



Rhode Island Needs & Strengths Assessment Report

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OVERVIEW OF THE ACT COLLABORATIVE

In October of 2006 the ACT Collaborative received funding from the Department of Justice's Office on Violence Against Women, through its Education & Technical Assistance Grants to End Violence Against Women with Disabilities Program. The ACT Collaborative is made up of three project partners: Day One (The Sexual Assault & Trauma Resource Center of Rhode Island), PAL (An Advocacy Agency for Families & People with Disabilities), and the RI Coalition Against Domestic Violence plus two affiliated member agencies: Advocates in Action (RI's statewide self-advocacy organization) and Blackstone Valley Advocacy Center (a domestic violence shelter and member agency of the RI Coalition Against Domestic Violence). These five agencies have agreed to collaborate together in support of the mission and vision jointly created through this initiative:

The Guiding Vision & Mission for the Work of the ACT Collaborative

The **VISION** of the ACT Collaborative is to create an accessible system that is person-centered in its service delivery, provides a comprehensive spectrum of services, and is delivered by informed and accountable professionals to individuals with disabilities and Deaf individuals, who are survivors of domestic and sexual violence.

Our **MISSION** is to ACT together through Advocacy, Collaboration and Training to better respond to violence against individuals with disabilities and Deaf individuals with the **PURPOSE** of fostering an environment that works to:

- Improve accessibility to advocacy and safety planning services for individuals with disabilities and Deaf individuals;
- Develop a collaborative network through open dialogue to improve the quality of supports individuals with disabilities and Deaf individuals receive;
- Provide cross-training, cross-fertilization, and bridge-building opportunities for professionals working in the fields of sexual assault, domestic violence and disability services to better detect, react to and reduce violence in the disability and Deaf communities.

Under the auspices of this grant-funded initiative, the ACT Collaborative is engaging in activities in two phases - a Planning Phase and an Implementation Phase. Through these activities the ACT Collaborative is working towards creating systems change by providing intensive technical assistance and support to disability advocacy and violence response/prevention agencies in two Rhode Island Communities of Focus (COFs). All work under this initiative is toward this goal of systems change and the better understanding of how to respond to the needs of individuals with disabilities who have experienced abuse.

Supported by technical assistance provided by the VERA Institute of Justice, the ACT Collaborative has already engaged in several activities of the Planning Phase including: creating a ***Collaboration Charter***, which outlines in great detail the way in which these five agencies will communicate and work together in support of the mission and vision jointly created through this initiative; and developing a ***Needs Assessment Plan*** that guides how the Collaborative will engage in conversations to better understand both the needs and strengths of our two COFs in regards to their ability to respond to women with cognitive disabilities who have survived abuse.

The present document – the ***Needs & Strengths Assessment Report*** – is the third deliverable of the Planning Phase and outlines the key findings which emerged from the many conversations in which we had the privilege to engage within our two Communities of Focus. The key findings that follow in this report will allow the ACT Collaborative to work with the eight agencies in our Communities of Focus to develop a ***Strategic Implementation Plan*** for systems change – the final deliverable in the Planning Phase of this Initiative.

Establishing our Guidelines & Narrowing Our Focus

As a precursor to the Needs Assessment process, the ACT Collaborative identified two Communities of Focus (COFs), target populations in which sustainable, systems change can be made to better respond to violence against individuals with disabilities. We utilized the same “non-negotiables” guiding the work of our Collaborative in deciding the agencies to participate in our COFs. We sought to work with agencies who demonstrated an ability and willingness to:

- Utilize a person-first approach for responding to violence against individuals with disabilities and Deaf individuals;
- Look beyond crisis intervention to also include long-term futures planning and support for and around these individuals who have experienced violence in their lives;
- Build community relationships and valued roles for individuals who have experienced violence in an effort to keep them safe in the future;
- Include Rhode Island’s strong network of self-advocates in the planning and implementation of all ACT initiative goals;
- Include survivors in the planning and implementation of all ACT initiative goals;
- Always ask the question "what will keep people safe?" and assure that it underlies all proposed interventions and implementations;
- Serve as the facilitator of conversations in an effort to create systems change, because it is our belief that change happens one conversation at a time;
- Foster a learning environment;
- Focus on the possibilities, and not on the deficits, within the service provider system;
- Always ask the question “what can we do together that we cannot do alone?”

Our Communities of Focus (COFs)

Through our “narrowing” work as a Collaborative in consultation with the VERA Institute of Justice, two communities emerged as our Communities of Focus – the City of Warwick and Newport County.

- Warwick, RI is the second largest city in the state, and as of the 2000 Census there were 85,808 people residing in the area with a median household income of \$46,483. The city covers 49.6 square miles of which 35.5 square miles are land and 14.1 square miles are water.

- Newport County is one of five counties in the state, and as of the 2000 Census is home to 85,433 people with a median household income of \$50,488. The entire county covers 314 square miles of which 104 square miles are land (66.83% of this county is water).

Through previous work of the ACT Collaborative, it became apparent over and over again which agencies in RI were truly ready to embark on systems change work. When the ACT Collaborative and its partner agencies hosted events and conversations around the intersection of violence and disability, it was the community service agencies working with adults with cognitive and developmental disabilities that continually showed up to the table. Therefore, the Collaborative narrowed the focus of our work in these two locations to the population of individuals with developmental¹ and cognitive disabilities. More specifically, the ACT Collaborative conducted this needs and strengths assessment within the following agencies:

City of Warwick:

3 Agencies serving individuals with developmental/cognitive disabilities: Avatar, MENTOR Shared Living, and The J. Arthur Trudeau Memorial Center (Kent County Arc).

The Domestic Violence Member Agency: Elizabeth Buffum Chace Center

The Sexual Assault Agency: Day One²

¹To be eligible for supports funded through the Division of Developmental Disabilities individuals must meet the following definition of developmental disability, as stated in RI State Law: “The term ‘*developmental disability*’ means a severe, chronic disability of a person which:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is manifested before the person attains age twenty-two (22);
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity:
 - personal care
 - communication
 - mobility
 - learning
 - self-direction
 - capacity for independent living
 - economic self-sufficiency; and,
- reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are life-long or extended duration and are individually planned and coordinated.”

² Day One is a project partner and the only agency in Rhode Island organized specifically to deal with issues of sexual violence as a community concern. Day One is both the state coalition and the statewide service provider. Day One is the sexual violence response agency in both Communities of Focus.

Newport County:

2 Agencies serving individuals with developmental/cognitive disabilities: Looking Upwards and Bridges, Inc.

The Domestic Violence Member Agency: The Women's Resource Center of Newport & Bristol Counties

The Sexual Assault Agency: Day One

GLOBAL QUESTIONS

The ACT Collaborative identified specific areas of inquiry which define the goals of our Needs Assessment, and the key findings of our Needs & Strengths Assessment will be organized around these four primary questions:

1. What are the existing strengths, best practices and possibilities that exist in our COFs for a person-centered, cross-discipline response to abuse?
2. What are the barriers survivors with developmental and cognitive disabilities face when trying to access advocacy and safety-planning services?
3. What are the entry points, if any, into the violence response system for individuals with developmental and cognitive disabilities, and how can we improve access to these entry points?
4. What capacities, skills and competencies need to be nurtured in agencies and staff who work with individuals with developmental and cognitive disabilities, who have survived abuse?

NEEDS & STRENGTHS ASSESSMENT METHODOLOGY

The ACT Collaborative sought to undertake a qualitative methodological approach to our Needs & Strengths Assessment. The Collaborative wanted to have face-to-face conversations with the widest range of stakeholders throughout the process in an effort to get a picture from both the macro- and micro- levels of the service delivery system for women with disabilities who have survived abuse. The ACT Collaborative wanted to understand both the day-to-day work that is being done with these individuals, as well as understand the larger system in which front-line staff and the individuals themselves must navigate. Understanding that any needs and strengths assessment in our COFs must look at these multiple layers, the following audiences were invited to be part of the Needs & Strengths Assessment process:

- Leadership (Executive, Department, Shelter Directors and Board Members) of COF Domestic Violence and Sexual Assault Agencies
- Leadership (Executive, Department, Residential Directors and Board Members) of COF Disability Service Agencies
- Clinical and Advocacy Staff of COF Domestic Violence and Sexual Assault Agencies
- On-call volunteer advocates for the Victims of Crime Helpline who provide hospital accompaniment for victims of domestic and sexual violence
- Direct Support Professionals and Residential House Managers of COF Disability Service Agencies
- Individuals with Developmental and Cognitive Disabilities receiving services within our COF agencies

One of the primary roles of our Collaborative is to serve as the facilitator of conversations in an effort to create systems change, because it is our belief that change occurs one conversation at a time. Because of this guiding principle – the ACT Collaborative chose three methodologies that allowed us to connect directly to our stakeholders and allowed stakeholders to connect with each other.

