

First (1st) Name Only: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Please check ONE of the following:

\_\_\_\_ I wish to participate in a focus group.

\_\_\_\_ I wish to participate, but only in a one-on-one interview.

Please contact me at this phone number for an interview. \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ I do not wish to participate.

Meeting Reminder Options:

\_\_\_ I would like an email reminder for focus group time and location.

Please provide e-mail: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ I would like a phone call reminder for the focus group time and location.

Please provide phone number: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ I will contact my recruiter if want to be reminded of the date and time.

In the event of inclement weather, we may need to cancel focus groups in-person interviews. All cancelation decisions will be made the evening before the scheduled focus group or in-person interview.

\_\_\_ I would like to be called if a focus group is cancelled.

Please provide phone number \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ .

\_\_\_ I would like to be emailed if a focus group is cancelled.

Please provide email \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

\_\_\_ I will call toll free number to check for cancellations: 877.739.3895 x117

We will do our best to make every accommodation necessary to ensure your full participation.

Please place a check next to any accommodations you will require during your focus group/interview.  Check all that apply for you.

|  |  |
| --- | --- |
| Yes, I need this accommodation. | Accommodation: |
|  | American Sign Language (ASL) interpreter |
|  | Spanish interpreter |
|  | Other language interpretation (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_ |
|  | Listening device |
|  | Large print |
|  | BrailleCART |
|  | Physically Wheelchair accessible site |
|  | Alternate personal care attendant (PCA)\* |
|  | Use of known communication partner |
|  | Dietary preferences/food allergies (for focus groups only) (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_OTHER, please list \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

\* Your own PCA is not permitted in the room during the focus groups/interviews, but may wait outside the room for you. If have questions or concerns about this, please inform your recruiter.

Recruitment Template Letter: CCN Focus Groups

Hello :

We are asking people with complex communication needs, sometimes referred to as a significant speech disability or limited functional speech to for your participate on in a focus group., specifically for people who *cannot meet their daily communication needs through conventional methods, with is also known as having complex communication needs. This can result from significant speech, language, and/or cognitive impairments caused from a variety of physical, sensory, and environmental causes which restrict independent communication.* The findings from the needs assessment will help us develop the goals for our strategic plan. This plan will guide our implementation activities for creating systemic changes for improved service delivery at both organizations going forward.

The PA Coalition Against Rape (PCAR) and PA Coalition Against Domestic Violence (PCADV) and PA Statewide Independent Living Council (PASILC) and Institute on Disabilities, Temple University (IOD) and Disability Rights Pennsylvania (DRP) form the Keystone Partnership and have received a three-year grant from the U.S. Department of Justice’s, Office on Violence Against Women to improve services in Pennsylvania for people with disabilities specifically those who have complex communication needs and have experienced sexual abuse or domestic violence.

We hope to learn what domestic violence programs, sexual assault centers and disabilities organizations can do to improve how we serve and support people with complex communication needs.  that may be victims of domestic violence, sexual assault, or stalking. We will not be asking about any specific experience/s of domestic violence or sexual assault that you or someone you know has been through. Although you or someone you know may have experienced some kind of abuse in the past, we will not be talking about that during this group.

It’s important to note that we are not to recruiting people with complex communication needs disabilities who are survivors of sexual assault or domestic violence. Rather, it is about learning how access services in the community, about their experiences when attempting to access services,  and what works or doesn’t work for them.

This focus group will be held on (date), (time) and( location)

**Before participating in the focus group, we would like you to know the following:**

·         Your participation is strictly voluntary.

·         If you agree to be at the focus group, you can participate at whatever level you’re comfortable with.

·     Those that participate will receive a gift card incentive for participation.

·         In addition to the meeting facilitator, there will be a note taker writing down all of the comments, but no participant will be personally identified or linked to any specific comment.

·         The information we collect today will be summarized put it into a summary and linked to the organization and group you are in. For example: “individual in focus group said…”

·         All of the information gathered will be kept in either a password protected computer or a locked file at the lead agency.

·         The findings from the needs assessment will help us develop the goals for our strategic plan, which will provide the foundation for service improvements at our agencies.

·         While we will not be asking you questions about personal or professional stories regarding violence or abuse, we would like to remind you of the exceptions to confidentiality. There are Mandatory  Reporting requirements for child abuse, and Imminent Threats to Self or others.

If you would like to participate, but prefer an individual interview for any reason, please let us know and we will be happy to arrange it.

I have attached a Frequently Asked Questions sheet with more details, or just let me know if you have additional questions.

