

# *Needs Assessment Plan*



**Promoting access and empowering people with disabilities who are survivors of sexual abuse**

A collaboration between Hills & Dales and Riverview Center in Dubuque County, Iowa



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## **Introduction**

**United for Change**, a collaboration between Hills & Dales and Riverview Center in Dubuque County, Iowa, is committed to promoting access and empowering survivors of sexual abuse/violence with disabilities. In the short-term, we aim to create systemic change within our organizations to provide excellent services for all survivors in our community. Our long-term goal is to create a sustainable collaboration which empowers people with disabilities to prevent, identify and heal from sexual abuse through equitable, holistic change in our organizations and in our service area. We recognize that people with disabilities face increased risk for sexual abuse/violence and abuse in general<sup>1</sup>. Environmental, cultural, and social-structural factors filtered through more proximal elements such as community, family, and supports and services impact individuals' risk for abuse/violence, their prevention and coping skills, and their ability to access necessary resources to heal. **United for Change** strives to understand the unique risks that people with disabilities face, and their challenges in disclosing experiences of sexual abuse/violence and accessing necessary services. This work is funded by a grant from the US Department of Justice, Office on Violence Against Women (OVW).

The population of Dubuque County includes people with a wide variety of disabilities. We believe that sustainable systemic change must start with a targeted population and goals in order to expand to effectively address the needs of the larger community. Based on the expertise of our two organizations, our work at this stage is concentrated on people in Dubuque County over the age of 18 who are survivors of sexual abuse/violence and have an intellectual disability. For the purposes of brevity and readability, this target population will be referred to interchangeably in this document as “survivors with disabilities”.

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<sup>1</sup> Casteel, C., Martin, S.L., Smith, J.B., Gurka, K.K., & Kupper, L.L. (2008). National study of physical and sexual assault among women with disabilities. *Injury Prevention*. 14: 87-90.

Hassounah-Phillips, D., & Curry, M.A. (2002). Abuse of Women with Disabilities: State of the Science. *Counseling Bulletin*. 45(2): 96-104.

Martin, S.L., Ray, N., Sotres-Alvarez, D., Kupper, L.L., Moracco, K.E., Dickens, P.A., Scandlin, D., & Gizlice, Z. (2006). Physical and Sexual Assault of Women With Disabilities. *Violence Against Women*. 12(9):823-837.

## **Vision**

**United for Change** will empower people with disabilities who are survivors of sexual abuse in their journey from crisis to healing. This collaboration between Hills & Dales and Riverview Center will advocate for a comprehensive service system that is person-centered and accessible.

## **Mission**

**United for Change** will create a cohesive and holistic service system for people with intellectual disabilities who are survivors of sexual abuse in Dubuque County, Iowa. This will be accomplished through innovative agency collaboration which:

- Utilizes multidisciplinary expertise in a person-centered approach to service provision at Hills & Dales and Riverview Center
- Enhances our policies as a way to better communicate and facilitate service provision between partner agencies
- Eliminates barriers to enhance accessible, equitable and flexible service provision
- Cultivates agency cultures that are respectful, safe and empowering

## **Collaboration Members**

### **Hills & Dales**

Hills & Dales is the lead agency in this collaboration. The organization currently serves and supports individuals at a Residential Center, through Home and Community Based Services (HCBS) in their homes, and at the Hills & Dales Community Center. Hills & Dales maintains a focus and emphasis on serving people who have significant physical and intellectual disabilities and who are medically fragile. Within the last two years, supports and services have been provided to approximately 2,800 individuals. Hills & Dales has two main facilities in Dubuque County: a Community Center and an Intermediate Care Facility for people with Intellectual Disabilities (ICF/ID). The Hills & Dales ICF/ID is Commission on Accreditation of Rehabilitation Facilities (CARF) accredited and home to 46 children and adults. Twenty-four hour nursing care is provided here.

The Community Center provides daily multi-generational programming, including a paid work program and skills training, day habilitation, therapy programs, community integration activities, and group respite. Hills & Dales also provides inclusive childcare and preschool for traditional youth aged 0-12 and non-traditional youth aged 0-18 at their Department of Human Services (DHS) licensed facility. Finally, Supported Community Living (SCL) programming and hourly support is provided to persons with developmental disabilities living in apartments and elsewhere in the community. Through offering services that support the whole person and enhance community inclusion, Hills & Dales serves its mission of building meaningful lives for individuals with disabilities. The organization values a quality of life that enhances dignity, upholds rights and encourages choice.

### **Riverview Center**

Riverview Center provides services specifically for victims of sexual abuse/violence in Dubuque, Iowa as well as northwestern Illinois. Unlike other agencies in the area, all services provided are free without regard to sex, race and socio-economic status. These services include a 24-hour crisis hotline, legal and medical advocacy, long and short-term counseling, transition assistance for survivors, and violence prevention education programs. Riverview Center Educators present in every classroom in every school in Dubuque County, and are available to all community groups and businesses. In 2010, over 22,000 people participated in professional trainings and public education conducted by Riverview Center, and the agency responded to almost 700 crisis and referral calls. Riverview Center is committed to providing culturally competent, compassionate, client-centered care for individuals affected by sexual abuse/violence. The organization aims to create a community free of violence through programming that empowers individuals, fosters empathy, and helps to develop skills that emphasize respect, equality and non-violent conflict resolution.

This is the first direct collaboration between Hills & Dales and Riverview Center, although we have created community relationships through various activities that have supported each agency. Both organizations recognize the need for services to holistically support survivors with disabilities, and the significant risks people with disabilities face for sexual abuse/violence. We share the belief that these individuals should have the same opportunity to heal as survivors without disabilities. We feel that building this collaboration, **United for Change**, is

essential to fully realizing our missions of building meaningful lives for persons with disabilities and providing free, comprehensive sexual assault prevention, intervention and advocacy services.

### **Purpose of the Needs Assessment**

To better serve survivors with disabilities, **United for Change** is conducting a needs assessment of our existing systems of service in Dubuque County, Iowa to develop an understanding of our strengths and assets as well as our weaknesses and where gaps in our collaborative system exist. We will engage a broad range of stakeholders including clients, direct service staff, leaders and Boards of Directors at each organization, guardians of Hills & Dales clients, and Riverview Center volunteers, as well as others who work with us to provide services. To create systems change, it is important to understand the unique perspectives and needs of the groups with which we work. The information collected through the needs assessment will be used to develop a strategic plan of action for creating a seamless, holistic system of services for survivors with disabilities in Dubuque County, Iowa.

### **Goals of the Needs Assessment**

The goals of our needs assessment are to:

1. Identify the **policies, procedures and practices** that exist at each organization which impact survivors with disabilities' ability to move from crisis to healing.
2. Identify the factors that stakeholders use to define **quality services** and our **strengths, barriers and challenges** to providing the best possible services and supports for survivors with disabilities.
3. Identify the **ways in which guardianship affects survivors' abilities to access services**, maintain safety, and to heal from experiences of sexual abuse/violence.
4. Identify areas where **connections between our organizations can be made, and the opportunities for change** in the system of services provided by Hills & Dales and Riverview Center for survivors with disabilities in Dubuque County.



## **Information Sources**

### **Existing Information**

*State Data:* Little recent data exists in regard to survivors with disabilities in Iowa, and no data currently exists for the Dubuque County area specifically. In Iowa, 14.5% of the non-institutionalized population report having some form of disability.<sup>2</sup> Forty percent of this group has a mental or cognitive disability, and many of those also have a physical disability.<sup>3</sup> Iowans with disabilities face social disparities, and are more likely to be in poverty and have less access to education and work opportunities. Even though Iowans with disabilities have greater access to governmental health insurance, almost one in six (14%) report skipping medications due to cost<sup>4</sup>.

The service system for people with intellectual disabilities is currently in flux in Iowa. It has been based at the county level in the past, creating diversity in the types, quality and amount of supports and services provided throughout the state. Disability services are being overhauled, and a more centralized system is currently in the planning stage. In 2008, 11,752 individuals received services in the state of Iowa through the Medicaid waiver for people with intellectual disabilities. Iowa ranks third in the number of Medicaid-funded services for people with intellectual disabilities in the nation, and third in the number of people of people with intellectual disabilities served in institutional facilities (when controlling for state population)<sup>5</sup>.

Qualitative data collected with people with developmental disabilities in Iowa show that they feel disempowered to engage in community processes. Common barriers include lack of confidence, stigma, and perceived lack of knowledge.

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<sup>2</sup> Iowans with Disabilities: 2009. State Data Center of Iowa. Accessible at: <http://www.statelibraryofiowa.org/datacenter/Publications/dis09>

<sup>3</sup> Disability in Iowa: Health and Social Characteristics of Iowans with Disabilities: 2002-2007. Prevention of Disabilities Policy Council, Iowa Department of Public Health. Accessible at: [http://www.idph.state.ia.us/bh/common/pdf/disability\\_health/disability\\_in\\_iowa\\_report.pdf](http://www.idph.state.ia.us/bh/common/pdf/disability_health/disability_in_iowa_report.pdf)

<sup>4</sup> Disability Report – BRFSS 2008. Prevention of Disabilities Policy Council, Iowa Department of Public Health. Accessible at: [http://www.idph.state.ia.us/bh/common/pdf/disability\\_health/2008\\_brfss.pdf](http://www.idph.state.ia.us/bh/common/pdf/disability_health/2008_brfss.pdf)

<sup>5</sup> Iowa State Profile Tool: An assessment of Iowa's Long-Term Support System. (2009). Thompson Reuters for the Iowa Department of Elder Affairs. Accessible at: [http://www.aging.iowa.gov/Documents/SPT\\_FinalReport.pdf](http://www.aging.iowa.gov/Documents/SPT_FinalReport.pdf)

People with disabilities also face logistic barriers including lack of transportation and lack of easy to understand or easy to read materials.<sup>6</sup>

Over 4,653 people were served by sexual violence centers in Iowa in Fiscal Year 2010, and over 72,000 crisis calls were placed to victim services (domestic and sexual violence).<sup>7</sup> Seven out of ten (70.8%) perpetrators of sexual violence were known to the survivor.<sup>8</sup> No data exists regarding sexual violence among people with disabilities in the state of Iowa.

The main sources of data regarding disability in the state are:

**Social and Health Impacts of Disability in Iowa: Analysis of the 2008 BRFSS<sup>9</sup> Data**

Published by: Iowa Department of Public Health

Data year: 2008

Accessible at:

[http://www.idph.state.ia.us/bh/common/pdf/disability\\_health/2008\\_brfss.pdf](http://www.idph.state.ia.us/bh/common/pdf/disability_health/2008_brfss.pdf)

**Iowa State Profile Tool: An Assessment of Iowa's Long-Term Support System**

Published by: Thomson Reuters for the Iowa Department of Elder Affairs

Data year: 2009

Accessible at: [http://www.aging.iowa.gov/Documents/SPT\\_FinalReport.pdf](http://www.aging.iowa.gov/Documents/SPT_FinalReport.pdf)

The main sources of data regarding sexual violence in the state are:

**Crime Victim Assistance Division: Three-Year Program Reports**

Published by: Iowa Department of Justice, Attorney General's Office

Data years: 2008, 2009 and 2010

Accessible at:

[http://www.iowa.gov/government/ag/helping\\_victims/contents/ARFY08\\_09\\_10.pdf](http://www.iowa.gov/government/ag/helping_victims/contents/ARFY08_09_10.pdf)

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<sup>6</sup> Political Participation Study: Focus Group Findings. (2000). IDACTION Office. Accessible at: <http://idaction.bwbhosting.com/LinkClick.aspx?fileticket=rZA5Fzx%2bwPI%3d&tabid=166>

<sup>7</sup> Crime Victim Assistance Division: Three-year Program Reports (2008-2010). Iowa Department of Justice, Attorney General's Office. Accessible at: [http://www.iowa.gov/government/ag/helping\\_victims/contents/ARFY08\\_09\\_10.pdf](http://www.iowa.gov/government/ag/helping_victims/contents/ARFY08_09_10.pdf)

<sup>8</sup> Iowa Sexual Assault Statistics. IowaCASA. Accessible at: <http://www.iowacasa.org/aspx/generalinfo/iowasexualassaultstatistics.aspx>

<sup>9</sup> BRFSS = Behavioral Risk Factor Surveillance System

## **2009 Iowa Uniform Crime Report**

Published by: Iowa Department of Public Safety

Data year: 2009

Accessible at:

[http://www.dps.state.ia.us/commis/ucr/2009/2009\\_UCR\\_Publication.pdf](http://www.dps.state.ia.us/commis/ucr/2009/2009_UCR_Publication.pdf)

*Local Data:* In Dubuque County, 358 individuals with intellectual disabilities received state services in 2009 (the most recent year with data available)<sup>10</sup>. Hills & Dales currently serves 46 individuals in their residential center, and 84 adults in SCL, day habilitation and respite services. Most of the individuals served by Hills & Dales are medically fragile or have severe behavior issues in addition to cognitive disabilities and verbal communication challenges. Other organizations in the community who serve people with disabilities include Goodwill Industries and Area Residential Care.

Twenty-eight rape kits were collected at Dubuque County medical facilities from July 2010 to July 2011, and 20 additional reports were taken by law enforcement. Riverview Center served 157 clients in Dubuque in 2010, and provided 1,194 hours of counseling.<sup>11</sup> No other organization serves survivors of sexual violence in Dubuque County.

These data will serve to add context to the information collected in the needs assessment. People with disabilities are at greater risk for abuse/violence in our communities, and they face significant challenges when attempting to access services and resources. Little information exists about the experience of sexual violence in the state of Iowa, or the experiences of survivors in navigating the response system. We know that sexual violence is under-reported in the state, and specifically in Dubuque County, and that survivors face many challenges in accessing supportive legal and medical resources to help them heal.

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<sup>10</sup> Iowa Department of Human Services

<sup>11</sup> Riverview Center Annual Report FY2010

## **New Information**

Overall, data indicate that a great need likely exists for services for people with disabilities who are survivors of sexual abuse/violence in the state of Iowa, and in Dubuque County specifically. The paucity of information on this topic compels us to conduct an in-depth needs assessment to fully understand how **United for Change** can be effective in improving the service system for survivors with disabilities in our community. The existing information about people with disabilities in Iowa and sexual abuse/violence in Iowa will serve to contextualize information developed in the needs assessment to help us understand the unique, and not so unique challenges that Dubuque County faces in serving people with disabilities who have experienced abuse. Through this needs assessment, we will better understand how our systems can better serve our community.

We will use a mixed-methods approach centered on qualitative methods such as semi-structured interviews and focus groups with clients, their guardians, staff, and volunteers at our organizations. This information will be supplemented by web-based surveys with other stakeholders including Boards of Directors, and people we work with outside of each agency such as case managers. This information will be triangulated to create a strategic plan for systems change to empower people with disabilities who are survivors of sexual abuse/violence in their journey from crisis to healing through person-centered and fully accessible services.

## **Methods**

### **Introduction**

We will use a mixed-methods approach to gather information and address the goals of the needs assessment. A broad range of stakeholders will be included through individual semi-structured interviews, focus groups and web-based surveys. Questions will focus on those factors which influence the ways that services are provided at both agencies, including formal policy and its implementation, existing strengths and weaknesses, stakeholders' perspectives on issues important to the work of **United for Change**, and unique considerations including guardianship and communication. The stakeholder groups of the needs assessment are:

1. Hills & Dales Clients
  - a. ICF/ID
  - b. HCBS
2. Guardians of Hills & Dales Clients
3. Riverview Center Clients
4. Hills & Dales Direct Service Staff
5. Riverview Center Service Staff
6. Riverview Center Volunteers
7. Hills & Dales and Riverview Center Management
8. Board of Directors of Both Agencies
9. Outside Collaborators of Both Agencies

This data will be systematically analyzed to understand how our organizations can strategically work together to build a holistic system of services for survivors of sexual abuse/violence with disabilities in our community.

### **Purpose of Methods**

Qualitative needs assessment methods of semi-structured interviews and focus groups will be used with clients and direct service staff of both organizations, guardians of Hills & Dales clients, and Riverview Center volunteers. Qualitative data provides in-depth insight into the perspectives of respondents, and will create a vivid understanding of experiences, motivations and needs of stakeholders to better survivors with disabilities. A semi-qualitative web-based survey will be conducted with Boards of Directors and outside collaborators. This

type of survey will allow us to include a broader range of stakeholders with little respondent burden.

*Semi-Structured Interviews:* Semi-structured interviews are an iterative, inductive way to develop an in-depth understanding of perspectives, knowledge, beliefs and assumptions. A pre-determined interview guide will be used to facilitate discussion of specific topics. Formal rules of question order, probing and note-taking will be used to standardize the processes and improve comparability across participants at both organizations. This style of interviewing will be used with key management staff who individually influence organization-wide systems and services.

Individual semi-structured interviews will also be provided as an alternative for those being asked to participate in a focus group. This is especially important for Riverview Center clients because the trust and rapport necessary to ensure a sense of safety and comfort in a group setting among survivors currently receiving therapy and advocacy services may not be feasible in a one-time focus group.

*Unstructured Interviews:* Residents at the Hills & Dales ICF/ID are an important stakeholder group, and their voice must be included in any assessment of the service needs of **United for Change**. Unstructured, multi-session interviews will be held with these clients to increase rapport and accommodate the unique communication strategies of these individuals. Session length will be determined based on the responsiveness and needs of the participant. Questions may be repeated during several sessions to check reliability. Question wording and format will be modified to the communication style and needs of each individual, and determined by the facilitator as an iterative process during the interview.

*Focus Groups:* Focus groups are very effective in eliciting points of view that differ from providers and policy makers. They provide an opportunity for discussion to more fully develop ideas and debate of issues, which is especially important in this needs assessment, since disability at Riverview Center, and sexual abuse/violence at Hills & Dales have not been explicit topics of programming or planning in the recent past. The social interaction which exists in the focus group setting can also help to develop understanding of shared perspectives as well as individual variation among participants. Although focus groups raise confidentiality concerns, they can also help to provide social support and increase

participants' comfort. Focus groups will be held with direct service staff at both organizations, Hills & Dales HCBS clients, guardians of Hills & Dales clients, and Riverview Center Volunteers. Due to confidentiality concerns, all potential focus group participants will be given the opportunity to participate in an individual interview instead. The topics discussed in individual interviews would be the same as those addressed in focus groups.

*Web-Based Surveys:* This type of survey method can provide a broad overview of perspectives based on semi-qualitative information. This method will be used with Boards of Directors and outside collaborators who have diverse relationships with our organizations. Many of these stakeholders have limited physical contact with Hills & Dales and Riverview Center, and have limited time due to other commitments. A web-based survey, which is quick and easy to administer, can reduce scheduling difficulties and work with individuals' time limitations, increase participation and eliminate the physical barriers to participation that may exist with in-person methods. We feel this method is the most effective way to increase participation in our needs assessment among these stakeholders.

## **Audience**

Each stakeholder group has a unique role in the service systems of our agencies, and unique perspectives, insights and needs regarding the systems change we hope to achieve.

*Hills & Dales Clients:* This is an essential audience to include in the needs assessment. They have firsthand knowledge of the strengths and weaknesses of the Hills & Dales service system, and will provide us with information about existing strengths, barriers and areas that can be improved to make current services more accessible, accommodating and responsive to their needs. All questions for clients will be carefully designed to address the specific goals of this needs assessment and to minimize the risk of disclosure of abuse. Participants will be asked questions about their experiences with guardianship to understand how clients perceive service provision and decision-making within this unique structure. Guardianship relationships are diverse, but are inherently asymmetrical in the distribution of power. By understanding these relational dynamics, we hope to assess how our organizations can best serve both clients

and their guardians to achieve the best outcomes for survivors. We do not intend to change the client/guardian relationship; rather we hope to optimize our organizational relationships with each of these stakeholder groups and how we approach service provision.

- ICF/ID Clients – These clients are adults who live in the Hills & Dales residential facility. They are individuals with severe and profound intellectual disabilities and are medically fragile. The voices of individuals with severe and profound disabilities have been silenced in the past. We aim to include this group to empower them to influence the planning process for services and supports they may receive. While extra time and dedication will be necessary to capture their voice, we are committed to including this crucial group. Special strategies are necessary to work within these clients communication needs. Questions will be modified to the specific needs and communication abilities of each individual client. Interviews with this stakeholder group will address service satisfaction, safety, empowerment, social networks, confidentiality and trust. Interviews will be held in clients' homes to increase comfort and familiarity.
- HCBS Clients – These clients live in supported community living facilities or private homes. Inclusion criteria are that clients are over the age of 18, and currently receiving SCL, day habilitation, individual or group respite, and/or other community-based services from Hills & Dales. In general, these clients are more verbal than ICF/ID clients. Similar topics to those discussed with ICF/ID clients will be covered with these stakeholders, but different methods will be used to elicit information. Additionally, knowledge and experience with Hills & Dales policies and procedures will be an explicit topic of discussion. Focus groups will be held as part of day habilitation activities, as well as at other convenient times such as evenings and possibly weekends for the clients who choose to participate. Signs will be used to facilitate responses among participants, and to make the process more engaging for clients. Questions will be specifically designed for use among people with severe cognitive disabilities and limited expressive verbal ability. This type of question/response structure will help to protect against acquiescence and increase understanding<sup>12</sup>.

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<sup>12</sup> Finlay, W.M.L. & Lyons, E. (2001). Methodological Issues in Interviewing and Using Self-Report Questionnaires with People with Mental Retardation. *Psychological Assessment*. 13(3):319-335.



*Guardians of Hills & Dales Clients:* Guardians have power in the process of healing for survivors with disabilities. They can be a great asset or a great barrier to services, and we must understand their perspectives, buy-in and expectations for systems change. Guardians will be engaged in the needs assessment in two ways: (1) they will provide passive consent for individuals with disabilities to participate, and (2) they will be a specific target group for focus groups discussions. Guardians will be eligible for inclusion in the needs assessment if they have any type of legal responsibility for a person over the age of 18 who is a client of any Hills & Dales services. In these focus groups, topics to be discussed include decision-making role and empowerment, knowledge and attitudes of Hills & Dales policy, service satisfaction, accessibility and safety issues of people with disabilities, and risks faced by people with disabilities and collaboration between service providers.

*Riverview Center Clients:* Clients of Riverview Center are a critical group to include in the needs assessment because they have firsthand knowledge of the best supportive practices of Riverview Center and the ways in which these services could be improved. They are the most important perspective regarding the needs of survivors in Dubuque County and the quality, accessibility, and safety of supports at Riverview Center and in the community at large. Topics which will be addressed in focus groups with Riverview Center clients include satisfaction with services, knowledge and experience with organizational policies, accessibility, trust and safety, and their experience of working with Riverview Center and other entities in the Dubuque community. We will include survivors of sexual violence who are over the age of 18 and clients of Riverview Center in Dubuque County.