The three methodologies utilized were:

I. **INDIVIDUAL INTERVIEWS** were conducted with the Leadership of our COF Domestic Violence, Sexual Assault and Disability Service Agencies. These interviews allowed the ACT Collaborative to look at the overall capacity of the individual agencies, while benefiting from the many years of experience these leaders bring to the fields of sexual assault, domestic violence and disability advocacy. These individuals have the unique perspective of understanding their agency’s current role within the larger service delivery system while being able to speak to their agency’s capacity for change. Participation in these one hour face-to-face interviews was solicited by phone and email. The interview took place at the interviewee’s home agency and was conducted by both an interviewer and a second individual who served as note taker. All interview participants signed a consent waiver which outlined both the benefits and risks of participation; the consent waiver also made clear the option to discontinue the interview at any time. Interviewees were not compensated for their participation in the hour-long interview. All written notes from these interviews are scheduled to be destroyed upon approval of this report. *A copy of the consent waiver and the actual interview questions can be found in Appendix A.*

In addition to interviewing all eight executive directors of our COF agencies, we were fortunate also to be able to recruit additional leadership from several of our agencies,

including an Assistant Executive Director from a disability agency, Director of Policy from the sexual assault agency, and the President of the Board of Directors of a disability agency.

Table 1 summarizes the dates and number of participants for the Leadership Interviews.

Table 1. Leadership Interviews		
DATE	Participants	# of Participants
9/12/08	Executive Director – Disability Agency	1
9/24/08	Executive Director - Domestic Violence Agency	1
10/14/08	Executive Director – Sexual Assault Agency	1
10/22/08	Director of Policy – Sexual Assault Agency	1
10/27/08	Executive Director – Disability Agency	1
10/28/08	Program Director – Disability Agency	1
10/29/08	Executive Director & Assistant Executive Director – Disability Agency	2
11/6/08	Executive Director – Domestic Violence Agency	1
11/6/08	Executive Director – Disability Agency	1
11/7/08	President of the Board of Directors – Disability Agency	1
TOTAL LEADERSHIP INTERVIEW PARTICIPANTS		11

II. **OPEN SPACE TECHNOLOGY** was utilized for Clinical, Direct Support Professional Staff, and Paid and Volunteer Advocates in our disability, domestic violence and sexual assault agencies. Open Space Technology is a variation of a traditional focus group, and a way to format a group conversation that generates communication, collaboration, innovation and other solutions to challenges and transitions.

Before Open Space participants began answering questions the group was given an overview of the grant and the goals of the needs assessment process. Then the group was led in generating “ground rules” for the time they would be spending in the session, including rules of mutual respect and maintaining confidentiality of what is said in the room. The participants for each Open Space Technology session were then broken up into “pods”; pods contained 5 – 8 people. Each pod had its own table and Recorder. The Recorder’s role was to guide the conversation and graphically record answers to the questions. The pod Recorder stated each question one at a time and documented responses on flip charts at each table. The flip chart notes are also scheduled to be destroyed upon approval of this report. *A copy of the Open Space Technology questions can be found in Appendix A.*

After all questions were asked and answered the entire group was re-convened, not as a formal reporting-out period (as everything is already graphically recorded on the flip charts), but to share interesting discoveries, new possibilities and key learnings. Participants listened as everyone is asked whether this process has helped them solidify their understanding of issues or has allowed them to change to a new perspective.

Recruitment for the Open Space was done by assisting the Communities of Focus (COFs) agencies identify a hierarchy of staff to participate in the Open Space sessions. The agencies in our Communities of Focus facilitated the recruitment of both their paid and volunteer staff to participate in the Open Space Technology process. The Open Space sessions were scheduled for two-hour time blocks and were conducted by ACT Collaborative members and a paid facilitator. Each of the eight COF agencies committed to allow work time and space for their staff to participate in Open Space. Light refreshments were served throughout the duration of the conversations, and attendees were not further compensated for their participation.

Table 2 summarizes the dates and number of participants for the Open Space Technology Groups.

Table 2. Open Space Technology Groups		
DATE	Agency/Participants	# of Participants
8/20/08	Disability Agency Direct Service Providers	7
9/9/08	Disability Agency Direct Service Providers	21
9/10/08	Domestic Violence Agency Service Providers	5
9/10/08	Disability Agency Direct Service Providers	5
9/19/08	Domestic Violence Agency Service Providers	7
10/23/08	Sexual Assault Agency Service Providers	17
10/24/08	Disability Agency Direct Service Providers	16
11/5/08	Disability Agency Direct Service Providers	24
TOTAL OPEN SPACE PARTICIPANTS		102

III. **CAFÉ CONVERSATIONS** were utilized in talking with Individuals with Developmental and Cognitive Disabilities who receive services in our COFs. The Café Conversation Process is a reasonable accommodation in itself and is an accessible and hospitable format for group discussion.

According to www.TheWorldCafe.com: Café Conversations focus on the future not the past and focus on how we can make things better rather than dwelling on things we cannot change, or past events that cannot be undone.

The Café Conversations were scheduled for two-hour time blocks – including a meal – and were facilitated by ACT Collaborative members, Ken Renaud (PAL) and Deanne Gagne (Advocates in Action). The ACT Collaborative created a space that was welcoming and non-threatening. The “Café” was set-up with small tables, table cloths, menus, flowers, and a “grab bag” of goodies – including a \$10 gift card. The Facilitator led the participants in the creation of “ground rules” for the conversation – rules that will make people feel safe and made clear the expectations for mutual respect in the exchange of ideas.

A light meal was served prior to beginning our conversation. Counselors and Volunteer Advocates were on site before, during and after our Café to assist those who would like someone to talk to and to provide resources if necessary. The Café started with a fun ice-breaker. The Facilitator then helped the group explore questions that will ultimately improve access to community services for individuals with developmental and cognitive disabilities. *A copy of the Café Conversation questions can be found in Appendix A.* A Graphic Recorder documented our conversation on charts posted in the front of the room. The Recorder then reviewed the notes with the group to ensure accuracy of the captured conversation. The Facilitator encouraged participants to share ideas and perspectives, and honored those who were active listeners.

Recruitment for the Café Conversations was done by assisting the Self-Advocacy Groups, affiliated with our COF agencies, to invite both members and others who receive supports to participate in the Café Conversation. Staff at COF agencies assisted the Self-Advocates in extending this invitation. The location was selected in consultation with the community agencies that provide support, and spaces familiar and accessible to our Café Conversation participants were utilized.

Table 3 summarizes the dates and number of participants for the Café Conversation Groups.

Table 3. Café Conversations		
DATE	Participants	# of Participants
9/11/08	Women with Cognitive & Developmental Disabilities	9
9/18/08	Women with Cognitive & Developmental Disabilities	15
10/8/08	Women with Cognitive & Developmental Disabilities	6
10/28/08	Women with Cognitive & Developmental Disabilities	8
TOTAL CAFÉ CONVERSATION PARTICIPANTS		38

SUMMARY OF KEY FINDINGS

It was our goal to paint a picture of survivors' experiences with navigating the current service delivery system, uncover the unmet needs of both survivors and the agencies that are trying to help them, and identify community strengths, best practice approaches and resources available within our Communities of Focus. The ACT Collaborative held 22 conversations with 151 individuals across two communities to uncover the possibilities and needs for individuals and agencies. What follows is a summary of the themes and key issues that emerged from these conversations organized around four primary areas of focus.

I. BUILDING ON A FOUNDATION OF STRENGTHS AND POSSIBILITIES

One of the primary “non-negotiables” guiding the work of the ACT Collaborative is to focus primarily on the possibilities, and not just on the deficits, within the service provider system. Throughout the Needs & Strengths Assessment Process the Collaborative guided the Communities of Focus in conversation around uncovering what the existing strengths, best practices and possibilities are that exist in our COFs for a person-centered, cross-discipline response to abuse. It was discovered that across the two communities three foundations of strength and possibility already exist:

1. **People appreciated and were open to the invitation to discuss abuse and its responses.** Overwhelmingly there was a sense of willingness (and excitement) on the part of the individuals and agencies in our Communities of Focus to collaborate and learn from each other. It is clear that there is an eagerness to learn how to serve individuals with disabilities better, and that agencies want to collaborate, not just in times of crisis, but as an on-going part of their work. The ACT Collaborative received positive feedback regarding the various methodologies employed during the Needs Assessment process. What was clear is that positive feedback really centered on the opportunity these conversations gave people to really dissect the issues, and work towards solutions. Many seemed very grateful to step away from the day-to-day work that they do to really grapple with the issue of improving services for individuals with disabilities who have experienced abuse. One Disability Direct Support Professional (DDSP) stated, “*We so rarely get an opportunity like this to really focus in on a topic that matters away from our day-to-day obligations.*” Most welcomed the opportunity to engage more frequently in these types of forums which asked them for their opinions and expertise, and allowed them to learn from others. The participants were asked to say ONE WORD³ that

³ As a means of evaluating the Open Space Technology process all participants were asked to give ONE WORD to summarize their experience with the methodology. The ACT Collaborative is happy to report that the responses were overwhelmingly positive and the words mentioned included: Alarming; Awareness; Awesome; Beginning;

summarized their experience with the Open Space Technology event. This question allowed the ACT Collaborative to evaluate the effectiveness of the Open Space process and whether it could be used as a tool during the Implementation Phase of this grant initiative. One sexual assault advocate said, *“Meeting like this is such a great start; I already have so much to think about and information I can use.”* Upon leaving one of our Café Conversations, one woman said, *“We loved this – let’s do this again!”*

- 2. All COF agencies are actively working toward a person-first approach to their service delivery; expressing a desire to meet the individual “where they are”.** One disability agency Executive Director summed it up by saying, *“we see the people we support as human beings with their own lives; they are in the driver’s seat; we are just along for the ride!”* One of the primary goals for the ACT Collaborative is to build community relationships and valued roles for individuals who have experienced violence in an effort to keep them safe in the future. The same Executive Director also stated, *“The people who are the safest in the world are women with DD who have relationships with people who are not paid staff.”* Another disability Executive Director summed it up, *“relationship building with and for the people we support is the key to our program’s success.”*