**RSVP to this invitation:**

* If you know now that you would like to attend this focus group, please tell the recruiter that discussed this with you and complete the RSVP form. r just let me know if you have additional questions. it.ersons who are a threat to themselves or others. he RSVP form.
* The recruiter will discuss with you any accommodations you may need and assist you in indicating this on the RSVP form. ns.
* If you prefer to participate in an in-person or telephone individual interview, rather than in a focus group, please specify that to the recruiter who helped you.
* If you would like to receive a reminder of the date/time please specify that in the RSVP form.

Your input as an individual with complex communication needs that receives disabilities services is critical to the success of our project.

Sincerely,

Name of Project Manager

Title(s)

Script: CCN Focus Group

Check-In Process

Prior to participants entering the room, the facilitator or note taker will greet each participant and ask for their first name. The purpose for this is to link each individual with any accommodations they have requested.

The greeter or facilitator will also provide them with their incentive and will then direct them to the room where the focus group will be held and the light refreshment are at.

Introductions and Overview

Hello, my name is X and this is Y. I will be facilitating the conversation and Y will be providing assistance and taking notes. This is [insert name], who is here as a “floater” to provide overall help in case any of us need anything during the focus group. Don’t hesitate to ask the floater for any assistance you need, such as leaving the room We are members part of a collaborative project, the Keystone Partnership, comprised of the Pennsylvania Coalition Against Rape, the Pennsylvania Coalition Against Domestic Violence, Disabilities Rights Pennsylvania, the Pennsylvania Statewide Independent Living Council, and Institute on Disabilities at Temple University. Our goal is to make services at our collaborative agencies safer, more welcoming, and more accessible for survivors with disabilities.

We invited you to meet with us to talk about how to make services safer, more welcoming, and more accessible. We’re asking for your help in identifying what you feel is working well and what we could do better for clients who use services.

I will ask you several open ended questions. Your experiences and thoughts are very important to us. There is no right or wrong answers. Please feel welcome to express yourself freely during this conversation and please give everyone the chance to express her or his experiences and thoughts. Anyone can stop participating at any point if you they are feeling uncomfortable. You do not No participant needs have to answer any question that makes you her or him uncomfortable.

We will not be asking you to share any information about any forms of violence or abuse that you or someone you know may have personally experienced. In fact, we prefer that you not share those experiences stories. Rather, we will be asking you about what works and doesn’t work for you when seeking services in your community.

Even though we will be focusing on services and not talking about specific instances of violence and abuse, we know that these discussions may can be difficult for some to participate in. As a result, a counselor is here for any one of you who would like to talk before, during, or after the group today. [Insert name] will be (give location). We also have a list of resources available to share with you.

Also, we ask that you keep what is discussed in this group private. What is shared in this group is not to be discussed outside of this room, including with other group participants when it is over.

This conversation will be recorded for accuracy, no identifying information will be used in note taking and planning process. This is only for the purpose of assisting us with fully documenting responses. The recording of this conversation will immediately be destroyed after transcription. The information collected from all the group discussions and interviews will be put into a final report. This report will go to our collaboration, the US Office on Violence Against Women, our funding source, and the Vera Institute of Justice, our technical support for the grant.

By participating in this focus group today you are telling us that you are okay with helping us collect information for our needs assessment.  Participating in our project which includes your participation today, Your comments are being used anonymously in a report and possibly also may be used in developing a plan and activities to address ways to improve services.

For any care attendants or communication partner present,  although we value the work you do everyday, this focus group is intended for the individual you are supporting, therefore as much as possible we would like to hear directly from the individual. We encourage you to refrain from providing your own perspective on the topics we are discussing today.

We are a small group of people, so I think I can get your attention without having to ask for your name. Are you OK with this?

I would also like to cover a few housekeeping items:

We encourage you to exercise self-care during our conversation.

The restrooms are located….

We ask you to please switch off your mobile phones.

If you need anything for any reason, including your attendant, please notify the floater.

We are about to get started, Again, we assume that you are freely choosing to participate by being here today. As a reminder, you may leave at any time if you change your mind about being here or if you simply decide you want to leave. We are about to begin the questions so if you’d like to discontinue before we get started; you are welcome to leave now with no consequences.

Are there any questions before we start?

CCN Focus Group Questions

1.       How do you learn about services available for people with disabilities?

a.       How do you find out about other helpful resources in your community?

b.      What is the best way to let you know about supports and services available in your community?