*Hills & Dales Direct Service Staff, HCBS Supervisors and Shift Leaders, Shift Nurses and Certified Medical Assistants (CMAs):* Direct service support and medical staff and shift leaders facilitate change, implement policies and services, and are the direct contact with clients. In many cases, they best know how to communicate with clients and have extensive knowledge of client needs and desires. Their understanding of issues, policies and procedures, their experience and their perceptions of strengths, barriers and challenges are essential to creating effective service systems. We will recruit all direct service staff who work at least occasionally with clients over the age of 18, and all non-supervisory medical staff, and first line supervisory staff who also provide direct care to clients (Shift

Leaders and HCBS Supervisors) to participate in these focus groups. Topics that will be discussed in all types of focus groups include knowledge and attitudes regarding risk, guardianship, Hills & Dales policy, strengths and challenges of service provision, safety and accessibility of Hills & Dales and in the community. Supervisors and medical staff will also be asked about collaboration with other providers. Groups will be separated by position and level (direct service staff, medical staff and supervisors (shift leaders and HCBS Supervisors)) to facilitate open communication and comfort in the interview setting. These interviews will be held at an off-site location to protect confidentiality.

*Riverview Center Direct Service Staff and Volunteers:* Riverview Center staff, including therapists, educators and advocates, facilitate change, implement policies and services, and are the direct contact with clients. Riverview Center hotline volunteers are often the first contact that people have with Riverview Center, and create an initial feeling of safety and accessibility. Both groups' experiences in providing services and their understanding of client needs are essential in creating effective systems change. We will recruit all staff and volunteers who serve the Dubuque office of Riverview Center. Topics that will be discussed with these stakeholders include knowledge and attitudes regarding disability, accessibility, and safety, strengths and challenges of service provision and policies at Riverview Center, community collaboration and support, and their resource needs for systems change. Questions will be tailored to the specific knowledge base of these two stakeholder groups, and separate focus groups will be held with each.

*Hills & Dales and Riverview Center Management:* Sustainable systems change will be driven by this level. We must understand how managers perceive the needs of survivors with disabilities, the importance of this issue, and the ways in which we can best create a holistic service system. They are also essential in measuring the changes we implement through this project and ensuring the effectiveness of **United for Change**. All management-level staff at both organizations will be asked to participate in semi-structured individual interviews. Organizational policies and procedures, strengths and challenges, staff needs in systems change, guardianship and collaboration will be discussed with this group. Executive Directors of each organization will be interviewed using the management questions with supplemental questions to address their unique role in systems change.

*Boards of Directors:* We must understand the standard of expectations of this level regarding the mission and goals of this collaboration, including safety, accessibility, empowerment, and quality of services. This level has the ultimate power in creating change within and between our organizations. All members of the Boards of Directors at both organizations will be asked to participate. A web-based survey will elicit information regarding systems change expectations, organizational strengths and challenges, opportunities for collaboration, and issue awareness/perceptions.

*Outside Collaborators:* In creating systems change and opportunities for collaboration, we must understand how we collaborate with our existing partners. Outside collaborators work with our service systems and have unique perspectives on the strengths and weaknesses of our services and the barriers and opportunities for collaboration with our organizations. These collaborators include DHS case managers, consultants and physicians at Hills & Dales, and the Sexual Assault Response Team (SART) at Riverview Center. We must understand what our existing long-term collaborators perceive as assets and challenges to working with us and our clients. A web-based survey will be used to understand essential collaborators' knowledge and perceptions of our agencies, and strengths, challenges and opportunities in their work with us and survivors with disabilities including our agencies' policies and practices, guardianship, and communication.

## Number

Table 1: Methods and number of participants for each stakeholder group

Stakeholder Group	Method	Target N
ICF/ID Clients	Individual multi-session open-ended interviews	8
HCBS Clients	Focus groups* (with individual interview option)	15-20 (3-4 focus groups)
Guardians of Hills & Dales Clients	Focus groups* (with individual interview option)	12 (2 focus groups)
Riverview Center Clients	Focus groups* (with individual interview option)	24-30 (4-5 focus groups)
Hills & Dales Direct Service Staff, Medical Staff and Shift Leaders	Focus groups* (with individual interview option)	24-30 (6-7 focus groups)
Riverview Center Service Staff	Focus group* (with individual interview option)	6 (1 focus group)
Riverview Center Hotline Volunteers	Focus groups* (with individual interview option)	12 (2 focus groups)
Management of both agencies	Individual semi-structured interviews	24
Board of Directors of both agencies	Web-based survey	28 (HD=15, RV=13)
Outside Collaborators of both agencies	Web-based survey	20

\*Each focus group will have 5-8 participants.

## Facilitation

In order to collect representative, valid information in a safe and accessible manner, specific strategies have been designed to facilitate this needs assessment. Interviews and focus groups will be held at Hills & Dales and Riverview Center facilities or at an accessible, off-site location. Location will be determined based on convenience and confidentiality concerns. The Project Coordinator will work with staff at both organizations to recruit participants and schedule facility use, and with participants to schedule their interview and focus

group times and facilitate and accommodations needed. All methods will be implemented by the Project Coordinator and Grant Team members. A Riverview Center advocate will be available at all client, guardian and Hills & Dales direct service staff interviews and focus groups to provide emotional support and referral information.

### **Semi-Structured Interview Facilitation**

Semi-structured interviews will be held with management at each organization and any people who wish to participate in the needs assessment but do not wish to be part of a focus group. Each interview will last approximately 45 minutes to one hour. All interviews will be conducted by the Project Coordinator, with a Riverview Center advocate available to provide support. All interviews will be audio recorded (with participant permission). At the beginning of each interview, the Project Coordinator will introduce the advocate support, interview process and informed consent information. S/he will also collect the pre-interview survey form. (This form may be completed at this time, or prior to the interview date.) S/he will ask questions and probes based on a structured interview protocol, and s/he will take interview notes. At the end of each interview, s/he will thank the participant and distribute participation incentives (if provided) and information about Hills & Dales and Riverview Center services and referrals.

Immediately after each interview, the facilitator will review the notes taken to ensure accuracy and impartiality. S/he will make note of any perceptions of the discussions, continued questions, and comments about the interview. At a later time, the facilitator will transcribe the notes and portions of the audio recording.

### **Unstructured Interview Facilitation**

Unstructured interviews will be held with Hills & Dales ICF/ID clients over the course of several sessions. Many of these individuals have severe limitations and unique communication systems. These interviews will be facilitated by a Grant Team member who has a long term, comfortable and safe relationship with each individual and in-depth expertise in their communication style and needs. This team member does not provide personal assistance or other daily essential supports. Each session will last ten to thirty minutes, based on client feedback<sup>13</sup>.

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<sup>13</sup> For more information on interviewing strategies among people with intellectual disabilities who have limited verbal abilities, see:

A Riverview Center advocate will be available to provide support at some sessions, depending on the topic being addressed. Prior to an individual's participation in the needs assessment, the facilitator will meet with the person's Personal Assistant to discuss confidentiality issues and schedule of interview sessions. A client's Personal Assistant will not be allowed to be present at any client interviews. An alternative Personal Assistant will be provided if necessary. At the first session, the facilitator will explain the needs assessment and informed assent information in a manner understandable to the potential participant. If the person assents to participation, the interviewer will complete a background information form about the participant with their help. The facilitator will also provide the client with the participation incentive. At the start of each subsequent session, the participant will be asked to provide verbal or physical assent to participation. The facilitator will then guide the interaction to gather information on the topic of the session and take detailed notes of each interaction. Immediately after each session, the facilitator and the Project Coordinator will discuss the notes, and record any continued questions, comments about the interview and any clarifications. The Project Coordinator will keep the notes between sessions to ensure confidentiality. Depending on client responses, the grant team may formulate more questions for the individual to better understand their perspectives regarding services, safety and access. At a later time, the Project Coordinator will transcribe the notes.

### **Focus Group Facilitation**

Each focus group will be conducted by three Grant Team members: the facilitator, the note taker, and the support staff. Focus groups will last between 1 and 1.5 hours. Focus Groups will be audio recorded (with participants' permission).

*The Facilitator:* In focus groups with staff, guardians and Riverview Center clients, the facilitator will be the Project Coordinator. For HCBS clients, the facilitator will

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Angrosino, M.V. (1997). Ethnography of Mental Retardation: an applied perspective. *Journal of Contemporary Ethnography*. 26(1):98-109.

Dennis, R. (2002). Nonverbal Narratives: listening to people with severe intellectual disability. *Research & Practice for Persons with Severe Disabilities*. 27(4):239-249.

Knox, M., Mok, M. & Parmenter, T.R. (2000). Working with Experts: collaborative research with people with an intellectual disability. *Disability & Society*. 15(1):49-61.

Booth, T., & Booth, W. (1996). Sounds of Silence: narrative research with inarticulate subjects. *Disability & Society*. 11(1):55-69.

be a Hills & Dales staff member who is on the Grant Team (see Appendix F). The facilitator will first introduce the focus group process and explain informed consent information. The facilitator will be responsible for distributing, explaining, and collecting all paperwork related to the focus group process. This includes informed consent, confidentiality agreement, background surveys, and in focus groups with Hills & Dales staff, the staff sign-in sheet. A sign-in sheet will be used to track Hills & Dales direct service staff's time spent at the focus group, and given directly to payroll to increase anonymity of participation. The normal electronic time clock must be approved by supervisors which may compromise participants' confidentiality. All Grant Team members present will assist participants in completing forms as needed.

The facilitator's main task will be to ask questions and probes and guide the discussion in each focus group. S/he will be responsible for keeping the discussion moving and on track, and maintaining the allotted timeframe. As part of this, s/he will try to guide the discussion to minimize any instances where disclosure of abuse may occur. S/he will also write major points on a flip chart to serve as a memory aid for participants. At the end of each focus group, the facilitator will thank participants and distribute participation incentives to clients and guardians.

*The Note Taker:* The note taker will be a Hills & Dales or Riverview Center staff on the Grant Team. The note taker will not be from the same organization as the stakeholder group participating in the focus group. S/he will take detailed notes of the discussion, and may contribute probes, follow-up questions, and ask for clarification if necessary. S/he will write down all responses to questions and prompts and maintain an accurate, unbiased written record of each group. S/he will maintain confidentiality by using codes rather than individuals' names. The note taker is also responsible for audio recording the focus group.

*The Support Staff:* The support staff will be a Riverview Center legal/medical advocate from the Dubuque office. S/he will contribute to the safety and comfort of the group. S/he will be available to meet with participants before, during and after each focus group in a confidential setting. S/he will provide emotional support and information to participants who may find discussion topics upsetting. As an expert in sexual abuse advocacy, s/he will help the facilitator identify precursors to disclosure so the discussion may be guided away from these

situations. S/he may also contribute probes, follow-up questions, and ask for clarification during the focus group discussions, if necessary. At the conclusion of each focus group, s/he will provide referral information for Riverview Center services and other community resources to participants.

Immediately after each focus group, the facilitator, recorder and support staff will discuss the notes taken to check accuracy and impartiality. They will make note of any perceptions of the discussions, continued questions, and comments about the environment of the focus group. The Project Coordinator will then collect written and audio information from the note taker to ensure its confidentiality. At a later time, the Project Coordinator will transcribe the notes and portions of the audio recording.

### **Web-Based Survey Facilitation**

The Project Coordinator will e-mail all potential Board of Director and outside stakeholder participants. This e-mail will include information about the collaboration, informed consent and a link to the survey. Both web-based surveys are designed to take twenty to thirty minutes to complete. Participants will be asked to respond to the Project Coordinator if/when they have completed the survey. The Project Coordinator then will send a thank-you response. A follow-up e-mail will be sent two weeks after initial contact to any potential participants who have not yet responded. The Project Coordinator will be responsible for maintaining the confidentiality of survey responses and participation. After all surveys are completed, the Project Coordinator will summarize survey information.

### **Information Management**

The Project Coordinator will be responsible for storing all information and maintaining participants' confidentiality. All individual identifiers will be immediately removed from the data. For all qualitative methods, the Project Coordinator will transcribe notes, and code information to identify recurring themes and variation among stakeholder groups. Direct quotes from participants may be used for illustrative purposes, but no actual names or identifying information will be included. S/he will summarize web-based survey information, and compare all information to address the goals of the needs assessment.



## **Recruitment Strategies**

Effective recruitment is important in gathering information which includes a broad span of perspectives related to our work. All potential participants will be provided with information about the needs assessment and their role in creating systems change. Interview and focus group participants will be asked to return an RSVP form to schedule their participation and facilitate any accommodation needs. Times and dates of the focus groups and interviews will be determined by the Grant Team based on organizational logistics, transportation accessibility, and staff and participant schedules. Based on information provided on the RSVP forms, the Project Coordinator will work with participants and other agency staff as necessary to ensure accessibility and safety requests are met, and that anyone who wants to participate can.

*Hills & Dales ICF/ID Clients:* Clients of the Hills & Dales ICF/ID will be recruited on an individual basis. Staff will identify candidates for participation based on communication ability and other individual-level factors. The Hills & Dales staff member who will facilitate the interview will introduce **United for Change** goals and the idea of needs assessment participation to the individual. S/he will explain the process and participation incentive. Recruitment fliers in plain language will be distributed to clients with reading ability. This information may be provided on multiple occasions to increase understanding and retention. If the individual wants to participate in the needs assessment, the staff will help them complete an RSVP form to identify accessibility needs and accommodations. The individuals' guardian will also be provided with information about the needs assessment and informed consent. This information will be sent to guardians at least two weeks prior to potential interview dates. On the day of the initial interview session, the facilitator will reiterate the purpose and processes of the interviews and explain informed consent concepts. If the person agrees to participation, the series of interviews will proceed.

*Hills & Dales HCBS Clients:* The Project Coordinator will visit all Hills & Dales facilities frequently in the months leading up to the needs assessment to increase staff and client familiarity of her, the needs assessment and **United for Change** in general. Meeting directly with clients will increase familiarity and comfort with the project, and, we hope, the number of participants. The Project Coordinator and a Hills & Dales staff on the Grant Team will present information about **United**

**for Change** and the purpose, process and incentives of the needs assessment at the Hills & Dales Community Center on several occasions. These informational sessions will be held during regularly scheduled activities, such as group respite, day habilitation and sheltered work time. Informational sessions will also be held at Hills & Dales supported community living facilities. Recruitment fliers using plain language will be distributed at these sessions, and they will be posted at Hills & Dales facilities. RSVP forms will be distributed to potential participants. The Project Coordinator and Hills & Dales Grant Team staff will assist clients in completing RSVP forms to schedule focus groups and identify accessibility and communication needs. Finally, information about the needs assessment and a guardian consent form will be distributed by mail and in person to individuals' guardians. Staff will follow-up with guardians to further explain the needs assessment and answer any questions. This information will be given out to guardians at least two weeks prior to potential focus group dates.

*Guardians of Hills & Dales Clients:* To recruit guardian participation in focus groups, guardians of Hills & Dales clients will be provided recruitment information including purpose, process, and incentives of participation in the needs assessment through mailings as well as during other contact with the agency. An informational flier and RSVP form will first be mailed to each potential guardian participant along with consent information for client participation. Hills & Dales Grant Team members will follow up with phone calls and/or e-mails to all guardians to improve participation rates. RSVP forms may be returned to the Project Coordinator via mail, e-mail or telephone. They may also be returned to Hills & Dales direct care staff who will forward forms to the Project Coordinator.

*Riverview Center Clients:* Participation in the needs assessment will be offered to all clients of the Riverview Center Dubuque office who are survivors of sexual violence and over the age of 18. Depending on the level of participation, invitations may also be extended to past clients as well. Fliers explaining the work of **United for Change**, the needs assessment, and why involvement of Riverview Center clients is important will be posted in the Riverview Center office and RSVP forms will be available in the common areas. Information about **United for Change**, the purpose, process and incentives of the needs assessment, and RSVP forms will be presented to all current clients who fit the inclusion criteria by therapists and advocates. Staff will assist clients in completing the RSVP form as needed. Due to confidentiality concerns, the Project Coordinator or Grant Team

members will not meet with Riverview Center clients for recruitment purposes, although they will be available to answer questions and address concerns. RSVP forms may be returned to the Project Coordinator via mail, e-mail or telephone. They may also be returned to any Riverview Center staff, who will forward forms to the Project Coordinator.

*Hills & Dales Direct Service Staff and Shift Leaders:* The Project Coordinator will present information about **United for Change** and the needs assessment at quarterly agency-wide Town Hall Meetings leading up to the needs assessment to increase familiarity and support, and ultimately, staff buy-in with the project. S/he will explain the purpose and process of the needs assessment and informed consent information including voluntariness and confidentiality. Informational fliers will be posted in break rooms and common areas of all facilities, and fliers and RSVP forms will be included as stuffers in at least two paycheck envelopes. RSVP forms will be available in common areas, break rooms and reception, and from Grant Team members and the Project Coordinator. Hills & Dales Grant Team members will also promote participation with staff through routine meetings and other personal contact. Supervisors will be asked to provide information to staff about the needs assessment and encourage their participation. (A staff member's participation will be confidential, and supervisors will not know who does and does not participate.) We feel that personally presenting needs assessment and collaboration information to staff will increase interest and participation. RSVP forms may be returned to the Project Coordinator in person, by mail, e-mail, telephone, or agency mailbox.

*Riverview Center Direct Service Staff:* The Project Coordinator will present information about **United for Change** and the needs assessment at monthly All-Agency Meetings leading up to the needs assessment to increase familiarity and support, and ultimately, staff buy-in with the project. S/he will explain the purpose and process of the needs assessment and informed consent information including voluntariness and confidentiality. Informational fliers will be posted in the copy room and other common areas of the Dubuque office. RSVP forms will be available in the copy room, and from Grant Team members and the Project Coordinator. The Riverview Center Executive Director will also send an e-mail to Dubuque office service staff encouraging participation. This e-mail will contain an electronic format RSVP form which can be returned to the Project Coordinator. RSVP information may be returned to the Project Coordinator in person, by mail,

e-mail, telephone, or to Riverview Center staff on the Grant Team. Due to the small number of staff at the Riverview Center Dubuque office (6), we hope that these recruitment activities achieve 100% participation.

*Riverview Center Hotline Volunteers:* The volunteer coordinator at Riverview Center will send an e-mail to all volunteers who may respond to a call in Dubuque County. This e-mail will provide information about **United for Change**, the needs assessment, and the participation role of volunteers. An electronic RSVP form will also be included. The volunteer coordinator will follow-up with volunteers through phone calls to improve participation rates. Depending on the schedule of the needs assessment, recruitment information may also be presented in periodic volunteer meetings. RSVP forms may be returned to the volunteer coordinator or the Project Coordinator via e-mail, phone, mail or in person.

*Hills & Dales and Riverview Center Management:* The Project Coordinator will send an e-mail to all management which provides information about the needs assessment process, purpose and how information will be used to create systems change. An electronic RSVP form will also be included. The RSVP form should be completed by all management, whether they wish to be interviewed or not. The Project Coordinator will follow up with any managers who do not RSVP. The three managers at Riverview Center will personally be contacted by the Project Coordinator to encourage participation and plan interviews. The Hills & Dales Executive Director will send an e-mail to Hills & Dales management staff encouraging participation. The Project Coordinator will also present information about **United for Change** at the weekly Hills & Dales Management meeting. This information will not only promote management's participation in individual interviews, but aims to increase supervisors' buy-in with the project to encourage their staffs' participation in direct service provider focus groups.

*Board of Directors:* The Executive Directors of each organization will present information about **United for Change** periodically at board meetings to increase familiarity and buy-in. To facilitate participation in the needs assessment web-based survey, the Project Coordinator will e-mail information about participating in the needs assessment and a link to all board members. The Executive Directors will also distribute a paper copy of this information in at least one board meeting. Based on participation rates, the Executive Directors may send a second recruitment e-mail to board of directors.

*Outside Collaborators:* The Grant Team will compile an e-mail list of important outside collaborators who are integral to our service systems and who bidirectionally affect and are affected by it. The Project Coordinator will send an e-mail to this group explaining the collaboration, the needs assessment, and their part in it. This e-mail will include a link to the web-based survey. A second e-mail about the needs assessment and participation will be sent two weeks later to encourage more to participate. Staff at both organizations who work closely with identified collaborators will be asked to provide information about the needs assessment and encourage collaborators' participation through routine meetings and other personal contact.

### **Incentives**

We understand that participation in the needs assessment requires a significant time commitment. We greatly appreciate stakeholders' willingness to help **United for Change** achieve our mission to create a cohesive and holistic service system for people with intellectual disabilities who are survivors of sexual abuse/violence in Dubuque County, Iowa through strategic systems change. Clients and guardians who participate in focus groups and interviews will receive a \$20 gift card to Wal-Mart. This business was chosen because of the usability of products and services they sell. Provision of the gift card will not be contingent on completion of the focus group or interview. If an individual agrees to participate, but leaves early because of emotional discomfort, he/s/he will still receive the gift card. Staff will be paid for their time out of each organization's general fund.

## **Informed Consent**

Informed consent is vital to upholding people's rights and the values of **United for Change**. It is an ongoing process, which includes four elements:

1. **Information** – A person must be provided with all the information relevant to making a decision concerning their participation in the needs assessment. This includes the risks and benefits of participation, participants' rights, and an overview of the goals, process and use of the information collected.
2. **Understanding** – This information must be presented in language and through a mode of communication that is understandable to the participant. It is the responsibility of the facilitator to ensure that concepts are understood by the participant, and that they *actually* authorize what they *intend* to authorize.
3. **Voluntariness** – Consent must be freely given, and represent the determination of the individual who will participate, and not that of any other person. A person must be given sufficient opportunity to consider whether or not to participate, and coercion, either overt or subtle, must be absolutely avoided. Care must be taken to consider environment, which may limit (real or perceived) opportunities of individual choice. Employees and service recipients will be assured that their relationship with either agency will not be affected by their choice to participate, nor the information they provide.
4. **Decision-making capacity** – Potential participants must have the ability to determine whether participation is consistent with their preferences. They must be able to assess the possible and realistic consequences of participation with respect to their individual situation. If a person does not have the right to autonomous choice (i.e. has a legal guardian), the guardian must give proxy consent and the individual must give assent before they can participate.

## **Process for Obtaining Consent**

Because informed consent is an ongoing process, participants will be given the opportunity to provide initial consent for participation, and allowed the opportunity to withdraw themselves or their information at any stage of the needs assessment process. Risks exist in participating in a needs assessment, especially for people who may be survivors of violence. Therefore, information

will be given to all potential participants regarding resources for services at both organizations. Contact information for the Project Coordinator will also be provided to address any ongoing concerns regarding participation and information collected.

An active consent process will be used among people who are their own guardians. Potential needs assessment participants will be presented with informed consent information prior to interviews or focus groups in a mode which is understandable to each individual. The goals of the needs assessment will be explained, along with the risks and benefits of participation. Informed consent information will also indicate that participation is voluntary and that the information gained will be used internally by **United for Change** to develop systems change. Participants will be reminded that they have the right to withdraw from the needs assessment at any time. Confidentiality measures will also be explained. Participants will be asked to sign an Informed Consent Form (see Appendix G). The facilitator will countersign and date the form.

Among participants who are not their own legal guardian, a model of informed consent will be used which draws on existing Hills & Dales policy for client satisfaction services, but adds extra protections for questions regarding guardianship. For questions regarding service satisfaction, safety and access, guardians will need to give passive consent for the client to participate in the needs assessment. Guardians are generally not involved in the day-to-day decision-making of clients, and this consent process is similar to the procedure used for agency client satisfaction surveys. Requiring active consent from guardians has been shown to systematically bias sampling, and disempower minorities, low income individuals and individuals at risk. It can also reduce the sample size by up to 70%<sup>14</sup>. To facilitate truly informed passive consent, Hills & Dales will provide information to the guardian regarding the goals, methods, use of information and confidentiality protocol of the needs assessment. A Hills & Dales staff will then follow up with the guardian to make sure that the information was received and understood, and to answer any questions they may have, and to encourage the return of the active consent form (see below).