It is important for agencies to see and look for the underlying needs, desires and hopes of the people they support and merely be a conduit to their ability to achieve them. A woman we spoke to who receives services at one of the disability agencies stated, *“I like it here. Staff give me good advice, I feel safe with them. They listen to me.”*

Domestic Violence and Sexual Assault agencies also share this desire to provide person-centered support in an inclusive way. The Executive Director of a domestic violence agency stressed that *“all of our work is person-centered; safety plans are individually tailored – the nature of the work makes it person-centered.”* A domestic violence advocate stated, *“we don’t ever turn anyone away – we don’t ever say, ‘we can’t help you’.”* In the same focus group with domestic violence advocates a participant also stated:

When we don’t know the answer – we try to process as a group to best serve the individual; we are motivated by the empowerment model and try to focus on an individual’s strengths and

Brainstorming; Challenges; Collaboration; Connections; Educational; Electrifying; Empowering; Energizing; Enlightening; Enriching; Entertaining; Evolving; Excellent; Exciting; Eye-opening; Healthy; Hopeful; Important; Informative; Inspiring; Interesting; Meaningful; Motivating; Necessary; Now; Patience; People; Possibilities; Powerful; Promising; Proud; Realization; Reassuring; Recognition; Relief; Rewarding; Safety; Thoughtful; Together

wants. I know we always ask, 'what can we do for you today?' and let the individual lead us where she needs to go.

One sexual assault advocate shared, *"We have a willingness and commitment to serve regardless of the ability to pay – we've stuck with this mission having to make difficult decisions to do so."*

- 3. A state-wide incident management model for responding to abuse in the developmental disability agencies already exists, but there is a disconnect between this policy and actual practice.** All disability agencies indicated that policies and procedures are already in place to respond to abuse, but it was very unclear as to how well-known or available these policies are to all levels of staff, families and the individuals themselves. One DDSP stated,

Oh, we do have the state response policy; everyone learns about it during orientation. Though now I'm not really sure everyone knows about it. We don't really have a mechanism to distribute information like that to line staff – at least it's not formalized. I guess we get information in staff meetings.

In 2000 a "Sexual Assault Incident Management Model: A Statewide System for Responding to Allegations of Sexual Assault" was jointly created by the Office of Quality Assurance (QA) of the Division of Developmental Disabilities (DDD) – the state's mandated reporting agency, Day One (then the Sexual Assault & Trauma Resource Center) and several of the community provider agencies, including three agencies in our COFs. This model was adopted and endorsed by QA as the procedure to use in the community provider agencies. The model outlined a process for providing immediate support to the victim; minimizing the number of times a victim has to be interviewed; identifying QA as a single point of contact; how to obtain minimal facts; and utilizing the forensic interviewing services of the Children's Advocacy Center (housed at Day One). But as one sexual assault advocate noted, *"we certainly are not getting consistent referrals here."* There seems to be a disconnect between this mandated approach and the actual adherence to it. One reason could be because of recent changes in the QA office, as one DDSP noted, *"We were left to our own devices because of all of the retirements at QA; we were told to handle our own investigations. QA was really our link to Day One."* Constant turn-over at the disability provider agencies may also be a factor. One disability agency Executive Director shared, *"there is a continuous need for response training for staff because of turn-over."*

Some work needs to be done to evaluate the effectiveness of the model and whether it still serves the community well in light of recent changes at Quality

Assurance. The core of what the model provides is certainly being embraced by one disability agency Executive Director, *“we embrace our imperfections through incident management. We look at our mistakes to figure them out and engage in conversation. We owe it to the people we serve to look at our practices.”* One DDSP though did express concern that *“sometimes the model really just does ‘to the victim’ rather than work ‘with the victim;’ the response seems to be for the agency, not the person.”*

II. ACCESSING ADVOCACY AND SAFETY-PLANNING SERVICES

While it seemed apparent that agencies were willing to assist individuals with disabilities who have experienced abuse, and the statistics and anecdotal information received in our conversations indicate that the incidence for abuse in this population is high – it is clear that women are not coming to the attention of abuse response agencies. Our conversations within the Communities of Focus sought to uncover the barriers survivors with developmental and cognitive disabilities face when trying to access community provider response, advocacy and safety-planning services.

1. **Domestic Violence and Sexual Assault agencies report that women with disabilities are not coming to their agencies.** The domestic violence and sexual assault agencies reported that they really are not seeing a *“critical mass”* of individuals with developmental and cognitive disabilities requesting their services. The thinking around possibilities for why this is the case centered on whether these agencies are *“welcoming enough,”* or if individuals with DD even understand when these services may be needed. One member of leadership at the sexual assault agency considered these possibilities:

I think there is a lack of understanding about our willingness to work with the DD population, or just not even knowing our services exist. There may even be a lack of understanding that they even need our services, not realizing what has happened is an assault. I have to wonder if we have a welcoming environment even with a brand new, physically accessible building.

A sexual assault advocate hypothesized: *“There is an attitude in the community that women with DD do not really understand what happened to them, that they may not need the same services as others.”* One domestic violence advocate offered a possibility, *“I know we could work with DD agencies to figure out safety planning together; we have a lot to offer.”*

2. **Individuals with cognitive disabilities feel they are not believed when they disclose abuse, or may feel it is their fault.** From both the Direct Support Professionals and from women with disabilities themselves we heard time and time again that there is an assumed lack of credibility for individuals with cognitive

disabilities. This assumption is both a risk factor for abuse and a barrier to receiving appropriate services. One woman in a Café Conversation said, *“Just because people have a disability doesn’t mean they are lying about abuse! Why would someone think that!?”* The women in our Cafés had a lot to share about how they don’t want staff to react when they disclose. One said, *“I try to tell my staff things and sometimes they give me a weird look like they want me to be quiet, or they don’t look me in the eyes.”* Another woman said, *“I hate when my staff ignore me or don’t believe me. They get mad or they use their computers while I’m talking.”* In one Café a woman very clearly gave instructions for the staff at her agency, *“Don’t ask me questions that make me feel it is my fault or that I did something wrong.”*

The sexual assault agency Executive Director shared, *“My fear is that the response has been ineffective every place before – even if they manage to get to our door they may think no one will believe them.”* A staff member from the sexual assault agency shared a story: *“I had one client who certainly felt it was her fault that the staff person got fired; she didn’t understand that he was the one in the wrong.”*

One of the disability agency Executive Directors hypothesized, *“There is a complete range of reasons why people don’t reach out. They may want to protect the perpetrator and the ‘relationship’. The situation may have started out one way and ended up somewhere else, and they may feel responsible.”*

- 3. Individuals with cognitive disabilities have difficulty participating in “traditional” counseling and safety planning services currently available at Domestic Violence and Sexual Assault agencies.** Many service providers identified difficulties in communication as a barrier to getting a clear disclosure or in an individual’s ability to access “traditional” sexual assault and domestic violence services such as support groups or one-on-one counseling. One sexual assault advocate expressed her concern, *“Our staffs are not specifically trained to work with people at all levels of cognitive functioning, especially if they are not amenable to the traditional therapeutic processes we use here.”* Many of the individuals that the disability agencies in our COFs support are non-verbal or have limited verbal skills. On domestic violence advocate asked:

We often use a peer counseling model – and I don’t know how someone with a cognitive disability or someone who is non-verbal would be integrated into that model with other survivors – would they get anything positive and beneficial from that experience?

The sexual assault and domestic violence agencies indicated that facilitators and survivors in their current support groups may be uncomfortable or unaware of

how to respond to a woman with a disability as part of their group. One of the domestic violence agency Executive Directors lamented:

We do what we can when (women with DD) come in for services and then refer out; we do not have a plan for (women with DD). We can provide safety, but if we can't move a woman into one of our other programs, then it is very challenging to get a person where they need to be.

One DDSPP offered a suggestion and a challenge for how it might be best to deliver services, “*Can someone come to the individual? Do they have to go to the service agency? People want to be in a comfortable, familiar place – can agencies accommodate that?*” A disability agency Executive Director echoed a similar sentiment:

There is not enough counseling for people with these issues; how do we integrate or complement counseling into our existing services and carry over therapy into everyday services in our group homes? The people we support are used to and like routine; disruption of that routine can be traumatic in itself.

4. **There are VERY few clinicians in RI with experience in both trauma counseling and disability issues, and many feel uncomfortable and unsure working at the intersection of violence and disability.** It was echoed over and over in all of our discussions with advocates and DDSPPs – there just aren’t enough counseling options in RI. One sexual assault advocate is very concerned: “*I have one person in the state on my referral list that is able to do this work; I need more options because we don’t have enough clinical staff here period, never mind clinicians with that expertise.*” One clinician at the sexual assault agency did offer this: “*We need to know what kind of treatments might be helpful, what are the alternatives to cognitive therapy? I think we are certainly willing, we just don’t know how.*” A DDSPP offered the “solution” they are using, “*Our clinical staff doesn’t necessarily have a deep understanding of trauma issues, but at least they know how to work with the consumers at our agency.*”
5. **There is a concerning lack of education for individuals with cognitive disabilities around healthy relationships, anatomy and health, appropriate boundaries, recognizing abuse, and available resources.** Many DDSPPs indicated that individuals with disabilities may question whether what happened to them was “good” or “bad” – and not know it is a reportable incident. Often there is a “*normalization*” of sexual abuse where abuse may be the first, primary, or only sexual experience for an individual. One DDSPP clarified, “*I really fear that there is a ‘normalization’ of sexual abuse for some of the people we support; I don’t know if they have ever been explicitly taught what is not okay.*” Another DDSPP stated:

Women with disabilities need earlier education intervention because we always feel like we are in crisis/response mode. There needs to be an open dialogue with a lot of the woman we support so they understand personal safety and reinforce their rights.