2.       What makes you feel welcomed when seeking and receiving supports and services?

a.   If you need accommodations, what is the best way for you to communicate your needs to staff?

b. What can staff do to ensure that your accommodations needs are met?

c. What can staff do to make you feel welcomed?

3. What makes you feel safe when seeking and receiving supports and services?

a. What is the best way for you to communicate your safety needs?

b. What can a provider staff do to make you feel safe when receiving services?

b. How would a provider staff know that they are meeting your safety needs?

g. How do you communicate to staff that they are meeting your expectations?

f.     What would be the most ideal (safest) way to communicate to staff that the services you are receiving is exactly what you expected?

4.  Think about a time when you were referred to another agency for services.

a. What worked well when you were being referred to another agency?

b. What didn’t work well?

c. How could’ve this process been improved?

5. What else would you like us to know about how to best support people with complex communications needs who are looking for services?

Email Recruitment for CCN Survey

The Keystone Partnership\*\* is looking for people over the age of 18 and have difficulty communicating verbally to participate in a brief seven question on-line survey. The purpose of the survey is to gather information on how sexual assault centers, domestic violence programs, and disability organizations can better serve adults that have difficulty communicating verbally. You **do not** need to ever have requested or used supports and services from these programs to participate in this survey. The survey will not ask any specific questions related to personal experiences related to sexual abuse or domestic violence. All information gathered will remain anonymous.

Before you start the survey we would like to remind you that:

* You are participating because you want to/
* You do not need to share any identifying information, such as your name, age, where you live, where you work, or other such information.
* You do not need to share any identifying information, such as your name, age, where you e answering.
* You can stop the survey any time you want to.
* By clicking on the survey you give your consent to participate.
* If you have any questions please contact Bev at x.

Although you may receive this email more than once, we ask that you take this survey only one time.

\*\*The Keystone Partnership is composed of five (5) statewide organizations that came together under a grant awarded by the Office on Violence Against Women, U.S. Department of Justice to address the needs of individuals with significant speech disabilities who have experienced sexual abuse or domestic violence in their lives.

The five partners are: Pennsylvania Coalition Against Rape (lead agency); Pennsylvania Coalition Against Domestic Violence; Disability Rights Pennsylvania; Institute on Disabilities at Temple University; and Pennsylvania Statewide Independent Living Council.

CCN Survey Questions

1. How do you find out about places and resources to help you?
* Social service agency
* Internet
* Medical Professionals
* Word of Mouth
* Other
1. How would you like to find out about supports and services in your community?
* Social service agency
* Internet
* Medical Professionals
* Word of Mouth
* Other
1. If speaking is hard for you, how can we help you feel welcome and listened to when you are looking for help?
2. What makes you feel safe when you are looking for help? (select all that apply)
	* Having someone who you know available to help with communication
	* Having people be familiar with different ways to help you communicate
	* Having a private area to meet and discuss your concerns
	* Being able to receive services and supports in your preferred location
	* Other? Please share
3. Have you run into any of the following issues when you went some place for help? (check all that apply)
	* The staff did NOT understand your wants and needs
	* The staff was NOT able to help you get the supports and services you needed
	* The staff did NOT make you feel safe (if not, how)
	* The staff did NOT make you feel welcome (if not, how)
	* The staff did NOT understand what you needed or wanted
	* -other? Please share
4. Is there anything else you would like to add?
5. Did a supports person assist you in completing this survey?

Statement on the Use of Known Communication Partners during CCN Focus Groups

The focus group that engages individuals with CCN will cover topics on safe, welcoming, and supportive services—and may also touch on topics of domestic violence, sexual assault, and stalking, Although, we will not be discussing specific instances of abuse or soliciting disclosures of abuse, we strive to ensure safety of the individuals participating so that they may discuss as freely as they choose on these potentially sensitive topics.

In a focus group discussing topics of this sensitive nature, where a participant’s known communication partner is present, especially if they may be a potential abuser, can potentially limit the individual’s participation or result in retaliation again the participant. We know that individuals supporting people with disabilities, including communication partners can be potential perpetrators of abuse due to their access to the individual, and due to other risk factors. Moreover, our hope is to engage with individuals with CCN and learn directly from the individual their perspective on the topics we are covering. Our expectation is not for support individuals, including a known communication partner to speak FOR an individual or to give their own perspective on the topics.