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<sup>14</sup> Tigges, B. B. (2003). Parental Consent and Adolescent Risk Behavior Research. *Journal of Nursing Scholarship*. 35(3):283-289.

Esbensen, F.A., Miller, M.H., Taylor, T., He, N. & Freng, A. (1999). Differential Attrition Rates and Active Parental Consent. *Evaluation Review*. 23(3): 316-335.

Guardians will also be provided contact information for the Project Coordinator and a two-week window to ask questions, address concerns, and/or opt out of participation. If no contact is made by the guardian, or if all questions are adequately addressed, consent will be assumed. We feel that this model empowers clients to have greater control in the needs assessment process.

It is also important to understand issues related to clients' experiences with guardianship to best serve both clients' and guardians' needs in service provision. However, these questions are outside of the normal satisfaction survey information and address issues not totally in agency control. Therefore, in order to ask clients about guardianship issues, we will require active written consent from guardians. If active consent is not obtained from all guardians of clients in a focus group, these questions will not be asked in this setting; they may be asked separately on an individual basis.

Based on federal guidelines (45 CFR 46), special efforts will be made to ensure that assent is obtained from adults who are not their own legal guardians. Prior to the time of the interview, the goals and methods of the needs assessment will be explained to the potential participant in a manner understandable to him or her. At the time of the interview, these concepts, along with risks and benefits of participation, and confidentiality will be explained to the potential participant using individually appropriate language and modes of communication. The participant will be asked to show they understand the information and what is being asked of them, and given the opportunity to ask questions or voice concerns. They will then be asked to verbally or physically assent or decline to participation. In multi-session interviews, participants will be asked to assent at the beginning of each session. The interview will be stopped if the participant indicates that they no longer wish to participate.

For e-mail/web-based survey methods, passive consent will be assumed based on completion and return of the survey. The recruitment information will include a description of the purpose of the needs assessment, use of data, and confidentiality protocol.



## **Confidentiality**

Confidentiality is a central value to **United for Change**. We believe that every person has the right to share information in a setting with people who are trustworthy, and every person has the right to have control (or input if they have a guardian) of the distribution of their information. We are committed to upholding this value. The accuracy of the needs assessment and the effectiveness of resulting strategic plans are based on the confidentiality ensured to participants.

*Mandatory reporting:* Hills & Dales and Riverview Center are mandatory reporters of dependent adult abuse. The structure of the needs assessment and the questions we will ask are designed to lessen the likelihood that mandated reporting requirements will be triggered by the information shared. However, disclosures of abuse may occur. We acknowledge that the confidentiality we aim to provide participants does not negate our responsibilities as mandated reporters. Iowa Code Chapters 235B (Adult Abuse) and 235E (Dependent Adult Abuse in Facilities and Programs) require that all persons, who in the course of employment, examine, attend, counsel, or treat a dependent adult and reasonably believe the dependent adult has suffered abuse shall report the suspected dependent adult abuse. This includes all facilitators of the needs assessment. Appendix M outlines statutory definitions associated with mandatory reporting in the state of Iowa.

If a situation arises where a mandatory report is required, the facilitator will discuss the report with the participant and offer Riverview Center advocacy services after the interview or focus group has concluded. Staff will follow their organization's respective reporting and confidentiality policies, including guardian notification practices. There is not the expectation that any mandatory reports filed in the course of our work will be shared with the Grant Team. Our work is based on the assumption that all policies and mandates have and will be correctly followed.

In addition to our mandatory reporting requirements, Riverview Center functions under Iowa Code 915.20A (Victim Counselor Privilege), and Hills & Dales is bound by Health Insurance Portability and Accountability Act (HIPAA) regulations. Both Hills & Dales and Riverview Center have organizational confidentiality policies.

These policies are in place to uphold our clients' best interest and safety. Employees of each organization will continue to follow these policies in their daily work, and in any needs assessment activities. When working within the collaboration, the confidentiality protocol outlined here and in the **United for Change** Collaboration Charter will be followed.

*Confidentiality in interviews and focus groups:* As part of the informed consent process, potential participants will be informed of mandatory reporting requirements and their consequences. During interviews, all participants will be allowed to skip any questions they do not wish to answer. They will not be asked why they wish to limit the information they provide. Audio recordings will be made of interviews and focus groups. Participants will be allowed to opt out of recording before the interview or focus groups starts. Focus groups with staff will be held away from their site of work to protect their confidentiality. They will be asked to sign in rather than use the time clock to receive pay for their participation. The facilitators and the payroll accounting staff will be the only people with access to the sign-in sheets.

Prior to focus groups, participants will be required to sign a confidentiality agreement (see Appendix H). The agreement is modeled on the Group Confidentiality Agreement used by Riverview Center for group therapy sessions. A persons' participation in a focus group is dependent on this agreement. Any participants who have concerns with focus group confidentiality will be given the opportunity to participate in the needs assessment through an individual semi-structured interview instead. As with informed consent documents, the confidentiality agreement will be presented in language and using a mode of communication understandable to the participant.

Notes taken during focus groups and interviews will not use participants' names, and will instead use codes to identify them. Information will be stored in a password protected Microsoft Word document, and any e-mail indicating participation or nonparticipation will be deleted.

*Confidentiality of partner organization information:* As part of assessing how to create systemic change to improve services for survivors with disabilities, information regarding partner organizations' policies, practices and procedures will be collected. This information may include, but is not limited to, personal

disclosures of abuse/violence, job-related concerns, organization financials, service delivery protocols, and personnel capacity. Collaboration partner information will only be used to guide and enhance our work, and not in any punitive manner. To ensure a safe and open collaborative environment, information about individuals and organizations involved in the collaboration will be treated with respect and care, and never shared outside the Grant Team.

*Confidentiality in data management and analysis:* All data collected during the needs assessment will be stored by the Project Coordinator in a locked cabinet at the Hills & Dales administrative offices, or in password protected electronic files. Signed informed consent documents and confidentiality agreements will be stored separately from needs assessment data. Individual identifiers will be removed from data by the Project Coordinator immediately after data collection. An alphanumeric code will be used to refer to participants. Debriefing sessions and Grant Team discussions of data will be held in a private location. Audio files will be destroyed after transcription is complete, or after the Needs Assessment Report is approved by OVW, whichever comes first. Any potentially individually identifying information provided in interviews or focus groups will not be included in the Needs Assessment Report or any other subsequent materials. Only aggregate data will be distributed outside of the Grant Team.

### **Safety Considerations**

The concern for safety is central to our work. We believe that everyone has the right to feel physically and emotionally safe, and live without fear. Our collaboration strives to create systems that support safety and healing and foster comfortable and open environments which provide options and choice to survivors with disabilities. We will uphold this value in our needs assessment through the outlined confidentiality protocol in addition to the following measures:

- All interviews and focus groups will be held at the Riverview Center Dubuque offices, the Hills & Dales ICF/ID, or the Hills & Dales Community Center. These locations provide safe and comfortable environments for our participants. Participants will be allowed to choose where they take part in the needs assessment.

- Potential participants will be contacted through the organization with which they work most closely during regularly scheduled contact. Some former clients of Riverview Center may be asked to participate in the needs assessment. People who do not have regular contact with a collaborating organization will be contacted through a safe method of communication which they have identified.
- Individuals will be informed of mandatory reporting requirements and consequences prior to participation, therefore they will be fully aware of the legal implications of any information they choose to share. They will be allowed to skip any questions or terminate their participation at any time without reason.
- Personal Assistants are welcome to accompany a participant to the interview or focus group site; however, they will not be allowed to observe needs assessment methods. To uphold safety and confidentiality, substitute Personal Assistants will be available to anyone that requests an additional attendant or translator to accompany them during the interview or focus group. Alternatively, participants will be allowed to temporarily pause the focus group or interview to access personal care services. Regular Personal Assistants will be expected to uphold a participant's confidentiality and not discuss an individual's participation in the needs assessment with anyone.
- This needs assessment is designed to identify ways to improve our system of services for survivors with disabilities. However, discussing sexual abuse/violence may make the participant feel uncomfortable, and disclosures of abuse/violence may arise. At all interviews and focus groups, a Riverview Center legal/medical advocate will be available to provide support and options to anyone who may feel emotional discomfort. Participants may access the advocate before, during and after the interview or focus group. Information regarding additional resources will be provided (in various formats) to all participants.
- Staff of either organization outside of the Grant Team (and select Personal Assistants) will not be made aware of any clients' or other staffs' decision to participate or not participate in the needs assessment. The Grant Team and Personal Assistants, and anyone else who works closely with an individual who may know of their participation, are expected to hold their knowledge of any individual's decision to participate as confidential.

- Separate focus groups will be held with clients of each organization, direct service staff, and management personnel to avoid judgment, criticism, or retribution in relationships of asymmetrical power.

### **Access Considerations**

We believe that all survivors have the right to welcoming and flexible services which provide choice and meet their individual needs. It is the responsibility of service providers to remove the physical, attitudinal, programmatic and/or communicative barriers that prevent access to any and all services and supports offered, including this needs assessment. The validity of any needs assessment depends on the inclusion of all stakeholders. To best understand how to provide holistic services to all survivors in our community, we aim to avoid systematic exclusion of potential participants based on accessibility needs. To achieve this, we will use the following strategies:

- Everyone who plans to take part in the needs assessment will be asked to complete an RSVP form (see Appendix E). This form includes information on accessibility accommodations. This information can be provided in writing, by phone, in person, or via e-mail to the Project Coordinator or a service provider at either organization. Staff will forward this information to the Project Coordinator. All reasonable accommodations will be made, provided sufficient notice (two weeks prior to the event) is given. The Project Coordinator will be responsible for coordinating accessibility needs of participants, with the input and support of staff at both organizations.
- Needs assessment events will be scheduled at times and locations convenient to participants, when accessible transportation is available. All locations where needs assessment events will be held (Riverview Center, Hills & Dales ICF/ID and Hills & Dales Community Center) are fully accessible. Room selection for needs assessment activities will be based on confidentiality and accessibility concerns.
- If a participant requires special transportation, including a lift-equipped vehicle, the Project Coordinator with the support of Hills & Dales staff, will make arrangements for this need. If reasonable accommodations cannot be made, individual interview locations may be changed to allow for participation.

- Upon arrival, participants will be given an orientation to the facility. They will be asked if they have any accessibility needs based on the facility.
- Alternative forms of printed materials will be available on request through the registration form. These include Braille (provided by the Tri-State Independent Blind Society, Inc. in Dubuque), large print, electronic format, audio and plain language options. All written materials will be constructed in easy to understand language, however further accommodations may be necessary for some participants.
- Communication supports such as interpretation or active listening devices, and alternative forms of communication will be available upon request.
- Participants may bring their Personal Assistants; however, these people will not be allowed to be present during interviews or focus groups. Alternate Personal Assistants will be provided upon request. These supports will be recruited through Hills & Dales.
- All interview and focus groups questions, as well as all other needs assessment materials, have been reviewed by the Grant Team and other experts at our organizations for accessibility considerations. All materials have been constructed using people-first language. Participants in focus groups will be asked to refrain from using derogatory language in any way.
- If a person requires an accommodation not identified on the registration form, they are expected to contact the Project Coordinator or their service provider at either collaboration agency. A reasonable effort will be made to work with the individual and develop an accessibility plan.

## **Training Plans**

### **Recruiters**

*Hills & Dales:* Supervisory staff will assist in the recruitment of participants among clients, guardians of clients, and direct service staff. A stand-alone training session will be held with supervisors. In this training, the Project Coordinator will provide background information about the needs assessment purpose and process, and an overview of confidentiality and access protocols. S/he will also outline the specific inclusion and exclusion characteristics for each stakeholder group, and the recruitment targets. Detailed instructions will be given to supervisors about the recruitment protocol in an effort to standardize the process and ensure that all potential participants are given the same information, but in a way that is appropriate and highlights their needs and concerns. Supervisors will practice the recruitment protocol in this training. They will also be provided with a written instruction sheet for recruitment. Finally, recruitment fliers, RSVP forms, and information sheets will be given to all supervisors to distribute to clients, guardians and staff. (See Appendix B for instruction sheets for recruiters, Appendix C for recruitment fliers, and Appendix E for RSVP forms.)

*Riverview Center:* Direct service staff will assist in the recruitment of clients for participation in the needs assessment. A training session will be held with Dubuque office staff as part of the monthly All-Agency meeting. This training will be very similar to the training for Hills & Dales management staff, but will focus specifically on recruitment and needs of Riverview Center clients.

### **Facilitators, Note Takers and Support Staff**

The Project Coordinator will conduct a training session with the Grant Team members and any other staff who will help in the facilitation of any needs assessment methods. Training will include information about the purpose and specific use of each method, confidentiality protocols and method facilitation. The goal of this training is to ensure consistency throughout the needs assessment and to make sure that everyone has a clear understanding of their roles and responsibilities. Specific topics to be covered are:

- Background information on the needs assessment goals and the methods to be used.
- Confidentiality including the importance of not disclosing a person's participation outside the Grant Team, use of codes rather than names in

note taking, protection of written documents and audio recordings, password protection of electronic files, and information storage.

- Informed consent including voluntariness and incentives.
- Access and safety considerations for participants, including the roles and responsibilities of the Riverview Center advocate.
- Mandatory reporting responsibilities and the protocol and expectations of mandatory reporting during the needs assessment.
- Facilitation procedures, including informed consent, incentive distribution, background surveys, questioning and probes, wrap-up comments and referrals.
- Note taking and audio recording protocols, as well as the protocol for post-focus group debriefing sessions.
- Interviewing obstacles such as inconsistency, bias, leading questions, and assumptions.
- Creating a supportive and open environment for discussion.
- Identifying and avoiding disclosures of abuse.

A significant amount of training time will be devoted to reviewing the specific questions to be asked to participants, their meaning, and the purpose for their inclusion. The training will also review probes and follow-up questions to flush out initial responses. By having an in-depth understanding of the questioning strategy and the goals of the needs assessment, all facilitators will be better able to elicit targeted, relevant information, and avoid disclosures of abuse and other extraneous information which may cause emotional discomfort and/or threaten participants' safety.

The training will occur over two sessions where information will be presented in the first session, and the second session will provide the opportunity to practice implementing the protocols and addressing possible challenges.

A separate training will be held with the staff who will conduct interviews with Hills & Dales ICF/ID clients. Special strategies are needed for this stakeholder group due to these individuals' unique communication needs. This training will focus on rapport building, use of response facilitation cards and other strategies to elicit valid, reliable responses. It will also outline the protocols for the initial ICF/ID client session, which includes informed consent and background



information, and all other sessions which will all focus on a unique topic of discussion. Finally, this training will discuss the unique confidentiality issues of Hills & Dales clients including working with Personal Assistants.

## **Work Plan**

The following is our plan of work. It is an estimate, and will be continually revised. All steps will be carried out with consultation from Vera and OVW, and work will not progress until each deliverable is approved by OVW. We have a three-year time frame for activities funded by this grant, however the work of the collaboration will continue indefinitely.

Table 2: Plan of Work

<b><u>Activity</u></b>	<b><u>Tasks</u></b>	<b><u>Time Frame</u> <u>/Completion Date</u></b>
<b>Collaboration Charter Approved</b>		June 16, 2011
<b>Develop Needs Assessment Proposal</b>	<ul style="list-style-type: none"> <li>▪ Develop methodology and data collection tools</li> <li>▪ Determine sampling protocol</li> <li>▪ Elicit feedback from Vera</li> </ul>	May 2011 – September 2011
<b>All-Site Meeting</b>		June 2010
<b>Submit Needs Assessment Proposal to OVW</b>		September 1, 2011
<b>Conduct Needs Assessment</b>	<ul style="list-style-type: none"> <li>▪ Implement needs assessment proposal</li> </ul>	Mid-October 2011- December 2011
<b>Develop Needs Assessment Report</b>	<ul style="list-style-type: none"> <li>▪ Analyze data (create themes, code, run statistics, etc.)</li> <li>▪ Determine key findings</li> <li>▪ Elicit feedback from Vera</li> </ul>	November 2011 – January 2012

	▪ Write report	
<b>All Site Meeting</b>		November 2011
<b>Submit Needs Assessment Report to OVW</b>		January 2012
<b>Develop Strategic Plan and Implementation Phase Budget</b>	<ul style="list-style-type: none"> <li>▪ Review needs assessment findings</li> <li>▪ Identify gaps in service provision</li> <li>▪ Determine priority areas for systems change</li> <li>▪ Develop implementation strategies</li> <li>▪ Determine implementation costs</li> <li>▪ Elicit feedback from Vera</li> </ul>	March 2012 – June 2012
<b>Submit Strategic Plan to BODs for approval</b>	<ul style="list-style-type: none"> <li>▪ Elicit feedback from BOD and other stakeholders</li> <li>▪ Revise and finalize plan</li> </ul>	June 2012
<b>Submit Strategic Plan to OVW</b>		July 2012
<b>Implement Strategic Plan</b>		August 2012

## **Appendices**

## Appendix A: Overview of Documents to be Used by Each Stakeholder Group

Document	Stakeholders										
	HD clients (ICFID)	HD clients (HCBS)	HD guardians for passive consent	HD guardians	RV clients	HD direct service staff	RV direct service staff	RV volunteers	Management	BODs	Outside collaborators
Recruitment Instructions 1					X						
Recruitment Instructions 2	X	X									
Recruitment Instructions 3				X							
Recruitment Instructions 4						X		X			
Recruitment flier 1					X						
Recruitment flier 2	X	X									
Recruitment flier 3						X	X		X		
Recruitment flier 4				X							
Recruitment flier 5 (e-mail)										X	X
Recruitment flier 6 (e-mail)								X			
Information Sheet 1			X	X	X	X	X	X	X	X	X
Information Sheet 2	X	X									
RSVP1				X	X						
RSVP2	X	X									
RSVP3						X	X	X			
RSVP4									X		
Focus Group Script 1				X	X	X	X	X			
Focus Group Script 2		X									
Script for ICF/ID Clients	X										
Interview Script									X		
Informed Consent 1				X	X						
Informed Assent/Consent 2	X	X									
Informed Consent 3						X	X	X	X		
Informed Consent 4			X								
Passive IC 1										X	X
Group Confidentiality Agreement 1				X	X	X	X	X			
Group Confidentiality Agreement 2		X									
Background survey 1					X						
Background survey 2	X	X									
Background survey 3						X	X		X		
Background survey 4				X							
Background survey 5								X			
Unique interview scripts	X								X		
Unique focus group scripts		X		X	X	X	X	X			
Unique e-mail/web-based survey										X	X
Community Resources	X	X	X	X	X	X	X	X	X		

**Appendix B: Recruitment Instructions**

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## **Instructions for Recruiting Riverview Center Clients**

**Staff recruiting Riverview Center clients:** Please invite **all of your clients** who fit the inclusion criteria to participate in the needs assessment. We would like to capture the perspectives of as many clients as possible, since they are the most important voice in what we do, and experts in our service provision.

### **Inclusion Criteria:**

People we want to interview are:

- At least 18 years of age
- Survivors of sexual abuse/violence
- Receiving advocacy OR counseling services
- Receiving services from Riverview Center's Dubuque Office

It is important that every potential participant receives the same invitation, and that they understand what participation involves.

### **You should explain to every client:**

- \_\_\_\_\_ The reason for the collaboration
- \_\_\_\_\_ The purpose of the needs assessment and how the information will be used
- \_\_\_\_\_ How they would participate
- \_\_\_\_\_ Benefits of participation
- \_\_\_\_\_ How we will protect their confidentiality
- \_\_\_\_\_ How participation is voluntary and will not affect their services here or elsewhere
- \_\_\_\_\_ Who they can contact with questions
- \_\_\_\_\_ How we will make accommodations so they can participate fully
- \_\_\_\_\_ How to register for participation

### **Steps of extending an invitation:**

1. Provide client with **recruitment flier, information sheet and RSVP form**.
2. Explain the **grant and collaboration**:
  - **United for Change** is a collaboration between Riverview Center and Hills & Dales, which aims to promote access and empower people with disabilities who are survivors of sexual abuse.
  - The purpose of our work is to (from mission):

- Utilize multidisciplinary expertise in a person-centered approach to service provision at Riverview Center and Hills & Dales
  - Enhance policy to better communicate and provide services between partner agencies
  - Eliminate barriers to enhance accessible, equitable and flexible service provision
  - Cultivate agency cultures that are respectful, safe and empowering
  - This is a long-term project initially funded by a three-year federal grant from the US Department of Justice, Office on Violence Against Women.
3. Explain the **needs assessment**:
- We are currently in the planning phase of this project. We are conducting a needs assessment to understand how our services can be improved to be more accessible to all people in our community, and how to best support people after they have experienced sexual abuse/violence.
  - In this needs assessment, we are talking to clients of Hills & Dales and Riverview Center, staff, management, and other stakeholders in our work.
  - We want to know about our services and how to make them more accessible and safe, not about experiences of sexual abuse/violence.
4. Explain **what clients are being asked to do**:
- We would like to interview YOU about your satisfaction with Riverview Center services, and ways we can improve and work with others to become more accessible and supportive.
  - You will be interviewed in a group with other Riverview Center clients
  - This interview will last approximately 1 to 1.5 hours
  - It will take place here at the Riverview Center office
  - It will be conducted by the **United for Change** Project Coordinator, a Riverview Center advocate and a Hills & Dales staff. No other Riverview Center or Hills & Dales staff will know what you say or even if you participated.
  - If you feel that you may be uncomfortable or unsafe in a focus group setting, you may opt to do an individual interview instead.
5. Explain the **benefits** of participation:
- All client participants will receive a \$20 gift card to Wal-Mart as a thank-you for their time and information.
6. Explain how we will protect their **confidentiality**:

- No information about your identity will be disclosed to anyone outside of the needs assessment facilitators.
  - No staff at Riverview Center will know if you participated, if you don't want them to know.
  - All individually identifying information will be immediately removed by the Project Coordinator, and notes will use a code for you, rather than your name.
  - Needs assessment results will only be reported in aggregate data, and will not include identifying information of any participant.
7. Explain how participation is **voluntary**:
- Participation will not impact the services you receive now, or any you may receive in the future in any way.
8. Explain **who to contact** with questions or concerns, or for an electronic RSVP form:
- Betsy Danforth – Project Coordinator  
1011 Davis Street  
Dubuque, IA 52001  
Phone: 563-556-7878  
E-mail: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)
9. Explain **accessibility accommodations**:
- The RSVP form asks for information about accessibility needs. We are committed to ensuring that every person who wants to participate can, this includes scheduling interviews at convenient times, and providing communication and other supports to facilitate participation.
  - Please DO NOT HESITATE to ask for accommodations. You can contact Betsy about any requirements you have.
  - Please contact her about this at least 2 weeks prior to your interview.
10. Explain how to **RSVP**:
- RSVP forms can be given to:
    - i. the counselor/advocate extending the invitation
    - ii. Jessica Pape or Emily Valentine at Riverview Center
    - iii. Betsy Danforth at the Hills & Dales administrative offices, in person, by mail, e-mail or over the phone
  - The counselor should offer to help the person complete the form, if necessary.



11. **Thank the potential participant**, and remind them of timeframe of the interview processes (weeks when they will be conducted) and **when RSVPs should be submitted**.