It is vital to give individuals with disabilities the language they need to report both positive and negative occurrences in their lives, and to understand the differences between sexual intimacy and sexual assault. A DDSP declared, *“We could make the individuals we support so much more powerful (with this information); they are so vulnerable without it.”*

One woman in our Café offered, *“Staff could warn me about touching and talking to others and to stay away from people I don’t trust.”* This was an idea that several other Café participants agreed with wholeheartedly.

6. **Individuals with disabilities need to know that they will not get in trouble for disclosing abuse, and that they will be safe after they tell.** Women with disabilities perceive “consequences” for disclosing abuse. Sometimes staff imposes restrictive safety measures if it is determined that the abuse occurred because the individual cannot keep herself safe. In the balancing of dignity of risk versus safety, staff often errs on the side of safety. Individuals with disabilities feel that staff should review when these “consequences” or loss of privileges that are imposed (like not being able to be in the community unsupervised; or not being allowed to live in an independent apartment) can be dropped, or the staff should provide the individuals with education on how to be aware of abuse. Individuals with disabilities need to know that they will not get in trouble for disclosing abuse, and that they will be safe after they tell. One Café participant pointed out, *“People in everyday life make mistakes all the time but don’t have the same consequences as us.”* Another woman in our Cafés offered this advice, *“Encourage me to talk about it and to let it out; tell me it is OK.”* One of the disability agency Executive Directors noted, *“Some people really don’t understand what has happened. They are so afraid to get staff in trouble and that then they’ll get in trouble.”*
7. **When abuse happens there are very few options for emergency or alternative long-term housing placement, and domestic violence shelters are not being utilized by women with cognitive disabilities; the survivor is often left out of this decision-making process altogether.** There was a lot of discussion about how difficult it is to move someone from a community agency placement into a different living arrangement. One of the sexual assault advocates complained, *“If someone doesn’t feel safe in a group home it takes so much red tape to move them, if it is even possible at all.”* A DDSP agreed, *“It’s like trying to move a mountain.”*

Domestic violence advocates expressed concerns about the appropriateness of shelter services. One Executive Director stated, *“There have been cases where we have taken women with DD into the shelter and then found out they needed more than we can give.”* One of the domestic violence advocates shared, *“I can only remember one situation where a woman (with DD) came to the shelter. We were able to have her and her staff support person stay here. If they come to our door, we try to work with them the best we can.”*

One Café participant was concerned about a former group home roommate: *“I think something mean happened to my friend and she moved out of our house; I don’t think she likes where she is now – she’s kind of sad.”*

One of the disability agency Executive Directors offered a hopeful direction:

There is currently no established system to provide respite in emergency situations, but I know that there are options and they need to be shared and cultivated. We need teamwork and resource sharing to advocate for ‘safe homes’ for people.

8. **Disability agencies are often faced with the challenge of supporting both the victim and the perpetrator.** A challenging situation identified by service providers is when an individual is assaulted by another individual with a disability; there are many occasions when the disability agency is supporting both the victim and the perpetrator and in many cases both are residing within the same group home. One disability agency Executive Director stated, *“Our reality is that we have to support the perpetrators as well; they need our services too.”* From July 2007 – June 2008, 52% of the calls received by the Division of Developmental Disabilities Office of Quality Assurance – the state’s mandated reporting agency – were of sexual assaults perpetrated “consumer to consumer”. In these cases the major barrier is in finding alternate housing arrangements for either the victim or perpetrator, and as previously stated – often there are no options for immediate respite or long-term living available. A sexual assault advocate offered an additional concern, *“I know of several situations where the offender wasn’t held accountable or even really educated, because of his disability.”*
9. **Direct Support Professionals at Disability Provider Agencies report that families exhibit attitudinal barriers which prohibit individuals with cognitive disabilities from accessing services.** Navigating the reaction of the individual’s family post-incident is challenging. In some cases lack of education for the family, or the family’s reaction is a barrier to the individual receiving appropriate services. Many families *“do not want to deal”* with the idea of abuse, according to one DDSP, or that the family decides for the individual with a disability whether services are necessary. One sexual assault advocate recounted,

“When I’ve worked with victims with DD, I feel that the guardian makes all of the decisions. It is important to listen to the client.”

One of the disability agency Executive Directors confided, *“Orienting families has probably not been a strength of ours.”* One of the DDSPs stated, *“We need to educate families, but we certainly don’t want to scare them in orientation.”*

Another disability agency Executive Director identified a particular scenario where she had faced some barriers: *“We have some challenges working with older parents with different beliefs about their children even engaging in relationships in the first place.”*

A domestic violence agency staff member recognized the importance of engaging families: *“We definitely need training on how, when and if to work with families and other networks of support; they could be important allies in safety planning.”*

III. UNDERSTANDING ENTRY INTO THE RESPONSE SYSTEM THROUGH OUTREACH, REFERRAL & COLLABORATION

The Needs & Strengths Assessment sought to uncover positive collaboration already taking place, the system gaps preventing a cohesive network of response and referral, and what women with disabilities wanted most from the response system. Our conversations within the Communities of Focus attempted to uncover the entry points, if any, into the violence response system for individuals with developmental and cognitive disabilities, and how can we improve access to these entry points.

- 1. Most Disability Agencies report that there is an immediate, internal response and investigation when an individual discloses, or when abuse is discovered, but referrals are not often made to Domestic Violence/Sexual Assault Agencies.** One of the DDSPs we spoke to was adamant: *“Any disclosure becomes an agency-wide priority.”* The participants in our focus groups tried to be as open and thoughtful as possible to explain why referrals were not happening. One reason was just not knowing the services that exist at DV and SA agencies. However many of the explanations seemed to point towards a distrust of out-of-agency referrals; whether this was based on previous negative experiences was unclear. One DDSP stated:

People (DDSPs) feel like they don’t necessarily have the skills to do the (trauma) work, yet I think maybe we don’t refer out because of fear of the unknown; no idea of what the outside systems are doing – what is going to happen to the person we support?

Another DDSPP stated, *“We know OUR system, but it is difficult to track the people we support in other systems.”* Yet another DDSPP stated her criteria for referrals: *“A response agency should have knowledge of our (DD) system before they can be a referral.”* Finally one disability agency Executive Director was very clear on what her agency has decided to do: *“Developing our own internal resources is the best idea. We have our own psychologists on staff here.”*

- 2. Disability Agencies investigate themselves in abuse cases.** This finding emerged in the discussion of the state’s Incident Management Model. The model was set-up so that the state’s mandated reporting agency would serve as a single point of contact and facilitate the investigation. The current “state of the state” in RI has forced many state employees to take early retirement or lose their pensions and health coverage. This statewide issue also affected the once sizable staff at the Division of Developmental Disabilities – Office of Quality Assurance (DDD QA). This fact led one disability agency Executive Director to point out, *“We do our own in-house investigations. DDD QA used to do a lot of them but they are very short staffed, all of their investigators have retired.”* Another Executive Director confirmed, *“In our agency we do our own investigations,”* but she also shared the need to have objectivity for this process stating, *“We need third party advocacy, have the victim sit with someone who is not part of the agency.”*

The same Executive Director shared how those investigations usually end: *“We have had accusations that were unfounded, we work with those situations the most. Sometimes people just don’t have the language to communicate with us.”*

One DDSPP shared, *“Obviously once we know that what has happened is of the criminal nature, we involve DDD QA and the police, though police don’t always know how to best approach these cases and talk to people with disabilities.”*

- 3. The system is perceived to be overloaded and overwhelmed with too few agencies able to provide needed abuse-specific response services.** Both the disability advocacy and violence response systems are a *“mystery to folks outside looking in,”* according to one DDSPP. Several Open Space participants described the current referral system as *“trial and error; sometimes you reach someone by phone who knows what to do with the information you are providing, sometimes you don’t.”* One of the DDSPPs stated:

The referral system is complete hit or miss. It can take a month or more to find appropriate support services for someone – it doesn’t matter where I call – mental health agencies, the rape crisis center, whatever. Everyone’s hands are tied; I know they are frustrated too.