The Keystone Partnership recognizes many times the communication modalities that individuals with CCN may use is unique to them, and may only be readily understood by their known communication partner, as they have learned over a period of time the individual’s means of communicating. Individuals with CCN may not be able to, or may not have received the training to use an assistive communication device, including low or high tech devices, or be able to communicate using ASL.  The facilitator or an unknown communication partner that the Keystone Partnership may provide as accommodations to the individual might not be as effective in communicating the individual’s thoughts and perspectives, as they have not been privy to the individual’s communication modalities.

If an individual requires the accommodation of their known communication partner to effectively communicate, we will not prohibit an individual’s communication partner from being in the focus group room, as doing so may limit the individual’s capacity to fully engage and communicate in the discussion. To address safety concerns of having a known communication partner in the room during the focus group, we will train our recruiters to discuss accommodations with the participant in relation to communication, so that the individual can best decide their safety and how to most effectively communicate. Our preference would be to offer an alternate communication partner for the individual. However, if the individual feels they can best communicate with their usual support person present, we will honor this communication accommodation. We will then discuss roles of support people in the focus group, to convey that we are not here to solicit the support person’s perspective on the topics.

The Keystone Partnership makes the distinction between accommodations for the purposes of communication, and for other needs. If an individual requires a support, but not for communication reasons, our recruiters will offer an alternative support person as an accommodation and list their specific accommodations on the RSVP form. The recruiter will discuss that the usual support person will be permitted to wait outside the door for them, and if they require their support person, someone from the group can retrieve them.

Recruiters will discuss with the individual the purpose of the focus group and the rationale for the support persons waiting outside the space. This rationale will include it being their time to talk about their experiences and this meeting is just for them.

Frequently Asked Questions

**What is the Keystone Partnership?**

This partnership of The Pennsylvania Coalition Against Rape (PCAR), the Pennsylvania Coalition Against Domestic Violence (PCADV), the Institute on Disabilities at Temple University (IOD), Disability Rights Pennsylvania (DRP), and the Pennsylvania Statewide Independent Living Council (PASILC) have come together to address these needs for sexual assault, domestic violence and stalking survivors with complex communication needs on a statewide level.

**What are the main goals of the Keystone Partnership?**

We will create a sustainable statewide partnership of committed and skilled victim and disability service organizations that respectively and effectively serve and support individuals with complex communication needs by:

• Continuing to raise awareness and enhance capacity within our own organizations and in all our connections

• Developing sustainable relationships between our own agencies that will benefit those doing work at the local level.

• Exchanging information and educating our partnership and their individual networks

• Revisiting organizational philosophies (e.g. mission, vision, values) that direct each partner’s policies and procedures.

• Advocating for equal justice

• Promoting cultural and linguistic sensitivity

**Why do a needs assessment?**

We want to understand where we are in Pennsylvania in providing services to survivors with complex communication needs.

**Who are we asking to participate?**

We are engaging people with complex communication needs

**Why do you need my input?**

You have critical information to inform how we do our work.

**Do I have to answer every question?**

No, you can answer any question you feel comfortable answering.

**Who should I contact if I can’t come?**

You can contact your recruiter or the Project Manager at knhouser@pcar.org or at 717-728-9740 x117

**Are responses confidential?**

Your answers will not be associated with your name or other identifying information. However, responses will be shared as part of our needs assessment findings.

**What if I want to help but don’t want to be in a group?**

You may request to be interviewed one-on-one.

**How is this information going to be used?**

This information will be become a part of our needs assessment report, and plan for improving services across the state.

**Who will get the information?**

This information will be shared with our partner organization, VERA Institute on Justice, and the Office of Violence Against Women.

**What are the safety considerations for my participation?**

We have considered the physical and emotional safety of participants. However, every participant should consider their own safety when deciding to participate. We believe every person has the right to make decisions that are in their best safety interests.

**What accommodations are available to support my participation?**

We have a prepared list of accommodations on our RSVP form. However, if you require other accommodations, please inform your recruiter.

**If I have a Personal Care Attendant (PCA) can they come with me?**

Because of the nature of this assessment, PCA’s are asked to stay outside the room during the focus group/interviews. If you require a PCA, please list this as an accommodation, and we will provide one for you.

**What if I use a known communication partner?**

We can provide to you an alternate communication partner during the focus group as an accommodation. If you require a communication partner please inform your recruiter. If you cannot use an alternate communication partner, and require the assistance of your known communication partner, please inform your recruiter.

**Who do I contact if I have any additional questions / concerns?**

You can contact your recruiter or the Project Manager at knhouser@pcar.org, or at 717-728-9740 x117.

Make sure to update appendix #’s