## **Instructions for Recruiting Hills & Dales Clients**

**Staff recruiting Hills & Dales clients:** Please invite **all of your clients** who fit the inclusion criteria to participate in the needs assessment. We would like to capture the perspectives of as many clients as possible, since they are the most important voice in what we do, and experts in our service provision.

### **Inclusion Criteria**

People we want to interview are:

- At least 18 years of age
- Receiving any (non-senior citizen) services/supports from Hills & Dales

It is important that every potential participant receives the same invitation, and that they understand what it involves. It is important that information is explained in a way that is understandable to the individual, and that the individual is allowed to ask questions and voice concerns.

### **You should explain to every client:**

- \_\_\_\_\_ The reason for the collaboration
- \_\_\_\_\_ The purpose of the needs assessment and how the information will be used
- \_\_\_\_\_ How they would participate
- \_\_\_\_\_ Benefits of participation
- \_\_\_\_\_ How we will protect their confidentiality
- \_\_\_\_\_ How participation is voluntary and will not affect their services here or elsewhere
- \_\_\_\_\_ Who they can contact with questions
- \_\_\_\_\_ How we will make accommodations so they can participate fully
- \_\_\_\_\_ How to register for participation

### **Steps of extending an invitation:**

(Please modify wording to relay concepts in a manner understandable to the client.)

1. Provide client with **recruitment flier, information sheet and RSVP form.**
2. Explain the **grant and collaboration:**

- **United for Change** is a collaboration between Riverview Center and Hills & Dales, which aims to promote access and empower people with disabilities who are survivors of sexual abuse.
  - The purpose of our work is to (from mission):
    - Utilize multidisciplinary expertise in a person-centered approach to service provision at Riverview Center and Hills & Dales
    - Enhance policy to better communicate and provide services between partner agencies
    - Eliminate barriers to enhance accessible, equitable and flexible service provision
    - Cultivate agency cultures that are respectful, safe and empowering
  - This is a long-term project initially funded by a three-year federal grant from the US Department of Justice, Office on Violence Against Women.
3. Explain the **needs assessment**:
- We are currently planning this project. We are asking questions to understand how our services can be improved to be more accessible everyone.
  - In this needs assessment, we are talking to clients of Hills & Dales and Riverview Center, staff, management, and other stakeholders in our work.
  - We want to know about our services and how to make them more accessible and safe, not about experiences of sexual abuse/violence.
4. Explain **what they are being asked to do**:
- We would like to ask YOU about your satisfaction with Hills & Dales services, and ways we can improve and work with others to become more accessible and supportive.
  - HCBS Clients:
    - i. We will interview you in a group with other Hills & Dales clients.
    - ii. This interview will last approximately one and a half hours.
    - iii. It will take place here at the Hills & Dales Community Center.
    - iv. The focus group will be conducted by the **United for Change** Project Coordinator, Michelle Schmitt, and a person from Riverview Center.
  - ICF/ID Clients:
    - i. We will interview you individually in your home.
    - ii. We may ask you questions on several days.
    - iii. Each session will last about 20 minutes.

- iv. The interview will be conducted by Kate Grebin.
  - No other people will know what you say, or even if you participated.
  - If you don't want to be interviewed in a group, you can do an individual interview instead.
- 5. Explain the **benefits** of participation:
  - You will receive a \$20 gift card to Wal-Mart if you participate.
- 6. Explain how we will protect their **confidentiality**:
  - No information about your identity will be shared with anyone outside of the needs assessment facilitators. However, all facilitators are mandatory reporters, so if you tell us about abuse you have suffered, we have to report it.
  - No staff at Hills & Dales will know if you participated, if you don't want them to know.
  - Your name will not be used in the notes we take.
  - Needs assessment results will only be reported in aggregate data, and will not include identifying information of any participant.
- 7. Explain how participation is **voluntary**:
  - Participation will not change the services you receive now, or any you may receive in the future in any way.
- 8. Explain **who to contact** with questions or concerns:
  - Betsy Danforth – Project Coordinator  
1011 Davis Street  
Dubuque, IA 52001  
Phone: 563-556-7878  
E-mail: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)
- 9. Explain **accessibility accommodations**:
  - The RSVP form asks for information about accessibility needs. We want to make sure that everyone who wants to participate can.
  - Please DO NOT hesitate to ask for accommodations. You can contact Betsy or Michelle about any requirements you have.
  - Please RSVP at least 2 weeks prior to your interview.
- 10. Explain how to **RSVP**:
  - RSVP forms can be given to:
    - i. the person extending the invitation
    - ii. Michelle Schmitt at the Hills & Dales Community Center
    - iii. Betsy Danforth at Hills & Dales administrative offices, in person, by mail, e-mail or over the phone

- The person extending the invitation should offer to help the person complete the form, if necessary.

11. **Thank the potential participant**, and remind them of timeframe of the interview processes (weeks when they will be conducted) and **when RSVPs should be submitted**.

## **Instructions for Recruiting Guardians**

**Staff recruiting guardians of Hills & Dales clients:** Please invite **guardians of adult clients** to participate in the needs assessment. We would like to capture the perspectives of as many stakeholders as possible. Guardians are an integral part of what we do, and experts in our service provision.

People we want to interview are **legal, medical, and/or financial guardians** of a person who is:

- At least 18 years of age
- Receiving any type of services/supports from Hills & Dales

It is important that every potential participant receives the same invitation, and that they understand what participation involves.

### **You should explain to every client:**

- \_\_\_ The reason for the collaboration
- \_\_\_ The purpose of the needs assessment and how the information will be used
- \_\_\_ How they would participate
- \_\_\_ Benefits of participation
- \_\_\_ How we will protect their confidentiality
- \_\_\_ How participation is voluntary and will not affect their services here or elsewhere
- \_\_\_ Who they can contact with questions
- \_\_\_ How we will make accommodations so they can participate fully
- \_\_\_ How to register for participation

### **Steps of extending an invitation:**

1. Provide guardian with **recruitment flier, information sheet and RSVP form.**
2. Explain the **grant and collaboration:**
  - **United for Change** is a collaboration between Riverview Center and Hills & Dales, which aims to promote access and empower people with disabilities who are survivors of sexual abuse.
  - The purpose of our work is to (from mission):
    - Utilize multidisciplinary expertise in a person-centered approach to service provision at Riverview Center and Hills & Dales

- Enhance policy to better communicate and provide services between partner agencies
  - Eliminate barriers to enhance accessible, equitable and flexible service provision
  - Cultivate agency cultures that are respectful, safe and empowering
  - This is a long-term project initially funded by a three-year federal grant from the US Department of Justice, Office on Violence Against Women.
3. Explain the **needs assessment**:
- We are currently in the planning phase of this project. We are conducting a needs assessment to understand how our services can be improved to be more accessible to all people in our community, and how to best support people after they have experienced sexual abuse/violence.
  - In this needs assessment, we are talking to clients of Hills & Dales and Riverview Center, their guardians, staff, management, and other stakeholders in our work.
  - We want to know about our services and how to make them more accessible and safe, not about experiences of sexual abuse/violence.
4. Explain **what they are being asked to do**:
- We would like to ask YOU about your satisfaction with Hills & Dales services, and ways we can improve and work with others to become more accessible and supportive.
  - We will interview you in a group with other guardians of Hills & Dales clients.
  - This interview will last approximately one and a half hours.
  - It will take place either at the Hills & Dales Community Center or the Hills & Dales Residential Center.
  - The focus group will be conducted by the **United for Change** Project Coordinator, a Hills & Dales staff member and a Riverview Center staff member.
  - No other people will know what you say, or even if you participated.
  - If you do not want to participate in a focus group, for safety, comfort or scheduling reasons, you may opt to do an individual interview instead.
5. Explain the **benefits** of participation:
- All participants will receive a \$20 gift card to Wal-Mart as a thank-you for their time and information.
6. Explain how we will protect their **confidentiality**:

- No information about your identity will be disclosed to anyone outside of the needs assessment facilitators.
  - No staff at Hills & Dales, or the person to whom you provide guardianship to will know if you participated, if you don't want them to know.
  - All staff of Hills & Dales are mandated by Iowa code to report any child or dependent adult abuse, so if you tell us about previously unidentified about, we must report it.
  - All individually identifying information will be immediately removed by the Project Coordinator, and notes will include a code for you, rather than your name.
  - Needs assessment results will only be reported in aggregate data, and will not include identifying information of any participant.
7. Explain how participation is **voluntary**:
- Participation will not impact the services you, your family, or the person you guard receive now, or any you may receive in the future in any way, or your relationship with Hills & Dales.
8. Explain **who to contact** with questions or concerns, or to get an electronic RSVP form:
- Betsy Danforth – Project Coordinator  
1011 Davis Street Phone: 563-556-7878  
Dubuque, IA 52001 E-mail: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)
9. Explain **accessibility accommodations**:
- The RSVP form asks for information about accessibility needs. We are committed to ensuring that every person who wants to participate can, this includes scheduling interviews at convenient times, and providing communication and other supports to facilitate participation.
  - Please DO NOT hesitate to ask for accommodations. You can contact Betsy about any requirements you have.
  - Please contact her about this at least 2 weeks prior to your interview.
10. Explain how to **RSVP**:
- RSVP forms can be given to:
    - i. the person extending the invitation
    - ii. Michelle Schmitt at the Hills & Dales Community Center
    - iii. Kate Grebin at the Hills & Dales Residential Center
    - iv. Betsy Danforth at Hills & Dales administrative offices, in person, by mail, e-mail or over the phone



- The person extending the invitation should offer to help the person complete the form, if necessary.

11. **Thank the potential participant**, and remind them of timeframe of the interview processes (weeks when they will be conducted) and **when RSVPs should be submitted**.

## **Instructions for Recruiting Staff and Volunteers**

**Management recruiting staff and volunteers:** Please invite **all direct service staff and Riverview Center hotline volunteers** to participate in the needs assessment. We would like to capture the perspectives of as many stakeholders as possible. Staff and volunteers are an essential voice. They facilitate the work of our organizations, and are experts in our service provision.

People we want to interview:

- Direct service staff at Hills & Dales and Riverview Center (Dubuque office only) who work at least occasionally with clients over the age of 18.
- Riverview Center hotline volunteers for Dubuque and Jo Davies Counties.
- Have been affiliated with the organization they serve for any length of time.

It is important that every potential participant receives the same invitation, and that they understand what it involves.

**You should explain to every staff or volunteer:**

- \_\_\_\_\_ The reason for the collaboration
- \_\_\_\_\_ The purpose of the needs assessment and how the information will be used
- \_\_\_\_\_ How they would participate
- \_\_\_\_\_ Benefits of participation
- \_\_\_\_\_ How we will protect their confidentiality
- \_\_\_\_\_ How participation is voluntary and will not affect their relationship with either organization
- \_\_\_\_\_ Who they can contact with questions
- \_\_\_\_\_ How we will make accommodations so they can participate fully
- \_\_\_\_\_ How to register for participation

**Steps of extending an invitation:**

1. Provide them with **recruitment flier, information sheet and RSVP form**.
2. Explain the **grant and collaboration**:
  - **United for Change** is a collaboration between Riverview Center and Hills & Dales, which aims to promote access and empower people with disabilities who are survivors of sexual abuse.
  - The purpose of our work is to (from mission):

- Utilize multidisciplinary expertise in a person-centered approach to service provision at Riverview Center and Hills & Dales
- Enhance policy to better communicate and provide services between partner agencies
- Eliminate barriers to enhance accessible, equitable and flexible service provision
- Cultivate agency cultures that are respectful, safe and empowering
- This is a long-term project initially funded by a three-year federal grant from the US Department of Justice, Office on Violence Against Women.

3. Explain the **needs assessment**:

- We are currently in the planning phase of this project. We are conducting a needs assessment to understand how our services can be improved to be more accessible to all people in our community, and how to best support people after they have experienced sexual abuse/violence.
- In this needs assessment, we are talking to clients of Hills & Dales and Riverview Center, their guardians, staff, management, and other stakeholders in our work.
- We want to know about our services and how to make them more accessible and safe, not about experiences of sexual abuse/violence.

4. Explain **what they are being asked to do**:

- We would like to ask YOU about your satisfaction with our services, your work with clients, and ways we can improve and work with others to become more accessible and supportive.
- We will interview you in a group with other staff or other volunteers.
- This interview will last approximately one and a half hours.
- It will take place either at the Hills & Dales Community Center or the Hills & Dales Residential Center for Hills & Dales staff. It will take place at the Riverview Center Dubuque office for the hotline volunteers.
- The focus group conducted by the **United for Change** Project Coordinator, a Hills & Dales and a Riverview Center staff member.
- No other people will know what you say, or even if you participated.
- If you do not want to participate in a focus group, for safety, comfort or scheduling reasons, you may opt to do an individual interview instead.

5. Explain the **benefits** of participation:

- Your participation will help us to create a more supportive environment for survivors with disabilities, and help to prepare staff to better serve these clients.
  - (for staff) You will be paid for your time.
6. Explain how we will protect their **confidentiality**:
- No information about your identity will be disclosed to anyone outside of the needs assessment facilitators.
  - No staff at either organization will know if you participated, including your supervisor.
  - All individually identifying information will be immediately removed by the Project Coordinator, and notes will include a code for you, rather than your name.
  - Needs assessment results will only be reported in aggregate data, and will not include identifying information of any participant.
7. Explain how participation is **voluntary**:
- Participation will not impact your relationship with Hills & Dales or Riverview Center in any way.
8. Explain **who to contact** with questions or concerns:
- Betsy Danforth – Project Coordinator  
1011 Davis Street  
Dubuque, IA 52001  
Phone: 563-556-7878  
E-mail: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)
9. Explain **accessibility accommodations**:
- The RSVP form asks for information about accessibility needs. We are committed to ensuring that every person who wants to participate can, this includes scheduling interviews at convenient times, and providing communication and other supports to facilitate participation.
  - Please DO NOT hesitate to ask for accommodations. You can contact Betsy about any requirements you have.
  - Please contact her about this at least 2 weeks prior to your interview.
10. Explain how to **RSVP**:
- RSVP forms can be given to:
    - i. the person extending the invitation
    - ii. Kate Grebin or Michelle Schmitt at Hills & Dales
    - iii. Jessica Pape or Emily Valentine at Riverview Center

- iv. Betsy Danforth at Hills & Dales administrative offices, in person, in her mailbox, by mail, e-mail or over the phone

11. **Thank the potential participant**, and remind them of timeframe of the interview processes (weeks when they will be conducted) and **when RSVPs should be submitted**.

## **Appendix C: Recruitment Fliers**

1. Riverview Center Clients .....	59
a. Passed out and placed in reception areas of Dubuque office	
2. Hills & Dales Clients .....	60
a. Passed out	
3. Staff .....	61
a. Passed out, placed in common areas, paycheck stuffer, e-mailed	
4. Guardians .....	62
a. Mailed, passed out	
5. Boards of Directors and Outside Stakeholders.....	63
a. E-mailed, passed out	
6. Riverview Center Volunteers .....	64
a. E-mailed, passed out	



**We want to talk to YOU about your experiences and your perspective on the services we provide.**

To promote access and empower our clients, Hills & Dales and Riverview Center are reviewing our existing services to create a better system of services for all members of our community.

**Client participants will receive a \$20 Wal-Mart gift card.**

We will be conducting focus groups, interviews and surveys with many stakeholders at both organizations. Interviews are confidential. No information about your identity will be disclosed outside of the needs assessment facilitators.

**HOW TO PARTICIPATE:** Please complete a **RSVP form**. RSVP forms can be found in the waiting area, or from a counselor or advocate. RSVP forms can be returned to any Riverview Center staff, or Betsy Danforth at Hills & Dales.

If you have questions, or would like more information or an electronic RSVP form, please contact:

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street**

**Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

This project is part of the Department of Justice, Office on Violence Against Women grant Hills & Dales and Riverview Center received.



**We want to know what you think!**

Hills & Dales is working with Riverview Center. We want to make our services better.

**We want to know**

- what you like and do not like about Hills & Dales
- what makes you feel safe
- what makes you feel welcome

You will receive a \$20 Wal-Mart gift card!

**Please tell a Hills & Dales staff if you want to help!**



# **We want to talk to YOU about your experiences and your perspective on the services we provide.**

To promote access and empower our clients, Hills & Dales and Riverview Center are reviewing our existing services and assessing the needs of our organizations

**to create a better system of services for people in our community.**



We will be holding focus groups with staff. Each focus group will last between 1 and 1.5 hours. Separate focus groups will be held with direct service staff, supervisors and volunteers. This is confidential and no information about your identity will be disclosed outside of the focus group participants and needs assessment facilitators.

**You will be paid for your time.**

**HOW TO PARTICIPATE:** Please complete a **RSVP form**. RSVP forms are located in the break room and at reception.

They can be returned to Kate Grebin or Michelle Schmitt (Hills & Dales), Jessica Pape (Riverview Center), or Betsy Danforth in person, by phone, or by e-mail.

If you have questions, or would like more information or an electronic RSVP form, please contact:

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street  
Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

Dear \_\_\_\_\_,

**You are invited to participate in an interview about services provided by Hills & Dales, and the needs of people with disabilities.**

In the Fall of 2010, Hills & Dales received a grant from US Department of Justice, Office on Violence Against Women to collaborate with Riverview Center to **promote access to services for all community members and empower our clients.** To achieve this goal, we are conducting focus groups, interviews and surveys with clients, staff, guardians and other stakeholders of both organizations.



**We want to talk to YOU about your experiences and your perspective on the services we provide.** Your participation is confidential and no information about your identity will be disclosed outside of the needs assessment facilitators.

**Participants will receive a \$20 Wal-Mart gift card.**

**HOW TO PARTICIPATE:** Please complete a **RSVP form**, and return it to Kate Grebin, Michelle Schmitt or Betsy Danforth at Hills & Dales by phone, mail, or e-mail.

If you have questions, or would like more information or an electronic RSVP form please contact:

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street  
Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

Dear \_\_\_\_\_,

You are invited by **United for Change** to participate in a survey about services provided by Hills & Dales and Riverview Center, in order to better serve our clients.

In the Fall of 2010, Hills & Dales received a grant from the US Department of Justice, Office on Violence Against Women to work with Riverview Center and develop a comprehensive system of safe, accessible services in Dubuque County.



The result of this collaboration is **United for Change**. Our **vision** is to empower people with disabilities who are survivors of sexual abuse in their journey from crisis to healing.

**To effectively and sustainably achieve these goals, Hills & Dales and Riverview Center is reviewing our existing services and assessing the needs of our organizations to create a better system of services for our clients.**

**We want to know YOUR experiences and your perspective on the services we provide.** The attached document explains the needs assessment, including the purpose, risks and benefits, and confidentiality protocol.

**If you wish to help us in our goal of better serving survivors with disabilities, please complete this short survey. We thank you for your participation.**

**([Web Link HERE](#))**

**If you do not wish to participate, simply ignore this invitation.**

**If you have any questions or would like further information, please contact:**

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street**

**Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

Dear \_\_\_\_\_,

**We want to talk to YOU about your experiences and your perspective on the services we provide.**

**To promote access and empower our clients, Hills & Dales and Riverview Center are reviewing our existing services and assessing the needs of our organizations**

**to create a better system of services in our community.**



We will be conducting focus groups, interviews and surveys with clients, staff, and other stakeholders of both organizations.

We will be holding focus groups with volunteers of Dubuque and Jo Daviess County. Each focus group will last between 1 and 1.5 hours. Your participation is confidential and no information about your identity will be disclosed outside of

the focus group participants and needs assessment facilitators.

**HOW TO PARTICIPATE:** Please complete the **RSVP form** attached to this e-mail and return it to Emily Valentine or Betsy Danforth in person, by phone, or by e-mail.

If you have questions, or would like more information, please contact:

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street**

**Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

This project is part of the Department of Justice, Office on Violence Against Women grant Hills & Dales and Riverview Center received.

## **Appendix D: Information Sheets**

1. General Information Sheet .....	66
2. Plain Language Information Sheet .....	67

## **Promoting safety and access in the Dubuque community.**

**Who:** **United for Change** is a collaboration between Hills & Dales and Riverview Center.

This project is funded by a three-year grant from the US Department of Justice, Office on Violence Against Women.

**What:** We are currently conducting a needs assessment to create a plan to improve service systems between our agencies. We want to know our existing strengths and weaknesses how we can make our services safe, accessible, and empowering.

Our **vision** is to create a comprehensive service system that is person-centered and accessible.

- We will empower people with disabilities who are survivors of sexual abuse/violence in their journey from crisis to healing.

Our **mission** is to create a cohesive and holistic service system for people with developmental disabilities who are survivors of sexual abuse in Dubuque County, Iowa. This will be accomplished through innovative agency collaboration which:

- Utilizes multidisciplinary expertise in a person-centered approach to service provision at Riverview Center and Hills & Dales
- Enhances policy to better communicate and provide services between partner agencies
- Eliminates barriers to enhance accessible, equitable and flexible service provision
- Cultivates agency cultures that are respectful, safe and empowering

**Why:** **People with disabilities are at an increased risk for sexual abuse/violence.**

- People with disabilities are 4 to 10 times more likely to be sexually assaulted than the general population.
- Women with intellectual disabilities are less likely to contact rape crisis centers in general.
- **All people have the right to equitable, accessible support services.**

**Hills & Dales and Riverview Center are committed to come together to break down barriers and injustice facing people in our community.**



## **Promoting safety and access in Dubuque.**

**Who:** **United for Change** is a project between

- Hills & Dales
- Riverview Center

**What we want to do:** We want to make sure that people can get services to help them. We want to make sure that everyone receives the best services for them. We can do this by working together.



**Everyone deserves respect.**

**Everyone should be safe.**

Everyone should have a say in the services they receive.

**Why: People with disabilities:**

- are more likely to be sexually abused.
- have less access to services.
- may not know who to contact when they need help.
- may not get the help they need.

**All people have the right to services to help THEM heal.**

**Every person is unique, and needs unique services.**

Hills & Dales and Riverview Center want to work together. We want to break down barriers for people to get help.

**We want to ask you what we can do to make services better for everyone.**

## **Appendix E: RSVP Forms**

1. RSVP Form for Hills & Dales Clients and Guardians, and Riverview Center  
Clients.....69
2. RSVP Form for Staff and Volunteers.....71
3. RSVP Form for Management.....73



**RSVP Form for United for Change Focus Group/Interview**

All information on this form is confidential.

Please tell us how we can make the session accessible for you.

Name: \_\_\_\_\_

- ☐ I wish to participate a focus group for **United for Change**

☐ I wish to participate, BUT ONLY in an alternative individual interview

If you want to participate in a **focus group**, please rate the top three best times for you to participate:

_____ Date 1	_____ Date 2	_____ Date 3
_____ Date 4	_____ Date 5	_____ Date 6

- ☐ Any of these options is fine
- ☐ None of these options work for me. A better time is: \_\_\_\_\_

If you wish to participate in an **individual interview only**, what are three good times for you?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

What is the best way to contact you? (Betsy will contact you to confirm date/time/accommodations.)

- ☐ Phone: \_\_\_\_\_ Is it safe to leave a message?    Yes    No
- ☐ Text Message: \_\_\_\_\_
- ☐ E-mail: \_\_\_\_\_
- ☐ Other: \_\_\_\_\_

What is the best time to contact you? \_\_\_\_\_

Do you require any of the following accommodations?