For the population of individuals with cognitive disabilities – the disclosure often takes place at the disability support agency rather than the sexual assault or domestic violence agency. When referrals are made across disciplines there is often very little follow-up. One domestic violence agency Executive Director shared, *“Historically when we’ve made referrals to the sexual assault agency there hasn’t been a prompt response; the waiting lists were long. It’s frustrating for both agencies.”* Another Executive Director stated, *“In most cases we need to refer out; we are not specialists and we already have very limited resources.”*

The sexual assault agency Director did point towards a solution, *“we are always looking for ways to do our jobs better, but as resources become scarcer in this state – we need to be better at collaborative advocacy.”* One of the sexual assault staff members offered another need, *“These cases need a lot more time and a person to coordinate all of the involved service providers.”*

- 4. Domestic Violence, Sexual Assault and Disability Agencies tend to work in isolation with little knowledge about services provided at other agencies or the protocols other agencies are mandated to follow in abuse cases.** There is recognition that resources in general are very scarce in the state of RI, and overall the individuals and agencies participating in these conversations want to work together across disciplines to help each other offer *“safe harbor”* to the people they support and make the best use of our collective resources. A domestic violence agency Executive Director declared, *“We have to rely on shared resources, now more than ever.”*

The agencies in our Communities of Focus also want to expand the collaboration to include other stakeholders in the community including mental health providers, police, medical professionals, and most importantly, the Division of Developmental Disabilities (DDD) – RI’s mandated reporting agency. However to do so would require overcoming years of working in isolation. One DDSP stated, *“We really need to be better at navigating turf issues; there are a lot of those in RI. We need to bust people out of their silos.”* A sexual assault advocate asked, *“How do we provide the framework to bring people together and get folks out of their boxes?”* A member of leadership at the sexual assault agency stated, *“We don’t always need to own the issue to work with it; it’s so necessary to have another perspective.”* A sexual assault agency staff member declared:

We need to improve our network of services. We do not overlap services enough; in RI too many agencies are not connected to each other that should be. We are all reinventing the wheel.

These sentiments were echoed in many other conversations. A disability agency Director said, *“We would love a forum that normalizes the collaborative environment.”* One DDSP asked:

Why do we only collaborate (with SA and DV agencies) during times of crisis?! The crisis would be a lot easier to navigate if we’d been working together all along. I don’t want the first time I call Day One to have to be during a crisis. I should know what kind of response I’m going to get before I even pick up the phone; the person I support doesn’t have time for me and them to be unsure.

A disability agency Executive Director agreed, *“We need to know what resources are available BEFORE the crisis happens,”* but many of the participants were unsure where to find those resources or how to tell others about what they have to offer. A domestic violence advocate stated, *“We don’t know where to refer or who to talk to so that they can refer to us.”* One of the domestic violence Directors declared, *“I had no idea there were so many community agencies working with people (with DD) – we would love to have a resource guide about other available resources and to make appropriate referrals.”* Realizing that if she didn’t know those agencies were in her community she then asked, *“Would those disability agencies even know to call us? I guess we need to make sure they know we are here.”* One of the disability agency Directors echoed the idea of a resource guide, *“I know there must be a lot of options – but what are they? We internally need a more comprehensive menu of resources for outreach and referral.”*

Some of our conversation participants spoke about policy and inquired about creating a network of response, so no one agency has to *“go it alone.”* A disability agency Director stated, *“Policy should not be cloaked in secret – other agencies and everyone in our own agency should know what they are from the executive director to the people we support.”* A sexual assault advocate inquired, *“If there is a sexual assault at a disability agency – does their policy require them to call us? Do they know we can help?”*

- 5. Individuals with disabilities and the staff that support them do not know about the services available at Domestic Violence and Sexual Assault Agencies or how to access them.** It is clear that more outreach on the part of the violence response system is needed, and women with disabilities need access to universally designed materials and resource information. One Café participant asked, *“Do you think the agencies that help people could visit us and tell us what type of organization they are and what they can do to help and make it better?”* Another Café participant said, *“Just give us their phone number – we can call them!”* Another Café attendee seemed to be inquiring about the confidential nature of services by asking, *“Can anyone call? Do I have to tell them my name?”*

The sexual assault director asked, “How can we do a better job at advertising our services? What kind of outreach would work? How will they know they are welcome?” A sexual assault staff agency member declared, “We need to get out there and explain what we do.”

One DDSF offered a helpful suggestion:

We use a lot of graphics for communication – that is a major component of our program. We could give the (DV & SA) agencies some good tips on how to use a similar approach.

- 6. Women with cognitive disabilities do not have an option of their entry point into the abuse-response system.** If there is a designated “investigator” at the disability agency – the individual often cannot disclose/speak to the person of her choosing. If the disability direct support professional (DSF) with whom the individual with a disability feels most comfortable and would prefer to disclose to is not the investigator - that often greatly affects the support that DSF can give during the investigation and follow-up process. The women who took part in our Café Conversations were very clear that staff “*does NOT have to tell everyone,*” and that while they understand mandated reporting in RI, they should be able to choose who knows beyond that mandated reporter. One Café participant made it very clear: “*I want to choose who should know; I want to talk about it in my own time, when I’m ready.*” Another Café respondent said, “*I want a choice of whether I talk to a man or a woman.*”

One DSF responded “*I think having a designated agency reporter does take away choices from the individual.*” Another shared:

As part of our protocol as soon as someone discloses to us we have to tell them we have to call DDD QA and I have to tell my supervisor or the (Executive Director); if it is a sexual assault – we have to take them to the hospital if we are directed to do so. All of a sudden – that’s a lot of people who know.

The women in our Cafés certainly understood that confidentiality seems to be difficult in the agency setting leading one woman to state, “*You really should try looking for help on your own before going to (the support agency) – because then everyone will know.*” In fact the women often felt left out of the decisions altogether. One woman said, “*I want to be in the room for meetings about me! Try getting the problems solved by talking to me.*”

It might point back to the disconnect between the state incident management model and its actual practice, but some DSFs did seem unsure of how many

people needed to know. One DDSP asked, *“Well if something happens, I have to call the family – don’t I?”*

- 7. Women with disabilities often disclose to each other; they want to be a resource for each other and for the service provider agencies.** In some instances the women in our Cafés felt they would be more comfortable disclosing to another individual with a disability. One woman stated, *“My friends can tell staff if I can’t tell them.”* Another woman shared, *“Sometimes it is better to talk to another (person with a disability). They can give advice and listen and they won’t talk down to you.”*

Women with disabilities indicated that they would like more opportunities to gather and talk to other individuals with disabilities and provide peer support and advice to each other. One Café participant offered, *“I could teach other people (with DD) that it is not okay for people to hurt you.”* A disability agency Executive Director concurred, *“I think support groups are enormously helpful for people in this situation; they can be a great comfort to each other.”*

Women with disabilities would also like to be a resource for direct support professionals and violence response agencies. They would like the opportunity to educate professionals about their needs and ideas. Several agencies were clearly already using this approach; one disability agency director shared, *“we ask the people we support what they want to learn, and they tell us!”* The same Executive Director stated, *“We have many clients here who are incredibly bright; one client in particular is very involved in our trainings.”* Another Executive Director stated:

Change happens in a lot of different ways here, but my favorite way is when the people we support here say, ‘change it!’ That’s the most powerful way – when they just say to us, ‘what is wrong with you people?’

A DDSP offered another opportunity: *“I think staff would certainly be enlightened and benefit from experiencing education with the people they support.”*

IV. STRENGTHENING CAPACITY AND SKILLS

Our Needs & Strengths Assessment was an opportunity to get to the specifics of what people within the system wanted to learn, and what capacities, skills and competencies need to be nurtured in agencies and staff who work with individuals with developmental and cognitive disabilities who have survived abuse. All COF agencies utilize in-service trainings, and orientations are well-integrated into the way agencies function, and there is great opportunity to introduce abuse- and disability-specific topics into these curricula and create new policies and procedures.

1. **Sexual Assault/Domestic Violence providers lack knowledge about the intersection of disability and violence and have little experience working with individuals with disabilities.** Most SA/DV advocates are completely unaware of what it means for an individual with a developmental or cognitive disability to “receive support” from a community disability agency and what their day-to-day lives look like. At an even more basic level, one domestic violence agency staff member asked, *“I hear the term all the time, but what does it really mean to have a developmental disability?”*

One domestic violence agency Director expressed confidence in her staff’s ability and capacity to work with individuals with DD, but the conversation with her staff revealed that they are not at all confident in their abilities. One domestic violence advocate stated, *“I don’t have enough experience with DD – how would I know if the person’s behavior is due to PTSD or DD?”* Another DV advocate suggested, *“We need practice; we’ve had so little exposure to the disability community.”* The Executive Director did acknowledge that it is *“a real barrier for us not having an ‘expert’ on staff.”* Another domestic violence Director stated, *“We have never really worked with the (DD) population; my staff really needs a basic understanding of disability issues.”*

The sexual assault agency director declared, *“As an agency, we are in a good position to learn what we need to know and hear what we are doing wrong,”* but that *“we don’t even know what we don’t know about the DD community.”*

One disability agency Director offered a working solution, *“We have skills we can share with SA & DV agencies such as what are the best practices for working with individuals with DD.”*

2. **Disability providers lack knowledge of the dynamics of sexual and domestic violence, the definitions of abuse, and the effects and symptom manifestation of abuse.** One DDSPP summed up this finding by stating, *“We ask ourselves all the time – are we hitting the mark in responding to abuse? Do we do enough? Do we know enough to be effective?”*

Many of the DDSPPs and disability agency Executive Directors we spoke to want to make “zero tolerance” for abuse an integral part of the way they run their agencies. These agencies would like support in integrating abuse awareness in all aspects of the agency including hiring procedures, orientation and workplace policies; they want to help eliminate the taboo nature of the subject. One DDSPP stated, *“There just needs to be a saturation of information so that we can eliminate the taboo nature of this topic.”* Another stated, *“I knew the numbers were bad, but all of our staff really need to know just how prevalent this may be for the people supported.”*

Several of our focus group participants pointed towards positive capacity building across disciplines. One DDSP said, *“We have abuse awareness trainings for our staff, and we think they are well constructed, but maybe we should be reaching out to the crisis centers to help us create our trainings?”* The sexual assault agency Director stated, *“We need to find a way to share our expertise on sexual assault with people in the (DD) field so that they have knowledge of trauma issues.”*

- 3. Direct Support Professionals at Disability Agencies (DDSPs) are challenged with balancing “dignity of risk” versus “safety” for the individuals they support.** DDSPs report that it is a challenge to allow space for the people they support to make their own decisions, when they have to be concerned about their safety as well. One DDSP said, *“There is no question in this agency that staff, family and individual intent is that safety is first,”* but that *“we need to be so careful about forcing our choices on the people we support, but we are so fearful that they could be hurt; we constantly worry about that.”*

One disability agency Director described a situation with which they had to work:

We work with women in group homes and family homes. One client put herself in a very unsafe situation; she was very attractive and invited men to come over and visit her all the time. We advised her to move and she finally did.