- ☐ Alternative written materials (please circle)  
                    large print    /    Braille    /    plain language
- ☐ Audio or help with reading
- ☐ Note taker
- ☐ Enhanced listening device
- ☐ Alternative communication method: \_\_\_\_\_
- ☐ Open captioning
- ☐ Orientation to facility
- ☐ Transportation coordination
- ☐ Interpreter            Type: \_\_\_\_\_
- ☐ Personal care attendant (Because of confidentiality, your regular Personal Assistant will not be allowed in the interview room.)
- ☐ Other requests: \_\_\_\_\_

**Please return this form to any staff at Hills & Dales or Riverview Center, attention Betsy Danforth.**

Please contact Betsy if you have any questions or concerns as well.

Hills & Dales  
Attn: Betsy Danforth  
1011 Davis Street  
Dubuque, IA 52001

Phone: 563-556-7878  
Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org).

Thank you, and we appreciate your participation. If you have any questions or concerns, please contact Betsy Danforth, **United for Change** Project Coordinator at 563-556-7878 or [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org).

**RSVP Form for Staff and Volunteers Focus Group/Interview**

All information on this form is confidential.

Please tell us how we can make the session accessible for you.

Name: \_\_\_\_\_

Position: \_\_\_\_\_

- ☐ I wish to participate a focus group for **United for Change**

☐ I wish to participate, BUT ONLY in an alternative individual interview

If you want to participate in a **focus group**, please rate the top three best times for you to participate:

_____ Date 1	_____ Date 2
_____ Date 3	_____ Date 4
_____ Date 5	_____ Date 6

- ☐ Any of these options is fine
- ☐ None of these options work for me. A better time is: \_\_\_\_\_

If you wish to participate in an **individual interview only**, what are three good times for you?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

What is the best way to contact you? (Betsy will contact you to confirm date/time/accommodations.)

- ☐ Phone: \_\_\_\_\_ Is it safe to leave a message?    Yes    No
- ☐ Text Message: \_\_\_\_\_
- ☐ E-mail: \_\_\_\_\_
- ☐ In person during 1<sup>st</sup> shift work hours
- Time/Day/Location: \_\_\_\_\_
- ☐ Other: \_\_\_\_\_

Thank you, and we appreciate your participation. If you have any questions or concerns, please contact Betsy Danforth, **United for Change** Project Coordinator at 563-556-7878 or [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org).

Do you require any of the following accommodations?

☐ Alternative written materials (please circle)

large print   /   Braille   /   plain language

☐ Enhanced listening devices

☐ Audio or someone to read to me

☐ Note taker

☐ Alternative communication method: \_\_\_\_\_

☐ Open captioning

☐ Orientation to facility

☐ Transportation coordination

☐ Other requests:

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**Please return this form to any one of the following:**

- **Michelle Schmitt or Kate Grebin at Hills & Dales**
- **Jessica Pape or Emily Valentine at Riverview Center**
- **Betsy Danforth. It may also be e-mailed to [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

Please contact Betsy if you have any questions or concerns as well.

Hills & Dales

Attn: Betsy Danforth

1011 Davis Street

Dubuque, IA 52001

Phone: 563-556-7878

Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org).

Thank you, and we appreciate your participation. If you have any questions or concerns, please contact Betsy Danforth, **United for Change** Project Coordinator at 563-556-7878 or [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org).

**RSVP Form for Management Interviews**

All information on this form is confidential.

Please tell us how we can make the session accessible for you.

Name: \_\_\_\_\_

Position: \_\_\_\_\_

- ☐ I wish to participate an interview for **United for Change**
- ☐ I do not wish to participate in the **United for Change** needs assessment

If you wish to participate in an **individual interview**, what are three good times for you?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

What is the best way to contact you? (Betsy will contact you to confirm date/time/accommodations.)

- ☐ Phone: \_\_\_\_\_ Is it safe to leave a message?    Yes    No
- ☐ Text Message: \_\_\_\_\_
- ☐ E-mail: \_\_\_\_\_
- ☐ In person during 1<sup>st</sup> shift work hours
- Time/Day/Location: \_\_\_\_\_
- ☐ Other: \_\_\_\_\_

Do you require any accommodations for the interview?

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**Please return this form to a United for Change Grant Team Member (Betsy Danforth, Michelle Schmitt or Kate Grebin at Hills & Dales, or Jessica Pape or Emily Valentine at Riverview Center), or e-mail information to [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org).**

Thank you, and we appreciate your participation. If you have any questions or concerns, please contact Betsy Danforth, **United for Change** Project Coordinator at 563-556-7878 or [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org).

## **Appendix F: Scripts for Focus Groups and Interviews**

1. Focus Group Script 1 – Staff, Guardians, Riverview Clients and Volunteers.....	75
2. Focus Group Script 2 – Hills & Dales Clients .....	79
3. Script for ICF/ID Clients .....	82
4. Interview Script.....	85

## **Focus Group Script 1**

**Introduction:** Hello, my name is \_\_\_\_\_. This is \_\_\_\_\_ and \_\_\_\_\_. They will be helping me with the focus group. We are representatives from **United for Change**. **United for Change** is a collaboration between Hills & Dales and Riverview Center. Our goal is to provide better services for people with disabilities who have experienced abuse.

**Purpose:** This focus group is part of a needs assessment we are conducting with staff, clients and other stakeholders at both organizations. We want to know how we can improve our services and better support people with disabilities who have experienced abuse. I will ask you a series of questions about the quality of services and how they can be improved. We want to know how we can change, expand and work together as a collaboration. We are not looking to identify abuse or talk about experiences of abuse. The information from you and other stakeholders will only be used to improve services to create a sustainable, effective collaboration between our organizations.

This will be structured as a discussion. It will last between an hour and an hour and a half. I will ask general questions, and we hope that your responses will develop into a discussion of the issues presented. \_\_\_\_\_ will take notes and may add comments. \_\_\_\_\_ is present to support anyone who may become uncomfortable during the focus group.

*Ask:* Does anyone have any questions?

*Pass out Informed Consent Form.* I'm now going to explain the informed consent information. To participate in the focus group, you need to sign and date this form indicating that you understand the information and agree to it. This form explains your rights in participation, confidentiality protections, and the potential risks and benefits of participation.

**Voluntariness:** Participation is voluntary. You do not have to do this if you don't want to, and you may choose to leave at any point. Your choice to participate or not will not affect your relationship with either organization or their staff in any way. You are not required to answer any questions do you want to. Because we

are focusing on services and protecting your confidentiality, we feel that participation is of minimal risk to you.

*(For clients and guardians):* As a thank you, you will receive a \$20 gift card.

*Ask:* Does anyone have any questions?

**Confidentiality:** Confidentiality is very important to us. No one outside the focus group facilitators will know if you participated in a focus group, or the information that you specifically provided. All identifying information, like names, will be stored in secure files. The notes we take will use codes rather than your name. If it is ok with everyone, we will audio record the focus group. This recording will only be used by the project team to make sure that our notes are accurate. It will be deleted as soon as we are done with our notes.

*Ask:* Is it ok to record this?

*Pass out Group Confidentiality Form.* Because this is a group, it is everyone's responsibility to ensure that confidentiality is protected. This form explains the confidentiality guidelines. You must commit to these terms to participate in the focus group. Essentially, you must agree to not share any information about what was said here today with anyone. This includes staff at either organization, clients, or other stakeholders.

*Ask:* Does anyone have any questions?

**Mandatory Reporting:** Confidentiality cannot be totally guaranteed because Iowa has laws which require staff at Hills & Dales and Riverview Center to report certain types of suspected abuse to state authorities. If you talk about an incident of abuse with a child or someone with a legal guardian we have to report this information to state authorities. If you disclose this type of abuse, we will meet with you privately after the focus group to talk about the report. Please keep in mind that the questions are not designed to identify abuse, and we are looking for information about experiences with services, not abuse.

*Ask:* Does anyone have any questions?



**Safety:** Safety is a top priority of **United for Change**. Participation is entirely voluntary, and if you feel the group environment is unsafe at any time, you are free to exit at any point. \_\_\_\_\_ is a trained advocate from Riverview Center. If you are uncomfortable about any part of the conversation, s/he is available to meet with you privately during or after the focus group to provide emotional support as well as advocacy services. Please catch the attention of any focus group facilitators if you need any type of assistance.

*Ask:* Does anyone have any questions?

**General Guidelines:** There are a few general guidelines I'd like to go over.

- We ask that everything that is said in the focus group stays in the focus group. Please do not speak about anyone's involvement in the group; that would break the confidentiality agreement and other participants' privacy.
- Be respectful of others. When one person is talking, please do not interrupt or speak over them.
- Also, please respect others' opinions even if they differ from yours. We want to hear from everyone, and welcome a diversity of perspectives. There are no "right" or "wrong" answers to any question. We want everyone to feel free to express themselves.
- No one will be pressured to comment on every question, but your participation is greatly encouraged and appreciated. We are eager to hear from you.
- We respect your time. We have a lot of topics to cover, so I will keep the conversation moving. I may end a discussion to move on to a new topic. This does not mean that I don't want to hear more. If you have more to add, I would love to speak to you after the focus group about it.
- We ask that you turn off or silence your cell phones during the focus group so as not to distract others. Please take a moment now to silence it.
- We do not have any breaks scheduled, so please feel free to leave the room at any time. Restrooms are located \_\_\_\_\_. Also, please feel free to get up and get snacks at any time as well.

*Ask:* Does anyone have any questions?

If you are ok with participating and agree to maintain group confidentiality, please sign and date these forms. *Collect signature sheets.*

*For clients and guardians:* We will now distribute the thank you gift cards. When you receive it, please sign the tracking sheet so we can keep track of how many we've given out. If you don't want to take it now, you may leave it here and pick it up at your convenience. We want to support your comfort and safety, and therefore feel free to leave the focus group without any negative consequences.

*Insert questions for specific stakeholder group here.*

**Conclusion Script:** Thank you very much for participating in this focus group. We appreciate your participation. Your insights have been extremely valuable to us. If you have any further questions or concerns, or more information to add feel free to speak to one of us. If you have any questions or comments after you've left the focus group, you may contact me. This card has my contact information.  
*Pass out business card.*

This card has \_\_\_\_\_ (Riverview Center Advocate)'s contact information.  
*Pass out advocate's business card.*

*Pass out Community Resources Sheet.* If you are interested in disability or abuse services, this sheet provides information about options in Dubuque County. Thank you again for your help in this project.

## **Focus Group Script for Hills & Dales HCBS Clients**

**Introduction:** Hello, my name is \_\_\_\_\_. This is \_\_\_\_\_ and \_\_\_\_\_. They will be helping me today. We are from Hills & Dales, and from the Riverview Center. We are working together to have better services for people with disabilities who have experienced abuse. This project is called **United for Change**.

**Purpose:** We want to know how we can make our services better. I will ask you questions about what you like and don't like about Hills & Dales. I will ask you about some other things too. What you say will help us make services better.

This will last between an hour and an hour and a half. I will ask the questions. \_\_\_\_\_ will take notes and may add comments. \_\_\_\_\_ is here to help you if you feel uncomfortable. Tell me or \_\_\_\_\_ or \_\_\_\_\_ if you want to talk to \_\_\_\_\_ (Riverview Center advocate), or if you need a personal assistant.

*Ask:* Do you have any questions?

*Pass out Informed Consent Form.* I'm now going to explain this form. To participate today, you need to sign this to show that you understand and want to participate.

**Voluntariness:** You decide if you want to do this interview. It is ok if you don't. It won't change your services or your relationships with staff. You can stop at any time. You can ask questions. You can skip questions that I ask.

To thank you, you will get a \$20 Wal-Mart gift card.

*Ask:* Does anyone have any questions?

**Confidentiality:** We will not tell anyone what you said. It is confidential, which is kind of like a secret. It means that what we say here stays here. The people who work with you will not know what you said. Your family or friends will not know what you said. I would like to tape record what you say to help me remember. This is just for us. I will get rid of it when I'm finished writing my notes. I just want to make sure that everyone's ideas are noted.

*Ask:* Is it ok to record this?

*Pass out Group Confidentiality Form.* What people say here is a secret. Because this is a group, everyone must help. Don't tell anyone who was here or what they said. This means don't put anything on Facebook about this focus group, and don't tell your friends about it. You promise to keep this information secret by signing this form.

*Ask:* Does anyone have any questions?

**Mandatory Reporting:** If you report being abused, we have to report it. If you tell us that someone else has been abused, we might have to report it. If you report abuse, we will talk to you after the focus group. Someone is here to help you. Remember that we want to ask about services, not abuse.

*Ask:* Does anyone have any questions?

**Safety:** Safety is important. You can leave at any time. \_\_\_\_\_ is here to talk to you if you feel uncomfortable or unsafe. S/he can talk to you during the focus group, or after. If you feel uncomfortable you can talk to \_\_\_\_\_ at any time. Just get her attention or go over to her. You can also tell me or \_\_\_\_\_ (note taker) if you want to talk. There are also personal assistants if you need one.

**General Guidelines:** There are a few rules.

- Remember that what people say is confidential, which is kind of like a secret.
- Don't interrupt people.
- There are no "right" or "wrong" answers. There are no 'bad' answers.
- You don't have to talk if you don't want to. But we want to hear from you.
- If you want to take a break, let us know. You can leave any time you want.

*Ask:* Does anyone have any questions?

*Ask:* Do you understand this information?

*Ask:* Do you agree to participate?

*Ask:* Do you promise not to tell anyone else what people say here today?

*Pass out gift cards. This is \$20 you can spend at Wal-Mart. This is for helping us.*

*Insert questions for specific stakeholder group here.*

**Conclusion Script:** Thank you for your help. What you said will make things better for people with disabilities, and people who are abused. You can talk to one of us if you want to say more. You can talk to Michelle or Kate about it later too.

### **Script for ICF/ID Clients**

This information is intended to be conveyed to the client in language and in a mode of communication understandable to the individual. It will be modified by the interviewer to fit each client's needs.

### **First Meeting:**

**Introduction:** Hello, my name is \_\_\_\_\_. I am working on a project to make services better for people with disabilities who have been abused. The project is called **United for Change**.

**Purpose:** I want to know how we can make services better. Today, I will ask you questions about what you like and don't like. I will come back other days and ask you more questions. What you say will help us make services better.

*Ask:* Do you have any questions?

*Give participant Informed Consent Form.* I'm now going to explain this form. To help us, you need to show me you want to participate.

**Voluntariness:** You decide if you want to answer my questions. It is ok if you don't. It won't change your services or your relationships with staff. You can stop at any time. You can ask questions. You can skip questions that I ask. I will come back again to ask more questions. You can decide not to participate then, too.

You will receive at \$20 Wal-Mart gift card.

*Ask:* Do you want to do this?

**Confidentiality:** We will not tell anyone what you said. It is confidential, which is kind of like a secret. It means that what we say here stays here. The people who work with you will not know what you said. Your family or friends will not know what you said. I would like to tape record what you say. This is just for me to help me remember what you say. I will get rid of it when I'm finished writing my notes.

*Ask:* Is it ok to record this?

**Mandatory Reporting:** If you report being abused, we have to report it. Someone is here to help you get support. Remember that we want to ask about Hills & Dales and your likes and dislikes, not abuse.

*Ask:* Do you have any questions?

**Safety:** Safety is important. You can stop at any time. Someone is here to talk to you if you feel uncomfortable or unsafe. Tell me if you want to stop or need support.

- There are no “right” or “wrong” answers. There are no ‘bad’ answers.
- You don’t have to talk if you don’t want to. But I want to hear from you.
- If you want to take a break, let me know. We can stop any time you want.

*Ask:* Do you have any questions?

*Ask:* Is it ok to ask you some questions about Hills & Dales?

*Pass out gift card.* This is \$20 you can spend at Wal-Mart. This is for helping us.

*Insert specific questions here.*

**Conclusion of First Meeting:** Thank you for your help. I will come back in a few days to talk to you again. What you say will make services better for people with disabilities, and people who are abused. See you soon!

### **Subsequent Meetings:**

**Introduction:** Do you remember when I came and asked you some questions? I want to ask you some more today. Today we will talk about \_\_\_\_\_. Is that ok?

What you say will help us make services better for people with disabilities who have been abused.

Remember that you can stop at any time.

- There are no “right” or “wrong” answers. There are no ‘bad’ answers

- You don't have to talk if you don't want to. But I want to hear from you.
- If you want to take a break, let me know. We can stop any time you want.

*Ask:* Do you have any questions?

*Ask:* Is it ok to ask you some more questions?

*Insert specific questions here.*

**Conclusion of Second and Third Meetings:** Thank you for your help. I will come back in a few days to talk to you again. What you say will make services better for people with disabilities, and people who are abused. See you soon!

**Conclusion of last meeting:** Thank you for your help. What you said will make services better for people with disabilities, and people who are abused.



## **Interview Script**

**Introduction:** Hello, my name is Betsy. I'm the Project Coordinator for **United for Change**, which is a collaboration between Hills & Dales and Riverview Center. Our goal is to provide better services for people with disabilities who have experienced abuse.

**Purpose:** This interview is part of a needs assessment we are conducting with staff, clients and other stakeholders at both organizations. We want to know how we can improve our services and better support people with disabilities who have experienced abuse. The questions I will ask are about your thoughts on quality of services, how they can be improved and how we can change, expand and work together as a collaboration. We are not looking to identify abuse or talk about experiences of abuse. The information from you and other stakeholders will only be used to improve services to create a sustainable, effective collaboration between our organizations. This interview will last about one hour. I respect your time. We have a lot of topics to cover, so I may end a discussion to move on to a new topic.

*Give participant Informed Consent Form.* I'm now going to explain the informed consent information. To participate in the needs assessment, you need to sign and date this form indicating that you understand the information and agree to it. This form explains your rights in participation, confidentiality protections, and the potential risks and benefits of participation.

**Voluntariness:** Participation is voluntary. You do not have to do this if you don't want to, and you may choose to stop at any point. Your choice to participate or not will not affect your relationship with either organization or their staff in any way. You are not required to answer any questions you do not want to. Just tell me if you want to skip them. Because we are focusing on services and have implemented measures to protect your confidentiality, we feel that participation is of minimal risk to you.

*Ask:* Do you have any questions?

**Confidentiality:** Confidentiality is very important to us. No one outside the **United for Change** team will know if you participated, or the information that you provided. All identifying information, like names, will be removed immediately after the interview and notes and forms will be stored in secure files. If it is ok with you, I will audio record the interview. This recording will only be used by me to make sure that my notes are accurate. It will be deleted as soon as we are finished with our notes.

*Ask:* Is it ok to record this?

**Mandatory Reporting:** Confidentiality cannot be totally guaranteed because of mandatory reporting laws, where I must report certain types of suspected abuse to state authorities. If you talk about an incident of abuse with a child or someone with a legal guardian, we have to report this information. Please keep in mind that the questions are not designed to identify abuse, and we are looking for information about experiences with services, not abuse.

**Safety:** Safety is a top priority of **United for Change**. Participation is entirely voluntary, and if you feel uncomfortable or unsafe, you are free to stop at any point. A trained advocate from Riverview Center is available to meet with you privately after the interview to provide emotional support as well as advocacy services if you feel uncomfortable about any part of this conversation. Please tell me if you want to stop the interview, or if you need any type of assistance. I will also give you her contact information at the end of the interview.

*Ask:* Do you have any questions about any of the information I just presented?

If you agree to participate, please sign and date the Informed Consent Form.

*For clients and guardians:* This is your thank you gift card. Please sign the tracking sheet so we can keep track of how many we've given out. If you don't want to take it now, you may leave it here and pick it up at your convenience. We want to support your comfort and safety, and therefore feel free to leave the focus group without any negative consequences.

*Insert questions for specific stakeholder groups here.*

**Conclusion Script:** Thank you very much for your participation. We at **United for Change** appreciate your participation and your insights have been extremely valuable to us. If you have any further questions or concerns, please contact me. This card has my contact information. This card has the contact information for a Riverview Center advocate in Dubuque County. *Pass out business cards.*

*Give participant Community Resources Sheet.* If you are interested in disability or abuse services, this sheet provides information about options in Dubuque County. This also has contact information for Riverview Center advocacy services. Thank you again for your help in this project.

## **Appendix G: Informed Consent Documents**

1. Informed Consent 1 (Guardian and Riverview Center Client Participants) ..	89
2. Informed Consent 2 (Guardians of Potential Client Participants) .....	92
3. Participation Agreement for Needs Assessment (Informed Assent for Hills & Dales Clients) .....	96
4. Informed Consent 3 (Staff, Volunteers and Management) .....	99
5. Passive Informed Consent for Web-Based Surveys (BODs and Outside Stakeholders) .....	102

## **Informed Consent for Needs Assessment (1)**

You are being asked to be part of a project to understand how to better serve survivors of sexual abuse who have disabilities in Dubuque, Iowa. **This information describes this project and what is being asked of you. Please ask us any questions you may have before agreeing to participate.**

**United for Change** is a project between Hills & Dales and Riverview Center. We want to promote access and empower people with disabilities who are survivors of sexual abuse. We hope to create a service system between our agencies that is person-centered and accessible and eliminate barriers to services. This project is funded by a grant from the United States Department of Justice, Office on Violence Against Women.

### **PURPOSE**

The purpose of this 'needs assessment' is to create a better system of services for survivors of abuse with disabilities. To do this, we must understand the existing strengths of our organizations and the barriers that exist for accessing services. We are talking to many people, including direct service staff, management and leaders, clients of both agencies, and other people involved in our organizations to understand how to best serve all stakeholders.

This session will last 1 to 1.5 hours. It will be audio recorded, and notes will be taken about what is being said. These notes and recordings will not be distributed beyond the facilitators of the needs assessment, and will be destroyed immediately after the completion of this needs assessment.

**How this information will be used:** This information will be used only to improve our services, and will not impact your relationship with either organization in any way.

### **RISKS AND BENEFITS**

Your participation in this needs assessment is considered to be of minimal risk to you. Questions will focus on your opinions about services at Hills & Dales and/or Riverview Center. Self-disclosure of personal experiences is neither expected nor encouraged. It is possible that you may become uncomfortable by a topic in the

interview. If this occurs, an advocate will be available to assist you. It is also possible that information you provide could trigger mandatory reporting, as described below.

There are several benefits to participation. Your participation will help us to better serve our clients at Hills & Dales and Riverview Center. You will also receive a \$20 Wal-Mart gift card in appreciation for your participation.

## **YOUR RIGHTS**

**Your participation in this needs assessment is entirely voluntary.** Your choice will not affect your relationship with either agency in any way. You may choose to withdraw from the needs assessment at any time during the interview. You may choose to skip any questions that are asked, and will not be expected to provide a reason for this decision. You have the right to ask questions about the process at any point.

## **CONFIDENTIALITY**

**United for Change** values confidentiality, and will do everything possible to protect your information. No information about your identity will be disclosed outside of the interview facilitators. All individually identifying information will be immediately removed by the Project Coordinator, and notes will include a code for you rather than your name. Signed documents (including this form) will be stored separately from other needs assessment materials. All information will be stored in a locked cabinet at the Hills & Dales facility or in password protected computer files. Needs assessment results will only be reported in aggregate data, and will not include identifying information of any participant.

**Your choice to participate or not participate will not impact your relationship with either organization in any way.** No staff at either organization outside of needs assessment facilitators will know of your participation.

## **MANDATORY REPORTING**

All facilitators are mandatory reporters. This means that we are required by Iowa law to report certain instances suspected abuse, such as among dependent adults or abuse by caretakers, to state authorities. Questions in the needs assessment are designed to minimize disclosures of abuse. However, if you provide information that identifies previously unreported abuse of a child or dependent

adult, we are obligated to report it. The facilitator will discuss the report with you after the interview, and a Riverview Center advocate will be present to assist you.

### **CONTACT INFORMATION**

You have the right to ask, and have answered, any questions about this needs assessment now, or in the future. For further information, please contact:

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street**

**Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

### **STATEMENT OF CONSENT**

I fully understand the information contained in this document. I have had the opportunity to ask questions, and have received adequate answers. I understand that my participation is voluntary, and will not affect my relationship with Hills & Dales or Riverview Center now or in the future. I understand the risks and benefits of my participation, and I agree to participate.

---

Signature of Participant

---

Date

---

Printed name of Participant

---

Signature of Facilitator

---

Date

## **Informed Consent for Needs Assessment (2)**

Your ward is being asked to be part of a project to understand how to better serve survivors of sexual abuse who have disabilities in Dubuque, Iowa. **This information describes this project and what is being asked of you and your ward. Please ask us any questions you may have before agreeing to allow your ward to participate.**

This document must be signed and returned for your ward to fully participate in the needs assessment.

You do not need to return this form if you only wish your ward to be asked questions similar to the annual Hills & Dales satisfaction survey.

If you **do not** wish for your ward to participate at all, please contact:

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street**

**Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

**United for Change** is a project between Hills & Dales and Riverview Center. We want to promote access and empower people with disabilities who are survivors of sexual abuse. We hope to create a service system between our agencies that is person-centered and accessible and eliminate barriers to services. This project is funded by a grant from the United States Department of Justice, Office on Violence Against Women.

### **PURPOSE**

The purpose of this 'needs assessment' is to create a better system of services for survivors of abuse with disabilities. To do this, we must understand the existing strengths of our organizations and the barriers that exist for accessing services. We are talking to many people, including direct service staff, management and leaders, clients of both agencies, and other people involved in our organizations to understand how to best serve all stakeholders.



All interviews will be audio recorded (with participant agreement), and notes will be taken about what is being said. These notes and recordings will not be distributed beyond the facilitators of the needs assessment, and will be destroyed immediately after the completion of this needs assessment.

**How this information will be used:** This information will be used only to improve our services, and will not impact your or your ward's relationship with either organization in any way.

### **RISKS AND BENEFITS**

Your ward's participation in this needs assessment is considered to be of minimal risk. Questions will focus on your ward's opinions about services at Hills & Dales and/or Riverview Center. Self-disclosure of personal experiences is neither expected nor encouraged. It is possible that your ward may become uncomfortable by a topic in the interview. If this occurs, an advocate will be available to assist them. It is also possible that information they provide could trigger mandatory reporting, as described below.

There are several benefits to participation. Your ward's participation will help us to better serve our clients at Hills & Dales and Riverview Center. They will also receive a \$20 Wal-Mart gift card in appreciation for participation.

### **YOU AND YOUR WARD'S RIGHTS**

**Participation in this needs assessment is entirely voluntary.** Your choice to allow or disallow your ward to participate will not affect your or their relationship with either agency in any way. If you consent to your ward's participation, they will choose if they would like to participate or not. They may choose to withdraw from the needs assessment at any time during the interview. They may choose to skip any questions that are asked, and will not be expected to provide a reason for this decision. You and your ward have the right to ask questions about the process at any point.

### **CONFIDENTIALITY**

**United for Change** values confidentiality, and will do everything possible to protect your ward's information. No information about their identity will be disclosed outside of the interview facilitators. All individually identifying

information will be immediately removed by the Project Coordinator, and notes will include a code rather than your ward's name. Signed documents (including this form) will be stored separately from other needs assessment materials. All information will be stored in a locked cabinet at the Hills & Dales facility or in password protected computer files. Needs assessment results will only be reported in aggregate data, and will not include identifying information of any participant.

**Your choice to participate or not participate will not impact you or your ward's relationship with either organization in any way.** No staff at either organization outside of needs assessment facilitators will know of your ward's participation.

### **MANDATORY REPORTING**

All facilitators are mandatory reporters. This means that we are required by Iowa law to report certain instances suspected abuse, such as among dependent adults or abuse by caretakers, to state authorities. Questions in the needs assessment are designed to minimize disclosures of abuse. However, if your ward provides information that identifies previously unreported abuse of a child or dependent adult, we are obligated to report it. The facilitator will discuss the report with you and your ward after the interview, and a Riverview Center advocate will be present to assist.

### **CONTACT INFORMATION**

You have the right to ask, and have answered, any questions about this needs assessment now, or in the future. For further information, please contact:

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street**

**Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

**STATEMENT OF CONSENT**

I fully understand the information contained in this document. I have had the opportunity to ask questions, and have received adequate answers. I understand that my ward's participation is voluntary, and will not affect my or my ward's relationship with Hills & Dales or Riverview Center now or in the future. I understand the risks and benefits of my ward's participation, and I agree to allow them to participate.

---

Signature of Guardian

---

Date

---

Printed name of Participant

---

Signature of Facilitator

---

Date

## **Participation Agreement for Needs Assessment**

We want to ask you questions about Hills & Dales and what makes you feel safe.  
**This form explains what we want you to do. Please ask any questions you have.**

This is a project between:

1. Hills & Dales
2. Riverview Center

We are talking to many people to make our services better.

### **We want to:**

- work together
- help people with disabilities who have been abused
- what you like and don't like about Hills & Dales

**This information will be used only to improve our services.** It will not change the services you get now or how people treat you.

### **What to expect:**

- This interview will take about 1 hour.
- We will tape record it and write notes. No one else will see the notes or hear the tape.
- We will ask questions to everyone at the same time. Other people will know your answers.

### **Risks:**

You may be uncomfortable about some questions. You do not have to answer all the questions. Someone is here to talk if you want.

### **Benefits:**

You will help us to give better services to you and others.  
You will receive a \$20 Wal-Mart gift card at the end.

## **Your rights:**

1. You decide if you want to do this interview. It is ok if you don't.
2. You may:
  - **stop** at any time
  - **ask questions** at any time
  - **take a break** at any time
  - **skip questions** for any reason

**We will not tell anyone what you said.** Only **a few people** can look at this information. The people who work with you will not know if you did this interview.

## **If you report abuse:**

- We must report it. Iowa law says we must report any abuse to them.
- We will talk to you about the report.
- Someone is here to help you.

The questions we will ask are only about services you receive from Hills & Dales. We want to know how to make services better. This interview is not about finding out about abuse.



## **For questions later:**

**Betsy Danforth** is in charge of this project.

Her address is:

**1011 Davis Street**

**Dubuque, IA 52001**

Her phone number is:

**563-556-7878**

Her e-mail is:

[bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)

☐ **I understand**

☐ **I know that what I say will not change the services that I get**

☐ **I want to be part of this interview**

My Name: \_\_\_\_\_

\_\_\_\_\_  
Printed name of Participant

\_\_\_\_\_  
Signature of Facilitator

\_\_\_\_\_  
Date

### **Informed Consent for Needs Assessment (3)**

You are being asked to be part of a project to understand how to better serve survivors of sexual abuse who have disabilities in Dubuque, Iowa. **This information describes this project and what is being asked of you. Please ask us any questions you may have before agreeing to participate.**

**United for Change** is a project between Hills & Dales and Riverview Center. We want to promote access and empower people with disabilities who are survivors of sexual abuse. We hope to create a service system between our agencies that is person-centered and accessible and eliminate barriers to services. This project is funded by a grant from the United States Department of Justice, Office on Violence Against Women.

#### **PURPOSE**

The purpose of this 'needs assessment' is to create a better system of services for survivors of abuse with disabilities. To do this, we must understand the existing strengths of our organizations and the barriers that exist for accessing services. We are talking to many people, including direct service staff, management and leaders, clients of both agencies, and other people involved in our organizations to understand how to best serve all stakeholders.

This session will last 1 to 1.5 hours. It will be audio recorded, and notes will be taken about what is being said. These notes and recordings will not be distributed beyond the facilitators of the needs assessment, and will be destroyed immediately after the completion of this needs assessment.

**How this information will be used:** This information will be used only to improve our services, and will not impact your relationship with either organization in any way.

#### **RISKS AND BENEFITS**

Your participation in this needs assessment is considered to be of minimal risk to you. Questions will focus on your opinions about services at Hills & Dales and/or Riverview Center. Self-disclosure of personal experiences is neither expected nor encouraged. It is possible that you may become uncomfortable by a topic in the interview. If this occurs, an advocate will be available to assist you. It is also

possible that information you provide could trigger mandatory reporting, as described below.

There are several benefits to participation. Your participation will help us to better serve our clients at Hills & Dales and Riverview Center. If you are an employee of Hills & Dales or Riverview Center, you will be paid for your time spent participating in this needs assessment.

## **YOUR RIGHTS**

**Your participation in this needs assessment is entirely voluntary.** Your choice will not affect your relationship with either agency in any way. You may choose to withdraw from the needs assessment at any time during the interview. You may choose to skip any questions that are asked, and will not be expected to provide a reason for this decision. You have the right to ask questions about the process at any point.

## **CONFIDENTIALITY**

**United for Change** values confidentiality, and will do everything possible to protect your information. No information about your identity will be disclosed outside of the interview facilitators. All individually identifying information will be immediately removed by the Project Coordinator, and notes will include a code for you rather than your name. Signed documents (including this form) will be stored separately from other needs assessment materials. All information will be stored in a locked cabinet at the Hills & Dales facility or in password protected computer files. Needs assessment results will only be reported in aggregate data, and will not include identifying information of any participant.

**Your choice to participate or not participate will not impact your relationship with either organization in any way.** No staff at either organization outside of needs assessment facilitators will know of your participation.

## **MANDATORY REPORTING**

All facilitators are mandatory reporters. This means that we are required by Iowa law to report certain instances suspected abuse, such as among dependent adults or abuse by caretakers, to state authorities. Questions in the needs assessment are designed to minimize disclosures of abuse. However, if you provide information that identifies previously unreported abuse of a child or dependent



adult, we are obligated to report it. The facilitator will discuss the report with you after the interview, and a Riverview Center advocate will be present to assist you.

### **CONTACT INFORMATION**

You have the right to ask, and have answered, any questions about this needs assessment now, or in the future. For further information, please contact:

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street**

**Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

### **STATEMENT OF CONSENT**

I fully understand the information contained in this document. I have had the opportunity to ask questions, and have received adequate answers. I understand that my participation is voluntary, and will not affect my relationship with Hills & Dales or Riverview Center now or in the future. I understand the risks and benefits of my participation, and I agree to participate.

---

Signature of Participant

---

Date

---

Printed name of Participant

---

Signature of Facilitator

---

Date

## **Passive Consent for Web-Based Surveys**

You are being asked to be part of a project to understand how to better serve survivors of sexual abuse who have disabilities in Dubuque, Iowa. **This information describes this project and what is being asked of you. Please contact the Project Coordinator ([bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)) to ask any questions you may have.**

### **PURPOSE**

The purpose of this 'needs assessment' is to create a better system of services for survivors of abuse with disabilities. To do this, we must understand the existing strengths of our organizations and the barriers that exist for accessing services. We are talking to many people, including direct service staff, management and leaders, clients of both agencies, and other people involved in our organizations to understand how to best serve all stakeholders.

**How this information will be used:** This information will be used only to improve our services, and will not impact your relationship with either organization in any way.

### **RISKS AND BENEFITS**

Your participation in this needs assessment is considered to be of minimal risk to you. Questions will focus on your opinions about services at Hills & Dales and/or Riverview Center. Self-disclosure of personal experiences is neither expected nor encouraged. It is minimally possible that information you provide could trigger mandatory reporting, as described below.

There are important benefits to participation. Your participation will help us to better serve our clients at Hills & Dales and Riverview Center.

### **YOUR RIGHTS**

**Your participation in this needs assessment is entirely voluntary.** Your choice will not affect your relationship with either agency in any way. You may choose to skip any questions that are asked. You have the right to ask questions about the process.

## **CONFIDENTIALITY**

**United for Change** values confidentiality, and will do everything possible to protect your information. No information about your identity will be disclosed outside of the needs assessment facilitators. Any individually identifying information will be immediately removed by the Project Coordinator. All information will be stored in a locked cabinet at the Hills & Dales facility or in password protected computer files. Needs assessment results will only be reported in aggregate data, and will not include identifying information of any participant.

**Your choice to participate or not participate will not impact your relationship with either organization in any way.** No staff at either organization outside of needs assessment facilitators will know of your participation.

## **MANDATORY REPORTING**

All facilitators are mandatory reporters. This means that we are required by Iowa law to report certain instances of suspected abuse, including abuse of dependant adults, to state authorities. Questions in the needs assessment are designed to minimize disclosures of abuse. However, if you provide information that identifies previously unreported abuse of a child or dependent adult, we are obligated to report it.

## **CONTACT INFORMATION**

You have the right to ask, and have answered, any questions about this needs assessment now, or in the future. For further information, please contact:

**Betsy Danforth, United for Change Project Coordinator**

**1011 Davis Street**

**Dubuque, IA 52001**

**Phone: 563-556-7878**

**Email: [bdanforth@hillsdales.org](mailto:bdanforth@hillsdales.org)**

**Your completion of the survey indicates that you have no further questions about the needs assessment and that you consent to participation. We thank you for your participation.**

**If you do not wish to participate, simply ignore this invitation.**

**Appendix H: Focus Group Confidentiality Agreements**

1. General Focus Group Confidentiality Agreement.....	105
2. Plain Language Confidentiality Agreement .....	107

### **Focus Group Confidentiality Agreement 1**

Confidentiality in a group setting is special in that it is a shared responsibility of all group members, and the leaders. The following policy in the form of an agreement is an attempt to provide you with as much protection as possible.

#### **What is not OK:**

I will not disclose to anyone outside of the group any information that may help to identify another group member. This includes, but is not limited to, names, physical description, biographical information, and specifics of the content of the interactions with other focus group members.

I understand that although all other participants have agreed to this confidentiality statement, my confidentiality cannot be guaranteed due to the nature of the focus group.

#### **What is OK:**

I understand that I am free to disclose the fact that I participated in a focus group. I may also disclose personal information about myself with respect to my focus group experience. This includes my personal interactions, thoughts and feelings related to my focus group experience. I am aware that by disclosing this information, I run the risk of jeopardizing my own confidentiality.

**Statement of confidentiality:**

I have carefully read, or have had read to me, and understand the information and policy above and agree to follow the guidelines established. I have asked and had answered any questions I have regarding this agreement and am aware that signing this agreement is required for admission to the focus group. I am also aware that my refusal to sign this agreement will exclude me from participating in the focus group, but not an alternative individual interview, if I choose to do so.

---

Signature of Participant

---

Date

---

Printed Name of Participant

---

Signature of Facilitator

---

Date

## **Focus Group Confidentiality Agreement 2**

It is important not to tell others about what was said here. Everyone must agree to this. **This agreement will help to protect your information.**



**I will not tell anyone:**

- what was said in here
- who else is here



**It is OK to tell people:**

- what I said
- that I was here

**I understand that:**

- I have to follow these rules to participate in the group.
- Even if everyone here signs this form, someone may tell people what I said.

☐ **I understand**

☐ **I will not tell anyone who else was here or what they said**

My Name: \_\_\_\_\_

\_\_\_\_\_  
Printed name of Participant

\_\_\_\_\_  
Signature of Facilitator

\_\_\_\_\_  
Date

## **Appendix I: Background Information Surveys**

1. Background Information Survey for Riverview Center Clients.....	109
2. Background Information Survey for Hills & Dales Clients .....	110
3. Background Information Survey for Staff and Management .....	112
4. Background Information Survey for Guardians .....	115
5. Background Information Survey for Riverview Center Volunteers .....	117



## **Background Information Survey**

### **Riverview Center Clients**

This information should be collected prior to the interview. It may be completed by the client, or with the assistance of the interviewer.

**1. Gender**              Man              Woman

**2. What is your current age range?**

19-21

22-29

30-39

40-49

50-59

60+

**3. What services have you ever received from Riverview Center? (check all that apply)**

- ☐ 24-hour crisis line
- ☐ Legal Advocacy
- ☐ Medical Advocacy
- ☐ Individual Therapy
- ☐ Group Therapy
- ☐ Violence Prevention Education

**4. How long have you/did you receive services from Riverview Center?**

- ☐ Less than one month
- ☐ 1 to 6 months
- ☐ 6 months to 1 year
- ☐ 1 to 2 years
- ☐ More than 3 years
- ☐ Don't know

**5. Were you offered any accessibility accommodation or other supports at Riverview Center?**

Yes

No

Don't know

**6. Do you have any other comments?**

## **Background Information Survey**

### **Hills and Dales Clients**

This information should be collected prior to the interview. It may be completed by the client, or with the assistance of the interviewer. A list of services received by the client will also be collected from client record.

**1. Gender**              Man              Woman

**2. What is your current age range?**

19-21              22-29              30-39              40-49              50-59              60+

**3. What services do you receive from Hills & Dales? (check all that apply)**

- ☐ ICFID (Residential center)
- ☐ Group Respite
- ☐ Individual Respite
- ☐ HCBS
- ☐ Supported Community Living
- ☐ Day Habilitation
- ☐ Pre-Vocational Training
- ☐ Group Therapy
- ☐ Paid work
- ☐ Don't know

**4. Are you your own guardian?**              Yes              No

**5. If no, who is your guardian?**

- ☐ Parent
- ☐ Other relative
- ☐ Non-relative
- ☐ Publicly appointed

**6. If no, what type of powers does your guardian have?**

☐ Comprehensive

☐ Financial Only

☐ Other: \_\_\_\_\_

**7. How long have you received services from Hills & Dales?**

☐ Less than one year

☐ 1 to 2 years

☐ 3 to 5 years

☐ 5 to 10 years

☐ More than 10 years

**8. Have you received services from a similar agency?**

Yes

No

**9. If yes, which of the following apply?**

☐ I currently receive services/supports from more than one agency

☐ I left another agency to receive services from Hills & Dales

☐ I was no longer able to get services from a previous agency, so I came to Hills & Dales

**10. Do you have any other comments?**

## **Background Information Survey**

### **Staff**

This information should be completed by staff prior to the interview.
---

**1. Gender:**            Man            Woman

**2. What is your current age range?**

19-21

22-29

30-39

40-49

50-59

60+

**3. Agency where you work:** \_\_\_\_\_

**4. Facility/office where you work:** \_\_\_\_\_

**5. Position title:** \_\_\_\_\_

**6. Have you held any other positions in this organization?**    Yes    No

**7. If so, please list:** \_\_\_\_\_

**8. Describe your three primary job duties:**

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

**9. How long have you worked here?**

- ☐ Less than one year
- ☐ 1 to 2 years
- ☐ 3 to 5 years
- ☐ 5 to 10 years
- ☐ More than 10 years

**10. Have you worked with a survivor with a disability in the past?**

Yes

No

Don't know

**Approximately how many hours of training have you received regarding:**

**11.Sexual Violence**                      None 1-5    6-10    10+

**12.Domestic Violence**                      None 1-5    6-10    10+

**13.Disability Issues**                      None 1-5    6-10    10+

**14.Mental Health**                      None 1-5    6-10    10+

**Please rate your agreement with the following statements:**

**15.I am adequately trained to work with people with disabilities.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**16.I am adequately trained to work with survivors of sexual violence.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**17.(Hills & Dales staff only) I know the procedure for responding to a disclosure or sexual abuse.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**18.(Riverview Center staff only) I know the procedure for responding to the accommodation needs of a person with a disability.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**19.I am comfortable working with a person with a developmental disability.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**20.I am comfortable working with a survivor of sexual abuse.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**21.What is the highest level of education you have achieved?**

---

**22.Do you hold any licensure or certifications?**

---

---

**23.Do you have any other comments?**

## **Background Information Survey**

### **Guardians of Hills and Dales Clients**

This information should be collected prior to the interview. It may be completed by the guardian, or with the assistance of the interviewer.

**1. Gender**              Man              Woman

**2. What is your current age range?**

19-21              22-29              30-39              40-49              50-59              60+

**3. What is the gender of the person you guard?**      Man              Woman

**4. What is the age of the person you guard?**

19-21              22-29              30-39              40-49              50-59              60+

**5. What are the services that this person receives from Hills & Dales?**

- ☐ ICFID (Residential center)
- ☐ Group Respite
- ☐ Individual Respite
- ☐ HCBS
- ☐ Supported Community Living
- ☐ Day Habilitation
- ☐ Pre-Vocational Training
- ☐ Group Therapy
- ☐ Paid work
- ☐ Don't know

**6. How long has this person received services from Hills & Dales?**

- ☐ Less than one year
- ☐ 1 to 2 years
- ☐ 3 to 5 years
- ☐ 5 to 10 years
- ☐ More than 10 years
- ☐ Don't know

**7. Have you ever worked with a similar agency to receive these services?**

Yes                      No

**8. If yes, which of the following apply?**

- ☐ I currently receive services/supports from more than one agency
- ☐ I left another agency to receive services from Hills & Dales
- ☐ I was no longer able to get services from a previous agency, so I came to Hills & Dales

**Please rate your agreement with the following statements:**

**1. I am comfortable discussing sexuality with the person I guard.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**2. I am comfortable discussing abuse with the person I guard.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**3. The person I guard is safe in the community.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**4. The person I guard is safe at their workplace.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**5. The person I guard is safe at home.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**6. The person I guard is safe at Hills & Dales.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**9. Do you have any other comments?**



## **Background Information Survey - Riverview Volunteers**

This information should be completed prior to the interview.

**1. Gender**              Man              Woman

**2. What is your age range?**

19-21              22-29              30-39              40-49              50-59              60+

**3. How long have you been a volunteer at Riverview Center?**

- ☐ Less than one year
- ☐ 1 to 2 years
- ☐ 3 to 5 years
- ☐ 5 to 10 years
- ☐ More than 10 years

**4. Have you worked with a survivor with a disability in the past?**

Yes    No    Don't know

**Please rate your agreement with the following statements:**

**5. I am adequately trained to work with people with disabilities.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**6. I am adequately trained to work with survivors of sexual violence.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**7. I am comfortable working with a person with a developmental disability.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**8. I am comfortable working with a survivor of sexual abuse.**

1. Strongly Agree      2. Agree      3. Disagree      4. Strongly Disagree

**9. Do you have any other comments?**

## **Appendix J: Interview and Focus Group Questions and Probes**

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Questions are structured as one major issue to ask about, and optional probes which may be used to guide the discussion. Not all probes will be used in all focus groups; they will only be used when necessary. We hope that natural discussion will develop in these groups, rather than a facilitator led question and answer session.