The key seems to be to find the balance between securing safety and providing informed consent for the individuals they support. One woman in our Café suggested, *“My staff could help me make the best decisions.”*

- 4. Domestic Violence and Sexual Assault advocates and clinicians need assistance in improving their communication skills to work with women who use “non-traditional” means of communication.** One DDSP explained, *“The reality is that most of the women I support in the group home are non-verbal or are limited verbally. Really, what can the crisis centers really do for them?”* A disability agency Executive Director concurred, *“There is never enough of this training. We have to ensure that assistance is available with specialized knowledge with the non-verbal population; we know they are most vulnerable.”*
- 5. Disability Direct Support Professionals indicated they need more skills in how to appropriately handle a disclosure, both in terms of being a caring listener and following the correct protocol.** It is always difficult to determine how a professional will respond in a moment of crisis, but many direct service staff indicated there are ways to better prepare them. One disability agency Director

confided, *“I think the biggest barrier is that front line staffs doubt their ability to respond confidently. Other staff with these abilities are further removed (from the frontline) into management.”*

Other participants really emphasized they wanted to learn skills on how to *“listen better.”* One DDSP said, *“With all that we do in our jobs it is really necessary to have effective listening and communication skills and to really be able to be in the moment and put other stuff aside to really, truly listen.”* The women in our Cafés really stressed that staff need to listen better. One woman said, *“Please listen to me; sometimes I just need you to listen, not to give me advice.”* Another woman was a bit blunter: *“They (staff) piss me off when they don’t listen to me.”* Another Café participant suggested, *“Give me a safe place to talk to you.”*

Many DDSPs expressed a desire to learn how to better validate the experience that is disclosed and to make the person feel heard and supported after a report. The concept of validation was supported by one woman in our Café who said, *“Let us know that what we are feeling is normal.”* Another woman stated, *“Staff can help by telling me it’s going to be OK.”*

Finally, most importantly staffs want information on how to conduct a minimal fact interview (so as to not negatively impact the investigation). One DDSP expressed her concern by saying, *“Abuse doesn’t happen here often enough that I would know what to do or what to ask.”*

- 6. Staffs at Domestic Violence, Sexual Assault and Disability Agencies want consistent, documented response policies on how to respond to abuse, and the opportunity to practice that response.** These policies need to be transparent and readily available (through signage, wallet cards, employee handbooks, etc.). A disability agency Director suggested that *“policies need to be uncomplicated and effective. Simplicity is best.”* A sexual assault advocate pointed out that *“we need to have a process that won’t change if someone (a staff member) leaves the agency.”* Another disability agency Executive Director stated, *“people with disabilities who are victims of violence certainly don’t want their experience to be what trains staff.”*

Providing opportunities for “practice” is a comment that emerged continually in our conversations. On disability agency Director stated, *“Contextual learning is very powerful! We have to set-up some experiences to train staff.”* Another Director shared: *“All of our staff received the specialized training on the Incident Management Model during orientation, but in my years here there have been no reports of sexual abuse, so how to we stay up to date on what to do?”*

7. **Disability Direct Support Professionals indicated that they are unprepared to better educate individuals with disabilities about abuse, abuse prevention and available community resources.** Staff at all agencies wanted to learn how to better educate individuals with disabilities about abuse, abuse prevention and available resources. One Executive Director made a request: *“We could really use some assistance in training, especially about human sexuality and safety.”* One DDSF summed up this finding by encouraging cross-discipline efforts:

Education needs to be done with mixed disciplines; we need to be a real presence in each other’s agencies – only then can we provide informed support to the people here and learn together how to teach them what they need to know.

8. **Rhode Island’s mandatory reporting statute is ambiguous and Domestic Violence, Sexual Assault and Disability advocacy and support professionals do not know to whom it applies.** The RI Duty to Report⁴ is a regulatory statute for the state’s Department of Mental Health, Retardation and Hospitals. Sexual assault and domestic violence advocates are very concerned about the ambiguous language and are truly unsure whether they fall under the requirements of the statute. One domestic violence advocate asked, *“We provide confidential services to our clients. Am I, as an advocate, a mandated reporter? Because I honestly don’t know...”*

Sexual assault staff clearly struggled with this issue as well. One advocate asked, *“how could a victim come to me for help, and then I turn around and tell someone they don’t want to be told!?”* Another staff member expressed how the ambiguity affects her role:

⁴ § 40.1-27-2 **Duty to report.** – (a) Any person within the scope of their employment at a program or in their professional capacity who has knowledge of or reasonable cause to believe that a participant in a program has been abused, mistreated or neglected shall make, within twenty-four (24) hours or by the end of the next business day, a written report to the Director of the Department of Mental Health, Retardation, and Hospitals or his or her designee. The report shall contain: (1) The name, address, telephone number, occupation, and employer's address and the phone number of the person reporting; (2) The name and address of the participant who is believed to be the victim of the abuse, mistreatment, or neglect; (3) The details, observations, and beliefs concerning the incident(s); (4) Any statements regarding the incident made by the participant and to whom they were made; (5) The date, time, and place of the incident; (6) The name of any individual(s) believed to have knowledge of the incident; and (7) The name of any individual(s) believed to have been responsible for the incident. (b) In addition to those persons required to report pursuant to this section, any other person may make a report if that person has reasonable cause to believe that a participant has been abused, mistreated, or neglected.

Mandated reporting is a tricky issue for an agency that prides itself on confidentiality and advocacy for everyone. The staff here needs a better understanding of the duty to report in RI and to whom it applies. I've heard yes it applies to me, and no it doesn't.

One Café participant asked, while the facilitators were going over the ground rules, “So, if I tell you (referring to a SA advocate in the room) something secret – you have to tell someone else?” Many of the individuals with disabilities who receive services from the community provider agencies understand that their staff have “to tell”, but without clarification of who is a mandated reporter in the state (because the assumption by many people is that everyone is a mandated reporter) individuals with disabilities do not feel they have an ally and likely will not disclose. One woman stated, “I don’t want everyone to know; I want to choose who I tell and I want to choose who they tell.”

- 9. DDSPs need an understanding of the effects of violence on individuals with DD/cognitive disabilities** - Disability staff need skills in providing long-term support to an individual with a past abuse history. Specifically, how would staff identify what behaviors are related to the disability itself versus what behaviors are potentially symptoms of PTSD or past abuse? One DDSP expressed:

I can only imagine how past abuse that we don't even know about from long before they came to our agency is impacting the individual today. I'm not sure some staff are equipped to respond to that, or to recognize that is what is happening.

A disability agency Executive Director stated:

We have a lot of people here from the Ladd Center (RI's now closed institution); we suspect they have come here with abuse histories. We know PTSD is very prevalent, but we don't know how to work with that on a daily basis, or how to really recognize it.

- 10. DDSPs and DV/SA advocates need a better understanding of the effects of secondary trauma, and the COF agencies need to recognize the role of interpersonal violence in the lives of their staff members and how that impacts their ability to provide support to others.** Abuse response can be a very draining and emotional process for staff. One DDSP stated:

When abuse happens our agency creates a circle around the individual – everyone is affected by this; we try not to let our personal feelings affect what we must do to help the person, but it is so hard.

A disability agency Director confessed, “Once the crisis is over we need to be better at debriefing and following-up with staff.” This debriefing is important because as one

DDSP shared, *“It is not a frequent occurrence; it is difficult to not allow it to be overwhelming and not allow our own emotions to impact the response or be the barrier.”*

There was also recognition of the fact that many staff members may be dealing with or are survivors of abuse in their own lives, and this can greatly impact how these staff members handle disclosures from the individuals they support, and provide on-going services. One DDSP stated, *“I think we know that some of our fellow staff have their own abuse histories. It’s no surprise that they would be drawn to a helping profession.”* One of the disability agency Directors said, *“We talk to staff about their feelings and emotions. Events here sometimes bring up things in their past life. They need to recognize the past abuse in their lives and think about how they react to clients.”*

ASSESSMENT IMPLICATIONS AND POSSIBILITIES FOR NEXT STEPS

In our work under this initiative the ACT Collaborative has frequently asked, “What can we do together that we cannot do alone?” This initiative has provided a focused opportunity in two communities to work across the disciplines towards systems change, and to truly positively impact the way individuals with disabilities experience the violence response system in Rhode Island. As one disability agency executive director put it, “*constant change is here to stay!*” We went directly to the stakeholders themselves and asked them what possibilities for change would have the biggest impact. The possibilities that were created will lead us to our next step of creating concrete strategic planning goals and activities for implementation in our Communities of Focus:

I. BUILDING ON A FOUNDATION OF STRENGTHS AND POSSIBILITIES	
KEY FINDINGS	IMPLICATIONS & POSSIBILITIES
1. People appreciated and were open to the invitation to discuss abuse and its responses.	1. Open Space Technology is a useful facilitation tool that could be used to engage agencies in cross-discipline conversation and build cross-agency capacity in our COFs. Café Conversations could create opportunities for women with Developmental Disabilities (DD) to talk about their experiences with each other, and offer individuals with disabilities the opportunity to generate ideas for professionals on how to best support them.
1. All Community of Focus (COF) agencies are actively working toward a person-first approach to their service delivery; expressing a desire to meet the individual “where they are”.	2. The ACT Collaborative needs to offer creative and on-going support to COFs on how to integrate person-centered planning, which is so prominently practiced at many disability support agencies, with traditional, survivor-driven safety planning approaches utilized by Domestic Violence (DV) and Sexual Assault (SA) agencies. There needs to be a shift from “doing for” the individual to “working with” the individual.
3. A state-wide incident management model for responding to abuse in Developmental Disability (DD) agencies already exists, but there is a disconnect between policy and practice.	3. The ACT Collaborative, together with the COFs and the individuals they support, need to address the disconnect between the existence of this adopted response model, and the actual adherence to and practice of it in the DD agencies. Also, there is a need to look for ways to better incorporate DV/SA agencies into this response model, and provide a voice for the survivor in the protocol.

II. ACCESSING ADVOCACY, SAFETY-PLANNING & CLINICAL SERVICES

KEY FINDINGS	IMPLICATIONS & POSSIBILITIES
1. DV/SA agencies report that women with disabilities are not coming to their agencies.	1. The ACT Collaborative needs to assist COF agencies with building cross-discipline networks, creating outreach strategies and materials, and building trust between agencies to support and facilitate referrals, and encourage co-advocacy.
2. Women with DD/cognitive disabilities feel they are not believed when they disclose abuse, or may feel it is their fault.	2. Disability Direct Service Professionals (DDSPs) need to be more comfortable and skilled at handling disclosures of abuse. Individuals with disabilities need to be educated on the dynamics of abuse and proper language they can use to disclose.
3. Women with DD/cognitive disabilities have difficulty participating in “traditional” counseling and safety planning services currently available at DV/SA agencies.	3. The ACT Collaborative needs to facilitate cross-discipline discussion and exploration of non-traditional counseling and therapeutic approaches. Women with disabilities need to be included in this planning.
4. There are very few clinicians in RI with experience in both trauma counseling and disability issues, and many feel uncomfortable and unsure working at the intersection of violence and disability.	4. Clinicians need to be skilled and comfortable working within the disability community and understand the dynamics of sexual and domestic violence for this community. Traditional counseling and safety planning are not always an option, and clinicians need alternative approaches to work with individuals with DD/cognitive disabilities.
5. There is a disturbing lack of education for individuals with DD/cognitive disabilities around healthy relationships, anatomy and health, appropriate boundaries, recognizing abuse and available resources.	5. The ACT Collaborative can assist DD agencies with moving into consistent practice with the sexuality policy/health education plans they are mandated by the state to have, and utilize these policies as the foundation for increased education for the individuals they support.
6. Individuals with DD/cognitive disabilities are afraid they will get into trouble for disclosing abuse.	6. Agency abuse response practices need to be transparent and available not only to the professionals, but to the individuals being supported by those agencies as well. Women with disabilities need to know they will be safe after they disclose abuse, and what will happen next.

7. There are very few options for emergency or long-term placement, and DV shelters are not being utilized.	7. The ACT Collaborative should provide guidance to COF agencies on making shelters more accessible, and help agencies create policies for securing “safe havens” and emergency respite.
8. Disability agencies are often faced with the challenge of supporting both the victim and the perpetrator.	8. DD agencies need to develop policies on how to specifically respond to peer-to-peer abuse, and clearly define what the agency responsibility is to both the victim and the perpetrator in these cases, being sure to address victim safety as the primary concern.
9. DDSPs report that families exhibit attitudinal barriers which prohibit individuals with DD/cognitive disabilities from accessing services.	9. The ACT Collaborative can help increase COF agencies’ capacity to facilitate and engage families in safety planning.

III. UNDERSTANDING ENTRY INTO THE RESPONSE SYSTEM – OUTREACH, REFERRAL & CROSS-DISCIPLINE COLLABORATION

KEY FINDINGS	IMPLICATIONS & POSSIBILITIES
1. Most disability agencies report there is an immediate internal response and investigation when an individual discloses, or when abuse is discovered, but referrals are not often made to DV/SA agencies.	1. The ACT Collaborative needs to build trust and create opportunities for the COF agencies to connect with each other around best practices for co-advocacy. DD agencies want a consistent contact at referral agencies.
2. Disability agencies investigate themselves in abuse cases.	2. The ACT Collaborative can help increase capacity of COFs to collaborate on objective agency investigations that are focused on multiple components - fact-finding, safety and advocacy for the survivor.
3. The system is perceived to be overloaded and overwhelmed with too few agencies able to provide needed abuse-specific response services.	3. The ACT Collaborative needs to cultivate a community of resource-sharing and co-advocacy among COF agencies.
4. DV, SA, and DD agencies tend to work in isolation with little knowledge	4. Formal agreements and connections between DD, DV and SA agencies need to be created to facilitate cross-

about the services provided at the other agencies or the protocols they are mandated to follow.	agency case consultation and referral, and cross training.
5. Individuals with disabilities and the staff that support them do not know about the services available at DV/SA agencies or how to access them.	5. DV and SA agencies need assistance in creating universally designed materials about their services and strategies for informing disability agencies and individuals on how to access them.
6. Women with DD/cognitive disabilities do not have an option of their entry point into the system.	6. The ACT Collaborative must assist COF agencies in navigating and fulfilling state mandated reporting requirements while providing cross-discipline advocacy, informed consent, and options to the survivor.
7. Women with disabilities often disclose to each other; they want to be a resource for each other and for the service provider agencies.	7. The ACT Collaborative can help increase the capacity of COFs to engage women with disabilities in the creation and implementation of agency-wide policy and education programs.

IV. STRENGTHENING CAPACITY AND SKILLS

KEY FINDINGS	IMPLICATIONS & POSSIBILITIES
1. SA/DV providers lack knowledge about the intersection of disability and violence and have little experience working directly with individuals with disabilities.	1. SA/DV providers need to be skilled and comfortable in working with individuals with disabilities who have survived abuse and understand the dynamics of abuse in the DD/cognitive disability community.
2. DDSPs lack knowledge of the dynamics of sexual and domestic violence, the definitions of abuse, and the effects and symptom manifestation of abuse.	2. DDSPs need to understand the dynamics of abuse in the community they support, recognize signs and symptoms and understand the prevalence of abuse in the DD/cognitive disability community.
3. DDSPs are challenged with balancing “dignity of risk” versus “safety” for the individuals they support.	3. The ACT Collaborative can help foster discussion within COF disability communities about providing informed consent for the individuals they support. Individuals with disabilities need to have the opportunity to make informed decisions about their choices.

<p>4. DV/SA advocates and clinicians need assistance in improving their communication skills to work with women who use “non-traditional” communication.</p>	<p>4. The ACT Collaborative can provide opportunities for experiential learning and practice, and help increase capacity of agencies to provide accessible services.</p>
<p>5. DDSPs indicated they specifically needed more skills in how to better handle a disclosure, both in terms of being a caring listener and following the proper protocol (minimal facts).</p>	<p>5. DDSPs need practice to feel comfortable hearing disclosures of abuse, and respond in a sensitive and informed manner.</p>
<p>6. Staffs at DV, SA and DD agencies want consistent, documented response policies on how to respond to abuse, and the opportunity to practice that response.</p>	<p>6. The ACT Collaborative needs to assist COFs to apply both agency-specific and system-wide collaborative practices of abuse response. Opportunities to practice implementation needs to be provided to build the abuse response capacity of COF agencies.</p>
<p>7. DDSPs indicated that they are unprepared to better educate individuals with DD/cognitive disabilities about abuse, abuse prevention and available resources.</p>	<p>7. The ACT Collaborative can help build COF agencies’ capacity to work collaboratively to educate the individuals being supported, and better utilize the skills of the individuals with DD.</p>
<p>8. RI’s mandatory reporting statute is ambiguous, and DV, SA and disability advocacy & support professionals do not know to whom it applies.</p>	<p>8. The ACT Collaborative must work with the Division of Developmental Disabilities, the state’s mandated reporting agency, to better clarify for professionals who is bound by mandated reporting laws. DV, SA and disability advocacy and support professionals need to understand their role in the mandated reporting system.</p>
<p>9. DDSPs need an understanding of the effects of violence on individuals with DD/cognitive disabilities</p>	<p>9. DDSPs need to understand behavioral manifestations of abuse for the individuals they support, and how to respond in the moment.</p>
<p>10. DDSPs and DV/SA advocates need a better understanding of the effects of secondary trauma, and the COF</p>	<p>10. DV, SA and disability advocacy and support professionals need a safe learning environment where they can discuss issues, ask questions and seek guidance</p>

agencies need to recognize the role of interpersonal violence in the lives of their staff members and how that impacts their ability to provide support to others.

in challenging situations and be encouraged to pursue avenues of self-care to combat secondary trauma and compassion fatigue.