## Focus Group Questions for Riverview Center Clients:

1. What things make you feel **comfortable and welcome** at an agency?
  - a. Think about people or agencies that have helped you in the past.  
How did you know you could trust them?
  - b. What characteristics do you like about an organization? (facility, staff, procedures, etc)
2. What things do agencies do that create **barriers or feel unwelcoming**?
  - i. Attitude
  - ii. Knowledge
  - iii. Culture
  - iv. Physical
3. What things at Riverview Center make you feel **welcome**?
  - a. Issues:
    - i. Staff
    - ii. Attitudes
    - iii. Facility/Physical characteristics
    - iv. Access
    - v. Services and resources provided
  - b. What happened the first time you contacted Riverview Center?
    - i. How did it make you feel?
4. What things at Riverview Center create **barriers or feel unwelcoming**?
  - i. Attitude
  - ii. Knowledge
  - iii. Culture
  - iv. Physical
  - a. How could they make their facility/services more welcoming?
5. What things make you feel **safe** at an agency or organization?
  - a. Think about people or agencies that have helped you in the past.  
How did you know you were safe there?
6. What things make you feel **unsafe** at an agency or organization?
  - i. Attitude
  - ii. Knowledge
  - iii. Culture
  - iv. Physical
7. What things make you feel **safe** at Riverview Center?
  - i. Staff

- ii. Physical space
  - iii. Practices and policies
- 8. What things at Riverview Center make you feel **unsafe**?
  - a. How could they make services safer?
  - b. How could they make their facility safer?
- 9. What do you **like** about Riverview Center?
  - i. Services offered?
  - ii. Confidentiality?
  - a. What are the benefits of coming here?
  - b. What promoted your healing? Do you feel like you can trust staff?
- 10. What can Riverview Center do to **improve**?
  - a. If any, think about a time when you felt disappointed by services you received (at Riverview Center or elsewhere). What made you feel that way?
    - i. What are some specific things they could have done differently?
  - b. What can Riverview Center do to make services easier for you to use?
  - c. What services/resources could be added?
- 11. How important is **confidentiality** to you?
  - a. Did staff explain the Riverview confidentiality policies to you?
  - b. Did they explain the limits of confidentiality protections?
  - c. How was this information presented to you?
  - d. Can you explain their confidentiality policy to me?
  - e. Was your confidentiality kept at Riverview Center? (please explain)
  - f. Did you feel safe to share information here (with the agency)?
- 12. What are some **important things that agencies need to know** about survivors of abuse? (*Alternative wording: When you go to agencies whose main focus is not sexual violence, what would you like them to know about survivors of violence?*)
  - a. About violence/abuse in general?
  - b. About providing services to those in the healing process?
  - c. What can organizations do to make you feel safer?
- 13. Has Riverview Center helped you **work with another agency**? If so, what happened?
  - a. Was it useful to you?
  - b. Were your needs met?

- c. Was it helpful to have Riverview Center involved?
  - d. Were you concerned about your confidentiality?
14. Is there any other information you think is important for us to know?

## Focus Group Questions for Hills & Dales HCBS Clients:

Participants will be provided with “yes”, “no” and “don’t know” cards and have signs on the wall to show them the icons. These cards will be used with close-ended questions to facilitate answers and help engage clients with more limited verbal ability.

Open-ended questions may be reformulated to be close-ended, and wording may be adapted to the communication needs and cognitive ability of the client. Follow up questions which reverse the concept may be asked to assess acquiesce. Questions may also be adapted to specifically apply to the services received by individual clients.

1. What is your favorite thing you did at Hills & Dales this Fall? *(to increase participant comfort)*
2. What do you **like** about Hills & Dales?
  - a. Staff
  - b. Building
  - c. Services
  - d. Other clients
3. What do you **dislike** about Hills & Dales?
  - a. Staff
  - b. Building
  - c. Services
  - d. Other clients
4. Do you feel **safe** at Hills & Dales?
  - a. What makes it feel safe?
5. Do you feel **safe** other places you go?
  - a. Examples: mall, boot scoot, etc.
6. Think about your **favorite personal assistant**. *(Facilitator will help each client identify an individual to think about as needed.)* What do they do that you like?
  - a. What do they do to help you?
  - b. Do you tell them when you are upset?
  - c. Do you tell them when you have a problem outside of Hills & Dales?
  - d. Now, think about all of the people that work with you at Hills & Dales.
    - i. Do they care about you?

- ii. Do they listen to you?
    - iii. Do they understand you?
    - iv. Are they patient with you?
  - e. Who do you tell when you have a problem?
7. **Questions involving guardianship:** These questions will only be asked in the focus group if all participants' guardians have provided written consent. These questions may be asked individually to those with written guardian consent if not asked in focus group setting. What things do you **like to do** here?
- a. Do you choose what services you get?
  - b. Who helps you make these choices?
  - c. If you do not choose, who does?
8. Does someone else help you **make decisions**?
- a. Do you know who your **guardian** is? *(Facilitator may help clients identify their guardian if necessary.)*
  - b. Do you have a relationship with them?
  - c. Does your guardian help you make decisions?
    - i. Do you want them more involved in your decisions?
    - ii. Do you want them less involved in your decisions?
  - d. Do you make decisions together?
  - e. Have you and your guardian ever disagreed about services?
    - i. (If yes) Did you tell someone about this?
    - ii. (If yes) Did you feel like people listened to you?
  - f. Does Hills & Dales and your guardian work together?
9. Where do you **get information**?
- a. What is the first place you go to get information?
    - i. Examples: news, internet, friends, guardian, Hills & Dales
  - b. Does Hills & Dales help you?
  - c. Does your guardian help you?
  - d. Do your friends help you?
  - e. Who would you ask to help you?
10. Is there anything else you want to say?

## **Interview Questions for Hills & Dales ICF/ID Clients**

These questions will be asked over one or more sessions depending on the responsiveness and needs of the client. Questions may be repeated on multiple occasions to check reliability.

These questions are written as separate yes/no questions, rather than as a main theme with optional probes as the other question sets are. This is due to the verbal ability of ICF/ID clients. No discussion is expected with these clients; therefore a larger number of questions is included.

Depending on the answers to questions, the grant team may meet to develop supplemental questions to gather more information. For example, if a client consistently answers that they feel unsafe, or that staff are mean to them, we may attempt to gather further details to better understand how we can improve services to be safer and more welcoming. Supplemental questions will be well considered to try to avoid leading questions or acquiescence, two major threats when interviewing people with cognitive disabilities. They will also be tailored to the unique individual needs and experiences of each client.

1. Do you like being at Hills & Dales?
2. Is there enough space here?
3. Is it easy to get places in the building?
4. Is it easy to get places in the community?
5. Do you like the services you get here?
6. Do you like the services you get \_\_\_\_\_ (fill in based on individuals' services – i.e. doctors, HCBS, etc)?
7. Are staff nice to you?
8. Do staff help you when you need it?
9. Do staff ask you before they do things?
10. Do staff care about you?
11. Do staff respect you?
12. Are staff patient with you?
13. Do staff listen to you?
14. Do staff here know what you like?
15. Do staff here know what you don't like?
16. Do staff help you when you have a problem?
17. Do you trust Hills & Dales staff?



18. Do you feel safe with staff?
19. Do you feel safe at Hills & Dales?
20. Do you feel safe at other places you go?

**Questions involving guardianship:** These questions will only be asked in the focus group if all participants' guardians have provided written consent.

1. Do you know who your guardian is?
2. Do you have a relationship with them?
  - a. If yes:
    - i. Do they (your guardian) help you?
    - ii. Do they (your guardian) do the best things for you?
    - iii. Do they (your guardian) listen to you?
    - iv. Do they (your guardian) help you when you have a problem?
    - v. Do you make decisions together?
    - vi. Have you and your guardian ever disagreed about services?

## Focus Group Questions for Guardians of Hills & Dales Clients:

1. When you are **looking for services** for \_\_\_\_\_, what are you concerned about?
  - a. Communication
  - b. Staff
  - c. Facility
  - d. Services
  - e. Attitudes
  - f. Accessibility/accommodations/flexibility
  - g. Advocacy
  - h. Cost
  - i. What qualities do you look for in services?
2. What kinds of things can agencies do to **show they care** about you and the person you guard?
  - a. To show they respect your perspective?
  - b. To show they value your input?
  - c. To make you feel welcome?
3. How are **decisions** made about services \_\_\_\_\_ receives?
  - a. Do you feel involved in decisions that are made about \_\_\_\_\_?
  - b. Does Hills & Dales do a good job coordinating with you to make decisions?
  - c. Do you think \_\_\_\_\_ is involved in decision-making?
  - d. Do you trust Hills & Dales to make good decisions about \_\_\_\_\_?
4. What **risks** do you worry about with \_\_\_\_\_?
  - a. What safety challenges have you faced with \_\_\_\_\_?
  - b. How do you deal with these?
  - c. What would help you in addressing these issues?
    - i. Training, education, staff support
5. How long have you worked with Hills & Dales?
6. Please tell me about how Hills & Dales fits into the **network of service providers** \_\_\_\_\_ works with.
  - a. Does Hills & Dales coordinate with other service providers?
    - i. If yes, what do they do well to coordinate their services with other providers'?
    - ii. If yes, what does Hills & Dales do that makes it hard to coordinate with other service providers?

1. What things could they do to better coordinate?
  - b. What other organizations would you want them to work with?
    - i. How do you find out about other service providers?
7. What does Hills & Dales **do well**?
  - a. Communication
  - b. Staff
    - i. Do you think that staff are well prepared to work with people with disabilities?
    - ii. Do you think staff are well prepared to respond to problems/issues that arise?
  - c. Facility
  - d. Services
  - e. Attitudes
  - f. Accessibility/accommodations/flexibility
  - g. Advocacy
  - h. Cost
8. What could Hills & Dales **do better**?
  - i. Services
  - ii. Communication
  - iii. Staff
  - iv. Facility
  - v. Policies
  - vi. Attitudes
  - vii. Accessibility/accommodations/flexibility
  - viii. Advocacy
  - ix. Cost
  - a. Have your perceptions of Hills & Dales changed over time?
9. Does Hills & Dales communicate their **policies** with you?
  - a. Are policies easy to understand?
  - b. Are policies effective in best serving the client?
  - c. Are you satisfied with Hills & Dales policies?
    - i. Policies:
      1. Confidentiality
        - a. Do other service providers do a good job protecting clients' confidentiality?
      2. Human Rights
      3. Safety

- d. Other issues:
  - i. Admissions process
- 10. What should non-disability service providers **know about working with people with disabilities**?
  - a. With guardians?
- 11. Is there any other information you think is important for us to know?

**Focus Group Questions for Hills & Dales Direct Service Staff (Personal Assistants, HCBS supervisors, Shift Leaders, Shift Nurses and CMAs):**

1. What do you do to make clients feel **welcome**?
  - a. What about Hills & Dales is welcoming?
  - b. What could Hills & Dales do to feel more welcoming?
  - c. What could other organizations do to feel more welcoming?
2. What do you do to make clients feel **safe**?
  - a. What about Hills & Dales facilities ensure safety?
  - b. What Hills & Dales practices and policies promote safety?
  - c. Are there things at Hills & Dales that are unsafe?
  - d. What can other organizations do to promote safety of clients?
3. What do you do to make clients feel **respected**?
  - a. What can other organizations do to make clients feel more welcome and respected?
4. What is Hills & Dales **confidentiality** policy?
  - a. Is it effective?
  - b. How do you know the policy?
  - c. Who has access to client information?
  - d. Do you think these protections are enough?
    - i. If no, what more could be done?
    - ii. If yes, do you think they are too strict? (How so? Why?)
5. Do you know the **signs that someone has been abused**?
  - a. What are they?
  - b. Are you confident in your ability to identify abuse?
6. If a client disclosed abuse, or you identified that a client was being abused, how would you **respond**?
  - a. How do you know what to do?
  - b. Are there policies/protocol to guide you?
  - c. Have you had training in identifying and responding to abuse? (If so, please explain.)
  - d. Do you feel prepared to respond to abuse?
    - i. If no, what would better prepare you?
  - e. Do you feel comfortable in responding to abuse?
    - i. If no, what would make you more comfortable?
7. What does Hills & Dales **do well**?
  - a. In meeting clients needs?

- b. In ensuring clients' safety?
  - c. In staffing/training?
  - d. In working with other service providers?
  - e. What is unique about your organization?
8. What are areas that Hills & Dales could **improve**? (*Alternative wording: Are there things that could be done differently?*)
- a. What are the main problems/challenges that you see here?
  - b. Think about a time that Hills & Dales didn't meet a client's needs. What happened?
    - i. What could be done to make sure this doesn't happen again?
  - c. What changes would you like to see?
    - i. To improve services in general?
    - ii. To better support staff?
    - iii. To improve staff skills?
    - iv. To improve staff interactions with clients?
    - v. To respond to abuse?
    - vi. To reduce client risk?
    - vii. To improve client safety?
    - viii. To better prepare staff for working with people who have experienced abuse?
9. (*for all staff EXCEPT ICF/ID Personal Assistants*) How do **guardians** affect your work?
- a. Can you talk about a time when a guardian made it easier to work with a client? What made it easier?
  - b. Can you talk about a time when a guardian made it more difficult for a client to get the services they need?
    - i. What were the challenges?
10. (*for shift leaders, HCBS supervisors and medical staff*) What **relationships** does Hills & Dales have with other service providers in the community?
- a. What works in these relationships?
  - b. What doesn't work?
    - i. Are there policies/practices that create barriers?
  - c. What could be done to make these relationships better?
11. Is there any other information you think is important for us to know?

### Focus Group Questions for Riverview Center Direct Service Staff:

1. What do you do to make clients feel **welcome**?
  - a. What about Riverview Center is welcoming?
  - b. What could Riverview Center do to feel more welcoming?
  - c. What could other organizations do to feel more welcoming?
2. What do you do to make clients feel **safe**?
  - a. What about Riverview Center's facility ensures safety?
  - b. What Riverview Center practices and policies promote safety?
  - c. What can other organizations do to promote safety of people who have experienced abuse?
3. What do you do to make clients feel **respected**?
  - a. What can other organizations do to make clients feel more welcome and respected?
4. What is Riverview Center's **confidentiality** policy?
  - a. Is it effective?
  - b. Who has access to client information?
  - c. How do you know the policy?
  - d. Do you think these protections are enough?
    - i. If no, what more could be done?
    - ii. If yes, do you think they are too strict? (How so? Why?)
5. What does Riverview Center **do well**?
  - a. In meeting clients' needs?
  - b. In responding to abuse?
  - c. In ensuring client safety?
  - d. In helping survivors heal?
  - e. In serving people with diverse needs?
  - f. In staffing/training?
  - g. In working with other service providers?
  - h. What is unique about your organization?
6. How could Riverview Center **improve**? (*Alternative wording: Are there things that could be done differently?*)
  - a. What are the main problems/challenges that you see here?
  - b. Think about a time that Riverview Center didn't meet a client's needs. What happened?
    - i. What could be done to make sure this doesn't happen again?
  - c. What changes would you like to see?
    - i. To improve services in general?

- ii. To better support staff?
  - iii. To improve staff skills?
  - iv. To improve accessibility?
  - v. To better prepare staff for working with people who have disabilities?
- 7. Have you had **experience working with a person with disabilities**?
  - a. If yes, how did you know the person had a disability?
  - b. If yes, can you tell me about how disability affected the way you provided services?
  - c. How comfortable are you working with people with disabilities?
    - i. Cognitive disabilities?
  - d. Do you feel prepared to work with people with cognitive disabilities?
  - e. Are you confident in your ability to serve people with disabilities?
  - f. What do you need to better serve people with disabilities?
  - g. Have you had training in working with people with disabilities? (If so, please explain)
    - i. What trainings would you like?
- 8. Have you had experience with adult **guardianship**?
  - a. If so, what happened?
    - i. How did it impact the way you provided services?
    - ii. How did you work with confidentiality?
    - iii. What were the challenges?
    - iv. In what ways was it beneficial?
  - b. If no, how may it impact your work?
- 9. What **relationships** does Riverview Center have with other entities in the community?
  - a. What works in these relationships?
  - b. What doesn't work?
    - i. Are there policies/practices that create barriers?
  - c. What could be done to make these relationships better?
- 10. Is there any other information you think is important for us to know?



### Focus Group Questions for Riverview Center Volunteers:

1. What do you do to make clients feel **welcome**?
  - a. What could other organizations do to feel more welcoming?
2. What do you do to make clients feel **safe**?
  - a. What could other organizations do to be safer?
3. What do you do to make clients feel **respected**?
  - a. What can other organizations do to make clients feel more respected and empowered?
4. What does Riverview Center **do well**?
  - a. In meeting clients' needs?
  - b. In responding to abuse?
  - c. In ensuring client safety?
  - d. In serving people with diverse needs?
  - e. In training?
  - f. In working with other service providers?
  - g. What is unique about this organization?
5. What are areas that Riverview Center could **improve**?
  - a. What are the main problems/challenges in your work?
  - b. Think about a time that you didn't meet a client's needs. What happened?
    - i. What could be done to make sure this doesn't happen again?
  - c. What could Riverview Center do to better support you as a volunteer?
  - d. What changes would you like to see?
    - i. To improve services in general?
    - ii. To better support volunteers?
  - e. To better prepare volunteers for working with people who have disabilities? In the community?
    - i. Service providers?
    - ii. Transportation?
    - iii. Accommodations?
6. Have you responded to a call of a **person with disabilities**?
  - a. If yes, how did disability affect how you respond?
    - i. How did you know they had a disability?
    - ii. Did you change the way you provided advocacy to the client?
      1. How?
    - iii. What unique issues did they face?

1. Legal
    2. Medical
    3. Safety planning
  - iv. What gaps/barriers were there?
    1. What improvements could be made?
    2. Are there tools/supports that would help you to respond?
  - b. Do you feel prepared in working with people with disabilities?
    - i. Confident? Comfortable?
  - c. Have you had training on disability issues?
    - i. Have you ever been offered opportunities for training on disability issues?
7. Have you had experience with adult **guardianship**?
  - a. If so, what happened?
    - i. How did it impact the way you provided services?
      1. How did you know what to do?
    - ii. How did you work with confidentiality?
    - iii. What were the challenges?
    - iv. In what ways was it beneficial?
  - b. If no, how may it impact your work?
8. What **relationships** does Riverview Center have with other entities in the community?
  - a. What works in these relationships?
  - b. What doesn't work?
    - i. What could be done to improve your interactions with other organizations?
9. Is there any other information you think is important for us to know?

## Interview Questions for Management:

1. What does your organization **do well**? (*Alternative wording: what are its strengths?*)
  - i. In meeting clients needs?
  - ii. In supporting staff?
  - iii. In responding to abuse?
  - iv. In serving people with disabilities?
  - v. In working with other service providers?
  - a. What is unique about your organization?
  - b. What does your organization do to protect client safety and reduce risk?
2. What **challenges** does this organization face in best serving clients?  
(*Alternative wording: What are barriers/gaps in services?*)
  - i. In supporting staff?
  - ii. In policies and procedures?
  - iii. In recognizing abuse?
  - iv. In responding to abuse?
  - v. In serving clients with diverse needs?
  - vi. In working with other service providers?
  - a. What frustrations do you have in your work?
3. (*for Riverview Center*) What does your organization do to identify individual's **accommodation needs**?
  - a. Is there a standard practice or policy to guide staff?
  - b. What policies and practices help staff provide service to people with disabilities?
    - i. Please talk about: intake, supports for survivors, other resources
    - ii. Do you think staff know these policies and procedures?
  - c. What types of accessibility accommodations do you provide?
  - d. How do you support your staff to provide accommodations?
  - e. What do you do if you are not able to provide necessary accommodations?
4. (*for Hills & Dales*) What happens when **abuse is suspected**?
  - a. What policies/practices tell staff how to respond to abuse?
    - i. Are these policies followed in practice?
    - ii. Do you think staff know these policies and procedures?
    - iii. How are staff trained to identify and respond to abuse?

1. Frequency, types of training?
  - iv. What other resources would be useful?
  - v. How do you support your staff in abuse situations?
    1. What would help you better support your staff?
  - b. Are there policies/practices to guide staff in helping survivors heal?
5. *(for Riverview Center)* Do you think staff are prepared to **respond to survivors with cognitive disabilities**?
  - a. What would help your staff provide better services?
  - b. Is there training for them on this issue? (if so, please explain)
  - c. How frequently do they receive training on this issue?
    - i. Training in general?
  - d. What types of trainings would be necessary for your staff to better serve survivors with disabilities?
  - e. What would help you to better support your staff?
6. *(for Hills & Dales)* How does **guardianship** affect how services are provided?
  - a. What types of decisions can clients make without their guardians?
  - b. What types of decisions does Hills & Dales make about clients without guardian input?
  - c. What is Hills & Dales role in client decision-making?
    - i. How are client decisions made?
    - ii. How do you advocate for clients?
    - iii. Are there others who should be involved in client decision-making?
      1. Are these people involved?
  - d. What policies exist to guide staff in working with adults who have guardians?
    - i. What policies exist to guide staff in working with guardians themselves?
    - ii. Do staff know these policies?
    - iii. How are staff made aware of these policies?
7. Do they follow these policies in practice? What **relationships** does this organization have with other service providers in the community?
  - a. What works in these relationships?
  - b. What doesn't work?
    - i. Are there organizational policies/practices that create barriers?
    - ii. Are there policies at other organizations that create barriers?

- c. What could be done to make these relationships better?
- 8. How does **change** occur at your agency?
  - a. How are decisions made within the organization?
  - b. How are policies and procedures developed?
    - i. Who initiates policy changes?
    - ii. Who reviews policy changes?
    - iii. Who approves new policy or policy changes?
    - iv. How are staff informed of policy changes?
      - 1. Is there training in the organization regarding policy?
        - a. How frequently does this occur?
      - 2. Is this process of informing staff effective?
  - c. What is your role in creating change?
  - d. What challenges exist to creating change at your organization?
- 9. What formal, **long-term changes** could be made in this organization to better serve people with disabilities who have experienced abuse?
  - a. Please consider:
    - i. Budget
    - ii. Staff
    - iii. Policy/procedures
    - iv. Resources
    - v. Collaboration
  - b. Which would be the most effective?
  - c. Which would be the easiest?
  - d. What would be required to make these changes?
  - e. How would you measure the success of these changes?
- 10. What are some important **things that other organizations need to know** to support
  - a. (*Hills & Dales*) people with disabilities?
    - i. What is the ideal organizational culture for disability services?
  - b. (*Riverview Center*) survivors of sexual violence?
    - i. What is the ideal organizational culture for trauma services?
- 11. Is there any other information you think is important for us to know?

**Supplemental Questions for Executive Directors:**

To be asked in addition to the questions for management.

1. What types of changes do you envision through this grant?
  - a. What is your role in this change?
2. How does this project fit into the strategic plan of the organization?
3. What can be done to make this project (and changes made) sustainable?
4. How would you describe the organizational culture of this organization?
  - a. Is it receptive to change?
  - b. How does the organizational culture impact response to abuse among people with disabilities?
5. What challenges, if any, do you face in the process of making change?
  - a. Please think about budget, staff, process of change, internal and external policies, procedures and regulations
  - b. Are there areas of the organization that are easier to change?  
Harder to change?
6. In what ways can you strengthen the relationship between Hills & Dales and Riverview Center?

## **Web-Based Survey Questions for Boards of Directors:**

### **General Information**

#### **Gender**

☐ Man

☐ Woman

#### **Which organization do you serve?**

☐ Hills & Dales

☐ Riverview Center

#### **How long have you served on the board? (in whole years)**

\_\_\_\_\_

#### **What are the top three strengths of this organization?**

1.: \_\_\_\_\_

2.: \_\_\_\_\_

3.: \_\_\_\_\_

#### **What are the three main challenges that face this organization?**

1.: \_\_\_\_\_

2.: \_\_\_\_\_

3.: \_\_\_\_\_

#### **What are the top three needs that this organization will have to address in the future?**

1.: \_\_\_\_\_

2.: \_\_\_\_\_

3.: \_\_\_\_\_

For Riverview Center Board Members:

#### **What are the most important services that Riverview Center provides?**

For Hills & Dales Board Members:

#### **What are the most important services that Hills & Dales provides?**

## **Service Provision**

**Does this organization meet your expectations for quality of services?**

- ☐ Yes, completely
- ☐ Somewhat, but could do better
- ☐ No, there are many improvements that could be made

**Comments about quality of services:**

**How much would you be willing to support the following to improve quality of services?**

*Please rate each on a scale from 1 to 5 where:*

*1=very likely to support*

*2=somewhat likely to support*

*3= somewhat unlikely to support*

*4=very unlikely to support*

*5=need more information before I could support*

Increased number of staff: \_\_\_\_\_

Staff training: \_\_\_\_\_

Minor facility modification: \_\_\_\_\_

Major facility modification: \_\_\_\_\_

Expansion of services: \_\_\_\_\_

Budget allocations: \_\_\_\_\_

Policy/programming changes: \_\_\_\_\_

Collaboration building: \_\_\_\_\_

Public advocacy: \_\_\_\_\_

**Does this organization meet your expectations for diversity of services?**

- ☐ Yes, completely
- ☐ Somewhat, but could do better
- ☐ No, there are many improvements that could be made

**Comments about diversity of services:**



**Does this organization meet your expectations for safety of its clients?**

- ☐ Yes, completely
- ☐ Somewhat, but could do better
- ☐ No, there are many improvements that could be made

**Comments about safety:**

**How much would you be willing to support the following to improve client safety?**

*Please rate each on a scale from 1 to 5 where:*

*1=very likely to support*

*2=somewhat likely to support*

*3= somewhat unlikely to support*

*4=very unlikely to support*

*5=need more information before I could support*

Increased number of staff: \_\_\_\_\_

Staff training: \_\_\_\_\_

Minor facility modification: \_\_\_\_\_

Major facility modification: \_\_\_\_\_

Expansion of services: \_\_\_\_\_

Budget allocations: \_\_\_\_\_

Policy/programming changes: \_\_\_\_\_

Collaboration building: \_\_\_\_\_

Public advocacy: \_\_\_\_\_

**Does this organization meet your expectations for accessibility?**

- ☐ Yes, completely
- ☐ Somewhat, but could do better
- ☐ No, there are many improvements that could be made

**Comments about accessibility:**

**How much would you be willing to support the following to improve accessibility?**

*Please rate each on a scale from 1 to 5 where:*

*1=very likely to support*

*2=somewhat likely to support*

*3= somewhat unlikely to support*

*4=very unlikely to support*

*5=need more information before I could support*

Increased number of staff: \_\_\_\_\_

Staff training: \_\_\_\_\_

Minor facility modification: \_\_\_\_\_

Major facility modification: \_\_\_\_\_

Expansion of services: \_\_\_\_\_

Budget allocations: \_\_\_\_\_

Policy/programming changes: \_\_\_\_\_

Collaboration building: \_\_\_\_\_

Public advocacy: \_\_\_\_\_

### **Making Change**

**What are your top three priorities for change at this organization in the next three years?**

1.: \_\_\_\_\_

2.: \_\_\_\_\_

3.: \_\_\_\_\_

**What is your role in determining priorities for change in this organization?**

**What is your role in creating change at this organization?**

**What information and/or resources do you need to make change?**

**What is your role in determining budget?**

**What is your role in creating collaborations among this agency and other entities in the community?**

**Do you feel that staff are open to change?**

☐ Yes

☐ No

☐ Don't know

### **United for Change**

The mission of United for Change is to create a cohesive and holistic service system for people with intellectual disabilities who are survivors of sexual abuse. This will be accomplished through innovative agency collaboration which:

- Utilizes multidisciplinary expertise in a person-centered approach to service provision at Hills & Dales and Riverview Center
- Enhances our policies as a way to better communicate and facilitate service provision between partner agencies
- Eliminates barriers to enhance accessible, equitable and flexible service provision
- Cultivates agency cultures that are respectful, safe and empowering

**To what degree do you think this project is consistent with the mission of this organization?**

- ☐ Completely consistent  
☐ Somewhat consistent  
☐ Not at all consistent

**Comments about mission of United for Change and this organization's mission:**

**To what degree do you see this project fitting in with the strategic plan of the organization?**

- ☐ Completely consistent  
☐ Somewhat consistent  
☐ Not at all consistent

**Comments about United for Change and organization's strategic plan:**

**What do you see as ideal changes or strategies your organization could undertake to better serve people with disabilities who have experienced abuse/violence?**

**To what degree would you be willing to support new initiatives to serve people with disabilities who have experienced abuse/violence?**

- ☐ Definitely would
- ☐ Likely would
- ☐ Unsure/need more information
- ☐ Likely would not
- ☐ Definitely would not

**Comments supporting of this type of initiatives:**

**In what ways would you be willing to support these new initiatives?**

*Please check all that apply.*

- ☐ Budget allocations
- ☐ Public support/advocacy
- ☐ Collaboration building activities
- ☐ Programming changes
- ☐ Policy changes
- ☐ Organizational media campaigns
- ☐ Other

**To what extent do you see challenges for your organization in addressing sexual abuse/violence among people with disabilities?**

- ☐ Significant
- ☐ Moderate
- ☐ Minimal
- ☐ None

**What challenges do you see?**

**What new resources would need to be created?**

**What benchmarks or standards would you like to see for an initiative to better serve people with disabilities?**

**Other comments**

**Is there any other information or comments you would like to share?**

## **Web-Based Survey Questions for Outside Collaborators:**

### **Page 1: General information**

**What is your profession?**

---

**Gender**

- ☐ Man
- ☐ Woman

**What is your age range?**

- ☐ 19-21
- ☐ 22-29
- ☐ 30-39
- ☐ 40-49
- ☐ 50-59
- ☐ 60+

**With which organization do you work most closely?**

- ☐ Hills & Dales
- ☐ Riverview Center

**How long have you worked with this organization?**

- ☐ Less than 1 year
- ☐ 1-2 years
- ☐ 3-5 years
- ☐ 5-10 years
- ☐ More than 10 years

**How frequently do you have contact with them?**

- ☐ Once a week or more
- ☐ A few times per month
- ☐ About once per month
- ☐ Once every few months
- ☐ Less than once every 6 months

## **Page 2: Hills & Dales Collaborators**

Those who work most closely with Hills & Dales, please answer questions 7-16 then continue to page 4.

Those who work most closely with Riverview Center, please skip this page and go to page 3.

**What do you feel are the top three strengths of Hills & Dales?**

- 1.: \_\_\_\_\_
- 2.: \_\_\_\_\_
- 3.: \_\_\_\_\_

**What do you feel are the top three weaknesses or barriers of Hills & Dales?**

- 1.: \_\_\_\_\_
- 2.: \_\_\_\_\_
- 3.: \_\_\_\_\_

**What are challenges you have experienced when working with this organization?**

**What could be done to address these barriers or improve your ability to work with this organization?**

(please comment on any policy, programming, staffing, communication, accessibility, or other changes you think will improve collaboration with this agency.)

**Do you think this organization is sufficiently safe?**

- ☐ Yes  
☐ No

**Comments about safety:**

**Do you think this organization is sufficiently accessible?**

- ☐ Yes  
☐ No

**Comments about accessibility:**

**Do you think this organization sufficiently protects clients' confidentiality?**

☐ Yes

☐ No

**Comments about confidentiality:**

**Page 3: Riverview Center Collaborators**

Those who work most closely with Riverview Center, please answer questions 17-26, then continue to page 4.

Those who work most closely with Hills & Dales, please skip this page and go to page 4.

**What do you feel are the top three strengths of Riverview Center?**

1.: \_\_\_\_\_

2.: \_\_\_\_\_

3.: \_\_\_\_\_

**What do you feel are the top three weaknesses or barriers of Riverview Center?**

1.: \_\_\_\_\_

2.: \_\_\_\_\_

3.: \_\_\_\_\_

**What are the challenges you have experienced when working with this organization?**

**What could be done to address these barriers or improve your ability to work with this organization?**

(please comment on any policy, programming, staffing, communication, accessibility, or other changes you think will improve collaboration with this agency.)

**Do you think this organization is sufficiently safe?**

☐ Yes

☐ No

**Comments about safety:**

**Do you think this organization is sufficiently accessible?**

☐ Yes

☐ No

**Comments about accessibility:**

**Do you think this organization sufficiently protects clients' confidentiality?**

☐ Yes

☐ No

**Comments about confidentiality:**

#### **Page 4: Disability and Abuse/Violence**

**What challenges do people with disabilities face in accessing your services?**

**What challenges do people with disabilities face in the community in general?**

**Have you worked with a client with an adult guardian?**

☐ Yes

☐ No

**If yes, how did having the guardian make it easier to provide services to the client?**

**If yes, how did having the guardian make it more difficult to provide services to the client?**

**Other comments about the strengths, challenges and any other issues related to guardianship of adults:**

#### **Page 5: Making Change**



**What types of changes do you think are necessary to provide a better system of services for people with disabilities who have experienced sexual abuse/violence?**

*Please check all that apply.*

- ☐ Disability agency staff training
- ☐ Sexual violence agency staff training
- ☐ Collaborator training on sexual violence issues
- ☐ Collaborator training on disability issues
- ☐ Better communication among partners in the system
- ☐ More community awareness of the risk of sexual violence among people with disabilities
- ☐ Violence prevention education for people with disabilities
- ☐ Violence prevention education for guardians
- ☐ Facility modifications for accessibility
- ☐ Facility modifications for safety
- ☐ More transportation resources in the community
- ☐ Other (please specify)

**Please comment on any changes you identified.**

**What would be most helpful to you when working with people with disabilities who may be survivors of abuse/violence?**

*Please check all that apply.*

- ☐ Training on working with people with disabilities
- ☐ Training on working with survivors of abuse
- ☐ Support from disability service providers
- ☐ Support from trauma service providers
- ☐ Referral system
- ☐ Ability to provide accessibility accommodations
- ☐ Ability to provide safety accommodations
- ☐ Other (please specify)

**Please comment on any supports identified.**

**Page 6: Other information**

**Is there any other information you would like to share?**

**Appendix K: Community Resources** (To be given to all participants after interviews and focus groups.)

## Community Resources

### Sexual Abuse/Violence:

#### **Riverview Center**

2600 Dodge Street

Dubuque, IA 52003

[www.riverviewcenter.org](http://www.riverviewcenter.org)

Hotline: 888-707-8155

#### *Services Provided:*

24-hour hotline

Medical and legal advocacy

Therapy/counseling

General advocacy

Violence Prevention Education

\*All services are free

### Domestic Violence:

#### **Riverview Center**

(See above)

#### **Dubuque Community Y Domestic Violence Program**

35 North Booth Street

Dubuque, IA 52001

[www.dubuquey.org](http://www.dubuquey.org)

Ph: 563-588-0048

Hotline: 563-556-1100 or 800-927-6646

#### *Service Provided:*

24-hour crisis line

Crisis intervention

Referrals for mental health needs

Education on effects of violence

Medical and legal advocacy

24-hour emergency shelter

\*All services are free

## Disability Services:

### **Hills & Dales**

1011 Davis Street  
Dubuque, IA 52001

3505 Stoneman Road  
Dubuque, IA 52002  
[www.hillsdales.org](http://www.hillsdales.org)  
Ph: 563-556-7878

### *Services Provided:*

Residential services  
Vocational/Paid work program  
Individual and group respite  
Supported community living  
Summer day camp  
Day habilitation  
Autism programs  
Child care and preschool  
Senior programs/congregate meals

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### **ARK Advocates**

PO Box 3024  
Dubuque, IA 52004  
[www.arkadvocates.org](http://www.arkadvocates.org)  
Ph: 563-556-1785

### *Services Provided:*

Financial assistance  
Information and referral  
Family companions  
Advocacy for people with disabilities  
and their families

## Multiple Disability, Health and Community Services:

### **Hillcrest Family Services**

Main Offices:

2005 Asbury Road

Dubuque, IA 52001

[www.hillcrest-fs.org](http://www.hillcrest-fs.org)

Ph: 877-437-6333

#### *Services Provided:*

Adult Residential Homes

Adult Vocational Program

Emergency Youth Shelter Care

Family Centered Services

Hillcrest Clinic

Residential Rehabilitation

Supported Community Living

Homeless Outreach

Intensive Psychiatric Rehabilitation  
Services

Transitional Family Housing

Mental Health Counseling

\*Not all services are provided free of  
charge

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### **Project Concern**

1789 Elm Street

Suite B

Dubuque, IA 52001

[www.project-concern.org](http://www.project-concern.org)

Ph: 563-588-3980

#### *Services Provided:*

Information and Referral

Mentoring Programs

Homeless Hotline and assistance

Shelter Plus Care for people with  
disabilities who are homeless

## **Appendix L: Guardianship In Iowa: Legal Definitions and Types**<sup>15</sup>

### **Legal Definitions:**

**Guardian:** A person appointed by the court to make decisions for the person of the ward about non-financial matters such as medical treatment, education, living arrangements, etc.

**Conservator:** A person appointed by the court to handle the property or estate of a ward.

**Incompetency (guardianship):** In the case of guardianship, an incompetent/incapacitated person is one who the court has decided has a decision making capacity which is so impaired that the person is unable to care for the person's personal safety or to attend to or provide for necessities of the person such as food, shelter, clothing, or medical care, without which physical injury or illness may occur.

**Incompetency (conservatorship):** In the case of a conservatorship, an incompetent/incapacitated person is a person who the court has decided has a decision making capacity which is so impaired that the person is unable to make, communicate, or carry out important decisions concerning the person's financial affairs.

**Substitute Decision-Maker:** A person who makes decisions regarding personal and medical issues and/or financial issues for a person who is incompetent. This can be done either informally, as a family member or friend, or formally, as an attorney in fact (power of attorney), proxy, agent, guardian, or conservator.

**Protected Person:** The ward/individual person for whom a conservatorship has been set up.

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<sup>15</sup> Adapted from: The Iowa Developmental Disabilities Council. (2011). *Guardianship and Conservatorship in Iowa: Issues in Substitute Decisions Making*. Accessible at:  
<http://idaction.bwbhosting.com/LinkClick.aspx?fileticket=qveJG1WPH0k%3d&tabid=177>

## **Types of Guardianships:**

**Guardianship of the Person:** This type of substitute decision making can cover all or only some decisions about a person's medical care, nutrition, clothing, shelter or residence, and other matters regarding the person, but not the person's finances. A guardianship can be full (or "general"), covering all aspects of the ward's personal life, or it can be "limited", only covering certain specific areas of the person's life.

**Conservator of the Estate:** This type of substitute decision making can cover all or only some decisions about a person's finances, property, and real estate. A conservatorship can be full (or "general"), covering all aspects of the person's finances, or it may be "limited", only covering certain specific proportions of the person's finances.

**Standby Guardianship:** The Iowa Code sets out a procedure for a competent adult to plan for a court-supervised guardianship. In a written petition, the person can say that a guardian shall be appointed when certain conditions have been met. These could be a particular event or the occurrence of a physical or mental condition. The petition also says how the occurrence of these events or conditions must be proven.

**Standby Conservatorship:** The Iowa Code sets out a procedure for a competent adult to plan for a court-supervised conservatorship. In a written petition, the person can say that a conservator shall be appointed when certain conditions have been met. These could be a particular event or the occurrence of a physical or mental condition. The petition also says how the occurrence of these events or conditions must be proven.

**Voluntary Guardianship or Conservatorship:** The Iowa Code sets out a procedure for a person to ask the court to appoint a guardian or conservator to handle the person's personal or financial affairs. A person must have the capacity to consent to the appointment of a guardian or conservator. Even in this situation, the court must decide whether a limited guardianship or conservatorship is appropriate.

### **Guardianship at Hills & Dales**

At the time of this needs assessment, there are currently 53 clients over the age of 18 who have full legal guardians. Eight clients are currently their own guardian; however several are pending court hearings about guardianship. Historically, the vast majority of clients at Hills & Dales have had full legal guardians.

## **Appendix M: Statutory Definitions**

### **Iowa Code Chapter 235B, “Adult Abuse”**

*Caretaker:* A related or nonrelated person who has the responsibility for the protection, care, or custody of a dependent adult as a result of assuming the responsibility voluntarily, by contract, through employment, or by order of the court.

*Dependent Adult:* A person eighteen years of age or older who is unable to protect the person's own interests or unable to adequately perform or obtain services necessary to meet essential human needs, as a result of a physical or mental condition which requires assistance from another, or as defined by departmental rule.

*Adult Abuse:* Any of the following of the willful or negligent acts or omissions of a caretaker or the denial of self-care:

*Physical Abuse:* Physical injury to, or injury which is at a variance with the history given of the injury, or unreasonable confinement or unreasonable punishment, or assault of a dependent adult.

*Sexual Abuse:* The commission of a sexual offense under Chapter 709 or Section 726.2 with or against a dependent adult as a result of the willful or negligent acts or omissions of a caretaker.

*Exploitation:* The act or process of taking unfair advantage of a dependent adult or the adult's physical or financial resources for one's own personal or pecuniary profit, without the informed consent of the dependent adult, including theft, by the use of undue influence, harassment, duress, deception, false representation, or false pretenses.

*Denial of Critical Care:* The deprivation of the minimum food, shelter, clothing, supervision, physical or mental health care, or other care necessary to maintain a dependent adult's life or health.



*Self-Denial of Critical Care:* The deprivation of the minimum food, shelter, clothing, supervision, physical or mental health care, and other care necessary to maintain a dependent adult's life or health as a result of the acts or omissions of the dependent adult.

*Sexual Exploitation:* Any consensual or nonconsensual sexual conduct with a dependent adult which includes but is not limited to kissing; touching of the clothed or unclothed breast, groin, buttock, anus, pubes, or genitals; or a sex act, as defined in Section 702.17. Sexual exploitation does not include touching which is part of a necessary examination, treatment, or care by a caretaker acting within the scope of the practice or employment of the caretaker; the exchange of a brief touch or hug between the dependent adult and a caretaker for the purpose of reassurance, comfort, or casual friendship; or touching between spouses.

### **Iowa Code Chapter 235E, "Dependent Adult Abuse in Facilities and Programs"**

*Dependent Adult:* A person eighteen years of age or older whose ability to perform the normal activities of daily living or to provide for the person's own care or protection is impaired, either temporarily or permanently.

*Caretaker:* A person who is a staff member of a facility or program who provides care, protection, or services to a dependent adult voluntarily, by contract, through employment, or by order of the court.

Abuse is any of the following as a result of the willful misconduct or gross negligence or reckless acts of omissions of a caretaker, taking into account the totality of the circumstances:

*Physical Injury & Unreasonable Confinement:* Physical injury to, or injury which is at a variance with the history given of the injury, or unreasonable confinement or unreasonable punishment, or assault of a dependent adult which involves a breach of skill, care, and learning ordinarily exercised by a caretaker in similar circumstances.

*Assault of a Dependent Adult:* The commission of any act which is generally intended to cause pain or injury to a dependent adult, or which is generally intended to result in physical contact with would be considered by a reasonable person to be insulting or offensive or any act which is intended to place another in fear of immediate physical contact which will be painful, injurious, insulting, or offensive, coupled with the apparent ability to execute the act.

*Sexual Offense:* The commission of a sexual offense under Chapter 709 or Section 726.2 with or against a dependent adult as a result of the willful or negligent acts or omissions of a caretaker.

*Exploitation:* A caretaker who knowingly obtains, uses, endeavors to obtain to use, or who misappropriates, a dependent adult's funds, assets, medications, pr property with the intent to temporarily or permanently deprive a dependent adult of the use, benefit, or possession of the funds, assets, medication, or property for the benefit of someone other than the dependent adult.

*Neglect of a Dependent Adult:* The deprivation of the minimum food, shelter, clothing, supervision, physical or mental health care, or other care necessary to maintain a dependent adult's life or health.

*Sexual Exploitation:* Any consensual or nonconsensual sexual conduct with a dependent adult which includes but is not limited to kissing; touching of the clothed or unclothed breast, groin, buttock, anus, pubes, or genitals; or a sex act, as defined in Section 702.17. Sexual exploitation includes the transmission, display, taking of electronic images of the unclothed breast, groin, buttock, anus, pubes, or genitals of a dependent adult by a caretaker for a purpose not related to treatment of diagnosis or as part of an ongoing investigation. Sexual exploitation does not include touching which is part of a necessary examination, treatment, or care by a caretaker acting within the scope of the practice or employment of the caretaker; the exchange of a brief touch or hug between the dependent adult and a caretaker for the

purpose of reassurance, comfort, or casual friendship; or touching between spouses or domestic partners in an intimate relationship.

### **Iowa Code 915.20A, “Victim Counselor Privilege”**

*Confidential Communication:* Information shared between a crime victim and a victim counselor within the counseling relationship, and includes all information received by the counselor and any advice, report, or working paper given to or prepared by the counselor in the course of the counseling relationship with the victim. Confidential information is confidential information which, so far as the victim is aware, is not disclosed to a third party with the exception of a person present in the consultation for the purpose of furthering the interest of the victim, a person to whom disclosure is reasonably necessary for the transmission of the information, or a person with whom disclosure is necessary for accomplishment of the purpose for which the counselor is consulted by the victim.

*Victim:* A person who consults a victim counselor for the purpose of securing advice, counseling, or assistance concerning a mental, physical, or emotional condition caused by a violent crime committed against the person.

*Victim Counselor:* A person who is engaged in a crime victim center, is certified as a counselor by the crime victim center, and is under the control of a direct services supervisor of a crime victim center, whose primary purpose is the rendering of advice, counseling, and assistance to the victims of crime. To qualify as a “*victim counselor*” under this section, the person must also have completed at least twenty hours of training provided by the center in which the person is engaged, by the Iowa organization of victim assistance, by the Iowa coalition against sexual abuse, or by the Iowa coalition against domestic violence, which shall include but not be limited to, the dynamics of victimization, substantive laws relating to violent crime, sexual assault, and domestic violence, crisis intervention techniques, communication skills, working with diverse populations, an overview of the state criminal justice system, information regarding pertinent hospital procedures, and information regarding state and community resources for victims of crime.

A victim counselor shall not be examined or required to give evidence in any civil or criminal proceeding as to any confidential communication made by a victim to

the counselor, nor shall a clerk, secretary, stenographer, or any other employee who types or otherwise prepares or manages the confidential reports or working papers of a victim counselor be required to produce evidence of any such confidential communication, unless the victim waives this privilege in writing or disclosure of the information is compelled by a court pursuant to subsection 7. Under no circumstances shall the location of a crime victim center or the identity of the victim counselor be disclosed in any civil or criminal proceeding.

## **Appendix N: Acronyms**

BOD .....	Board of Directors
BRFSS .....	Behavioral Risk Factor Surveillance Survey
CARF .....	Commission on Accreditation of Rehabilitation Facilities
CMA .....	Certified Medical Assistant
DHS .....	Department of Human Services
HCBS .....	Home Community Based Service
HIPAA.....	Health Insurance Portability and Accountability Act
IC .....	Informed Consent
ICF/ID .....	Intermediate Care Facility for the Intellectually Disabled
OVW .....	US Department of Justice, Office on Violence Against Women
SART .....	Sexual Assault Response Team
SCL .....	Supported Community Living