RECOMMENDATIONS & CONCLUSIONS

Our next steps for the implementation of systems change in the two Communities of Focus will center on working to alleviate the barriers to violence response services for women with disabilities, building the capacity and skills of agencies and individuals to provide immediate and appropriate responses to abuse, create clear and welcoming entry points into the violence response system for women with disabilities and the agencies who support them, and establish response policies within the COFs that are truly survivor-driven and informed. Taking the findings, and the implications and possibilities that follow from them, the ACT Collaborative is suggesting five recommendations on which to focus the efforts of implementation:

1. Great energy and opportunities are needed to build trust and partnerships among domestic violence, sexual assault and disability agencies. Work has been done in “silos” for many years and this is the time for moving towards a system of shared resources and co-advocacy.
2. Women with cognitive and developmental disabilities must be given a stronger voice in selecting their entry into the violence response system. These women want to be a resource for each other and agencies in the community.
3. Clarification for sexual assault and domestic violence advocates is needed on the nature and intent of the state’s mandated reporting statute. The ability to provide confidential response services hinges on the clarification of this issue.
4. Staff at DV, SA and disability agencies still need some basic skills and understanding about the intersection of disability and violence, providing a ripe opportunity for building a foundation for cross-discipline networks and facilitating the exchange of ideas and knowledge.
5. Alternatives to “traditional” counseling and safety planning need to be cultivated in consultation across disciplines.

It was truly a privilege for the ACT Collaborative to be welcomed into the Communities of Focus and to converse with such motivated, caring and curious individuals. The Needs Assessment was just a first step in what will be an on-going conversation across the disciplines. It is clear that the intentions of all involved agencies are good, but the know-how and capacity to truly create a network of response to abuse need to be bolstered.

APPENDIX A:
Needs & Strengths Assessment Tools

CONSENT FOR PARTICIPATION

in the ACT COLLABORATIVE NEEDS & STRENGTHS ASSESSMENT

Purpose of Assessment:

The **MISSION** of this initiative is to ACT together through Advocacy, Collaboration and Training to better respond to violence against individuals with cognitive and developmental disabilities. Our **PURPOSE** is to foster an environment that works to improve accessibility to advocacy and safety planning services for individuals with disabilities; develop a collaborative network through open dialogue to improve the quality of supports individuals with disabilities receive; and provide cross-training, cross-fertilization, and bridge-building opportunities for professionals working in the fields of sexual assault, domestic violence and disability services to better detect, react to and reduce violence in the cognitive and developmental disability community.

Process:

If you consent to be part of this assessment, you will be asked to participate in an hour-long, face-to-face interview. The interview questions are focused on the organizational capacity that exists, or is needed, in your agency to better serve women with cognitive disabilities, who have survived abuse. One individual will ask the interview questions, while a second individual will take detailed written notes.

Risks & Benefits:

The interview will focus on responses to sexual and physical violence. Our Collaborative understands that interpersonal violence affects many individuals, and service providers are not immune. You have the choice at any time to decline to answer a specific question, or end the interview completely.

The interview will also ask you to reflect on the capacity of the agency you lead and the larger community and system of which your agency is a part. If you feel answering any of these questions is harmful, you may decline to answer.

You may withdraw your interview from the Needs & Strengths Assessment at any point after the interview.

By consenting to be part of this Needs & Strengths Assessment you are contributing to an increased knowledge about the service delivery system for individuals with cognitive and developmental disabilities, who have survived abuse. Your input will assist in developing both local and national best practice models to providing accessible service.

Confidentiality:

Your name and agency will not be recorded on any written notes from the interview. The content of the interviews will be known by the interviewer and note taker, and written notes without identifiers will be shared with the five members of the ACT Collaborative for use in the thematic analysis. The written notes will be stored in a locked filing cabinet, and all notes from the interview will be destroyed within 180 days of the interview, once responses are integrated into a thematic analysis report. This final report is available to you upon request.

Both the interviewer and note taker are bound by ¹ § 40.1-27-2 **Duty to report.** – (a) Any person within the scope of their employment at a program or in their professional capacity who has knowledge of or reasonable cause to believe that a participant in a program has been abused, mistreated or neglected shall make, within twenty-four (24) hours or by the end of the next business day, a written report to the director of the department of mental health, retardation, and hospitals or his or her designee. The report shall contain: (1) The name, address, telephone number, occupation, and employer's address and the phone number of the person reporting; (2) The name and address of the participant who is believed to be the victim of the abuse, mistreatment, or neglect; (3) The details, observations, and beliefs concerning the incident(s); (4) Any statements regarding the incident made by the participant and to whom they were made; (5) The date, time, and place of the incident; (6) The name of any individual(s) believed to have knowledge of the incident; and (7) The name of any individual(s) believed to have been responsible for the incident. (b) In addition to those persons required to report pursuant to this section, any other person may make a report if that person has reasonable cause to believe that a participant has been abused, mistreated, or neglected.

Cost and Compensation:

There is no cost to you as a participant. You will not be paid for your time. Your responses during the interview will assist in developing an implementation plan within our Communities of Focus which may directly or indirectly benefit your agency in terms of improved capacity.

Questions:

Any questions or concerns you have before consenting to participate or after the interview has been conducted should be directed to Karyn Hadfield, ACT Collaborative Director, at (401) 421-4100 x162 or khadfield@dayoneri.org.

Consent:

I am voluntarily consenting to be interviewed for the Needs & Strengths Assessment. I understand I will be given a copy of this consent waiver. I also understand that I may request a copy of the finished thematic analysis for which my input is needed.

Interviewee's Name (Printed)

Interviewee's Signature

Date



The Leadership Interviews: Questions for Leadership

- What experiences has your agency had in providing support to women with cognitive disabilities who have survived abuse?
 - How did these women in need of support come to the attention of your agency?

- Why do you think women with cognitive disabilities may be reluctant or unable to reach out to your agency for support when abuse happens?

- What barriers and challenges does your organization face when providing support to individuals with cognitive disabilities who have survived abuse? (Interviewer Note: prompt interviewee to think about issues related to staff time, access to financial resources, staff level of knowledge, and external challenges).
 - How can the ACT Collaborative assist your organization to overcome these barriers? What resources would you need?

- Has your agency developed any policies or protocols on how to respond to abuse against women with cognitive disabilities? How do you make these policies known to staff?
 - How does your agency handle abuse cases that come to the attention of the media? (*Disability Agencies Only*)
 - Does your agency provide orientation information to individuals and their families, new to the service delivery system, about how to recognize and report abuse, or obtain referrals for advocacy services? (*Disability Agencies Only*)

- Has your agency addressed issues of accessibility for individuals with disabilities? (Interviewer Note: prompt interviewee to think about all kinds of accessibility – physical, attitudinal, programmatic and educational)
 - How could the ACT Collaborative help your agency work toward the goal of better accessibility?

- Of what are you most proud about the way your organization responds to women who have survived abuse?

- How does change happen in your organization?

- What is your agency's relationship with other agencies in the COF?
 - Is there positive collaboration already taking place?
 - How might you work with the other agencies to improve accessibility to services for women with cognitive disabilities?

- What can your agency do to ensure that the voices of women with disabilities are heard, and how can the ACT Collaborative help your agency assure that service responses are person-centered?

- Is there anyone else in your agency (e.g., Program Directors or Board members) that we should talk to regarding these questions?



*Open Space Technology:
Questions for Direct Support
Professionals, Volunteers and
Advocates*

These questions and conversation facilitation tools will identify, document, and guide our process for the development of our Implementation Plan.

- What makes you most proud about the way your agency responds to women with cognitive and developmental disabilities who have survived abuse?
 - What additional resources would your organization need to improve the response to women who experience abuse? (Facilitator Note: prompt group to think about resources related to staff time, budget, staff level of knowledge, and improving collaboration with other agencies.)

- What are the barriers and challenges you face when providing support to individuals with cognitive and developmental disabilities who have survived abuse? (Facilitator Note: Accessibility for women with disabilities encompasses four major areas: environmental, attitudinal, education/experience, and programmatic – encourage participants to consider ALL areas of accessibility.)
 - How can the ACT Collaborative assist your organization to overcome these barriers? What resources would you need?

- Does your organization have established policies and protocols for providing services to women with cognitive and developmental disabilities who have experienced abuse?
 - How could disability and domestic violence/sexual assault agencies streamline the process of referral?
 - How could your organization inform women with cognitive and developmental disabilities about your services?
 - How would your organization ensure the response to individuals with cognitive and developmental disabilities is person-centered?

- What capacities, skills and competencies do you need to work with individuals with cognitive and developmental disabilities who have survived abuse?

- What can your organization, or other organizations in the community do to build these capacities?
- What are the possibilities for cross-discipline collaboration in responding to abuse against individuals with cognitive and developmental disabilities?
 - What organizations are missing from this collaboration to improve responsiveness to individuals with cognitive and developmental disabilities who have survived abuse?

Final Question - Consensus Statements from the Table:

- What would be the single most meaningful change that would improve the quality of violence response services for women with cognitive and developmental disabilities in your organization? Within the COF?



*Café Conversations:
Questions for Women with
Cognitive & Developmental
Disabilities*

These questions and conversation facilitation tools ACT created will identify, document, and guide our process for the development of our Implementation Plan.

- How should staff and organizations respond when you need help?
- How should staff and organizations NOT respond when you need help?
- How could individuals with disabilities find out about organizations that can help them?
- How can agencies that help people reach out to people with disabilities?
- When do individuals with disabilities feel safe and comfortable enough to talk with staff about the help they need?
- How can you help your organization create better ways to respond to individuals with disabilities who need help?