Sidewalks to Sexual Violence Prevention

a Guide to Exploring Social Inclusion with Adults with Developmental & Intellectual Disabilities

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About ICADV

ICADV works for the prevention and elimination of domestic violence – until the violence ends. ICADV pursues a vision where all people engage in healthy relationships characterized by the mutual sharing of resources, responsibilities and affection; where youth are nurtured with those expectations; and where all people are supported within a society committed to equality in relationships and equity in opportunity as fundamental human rights.

About Cierra Olivia Thomas-Williams

Cierra Olivia Thomas-Williams, M.A. (she/her/hers pronouns) joined the movement to end sexual and domestic violence in 1998 as an activist survivor. In 2005, Ms. Thomas-Williams began volunteering for programs developed through the Rape Prevention and Education grant shifting the orientation of the work away from serving individuals in crisis to addressing the conditions that allow for violence to occur. After 17 years advocating for and with people harmed by intimate partner and sexual violence in Oregon and Indiana, Cierra joined the Indiana Coalition Against Domestic Violence (ICADV) prevention team in 2015. Ms. Thomas-Williams now works collaboratively with the ICADV prevention team to develop, implement, evaluate and report on strategies supporting Indiana’s sexual violence prevention plan and intimate partner violence prevention plan as they relate to special populations, including Hoosiers with developmental and intellectual disabilities.

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Photography, painting, writing and other art forms give voice to perspectives that are misunderstood, discounted or simply not verbal. Art provides a means to express feelings about community—including experiences of isolation and inclusion—without the need for written English. These perspectives are part of the many who participated the project. Art in this image created by Stone Belt stakeholders in collaboration with Van Go Mobile Art Studio, January 28, 2017.
My dream is to work on my relationship with my ex-boyfriend. I was with him for 8 years and decided to go back to my husband. It never works. He is very verbally abusive.

Written in collaboration with Women Writing for a Change by a woman with multiple disabilities

Acronyms

BRFSS: Behavioral Risk Factor Surveillance System
BT: Bloomington Public Transit Corporation or Bloomington Transit
CDC: The Centers for Disease Control and Prevention
DSP: Direct Support Provider
MCCAM: Monroe County Coalition on Accessibility and Mobility
MCPL: Monroe County Public Library
MOU: Memorandum of Understanding
NISVS: National Intimate Partner and Sexual Violence Survey
PS: Prevention Specialist (the author and project coordinator)
RT: Rural Transit
RPE: Rape prevention and education grant
SEM: Social-Ecological Model
SB: Stone Belt

The ARC: The Arc is the name of the national association for disability advocacy started in 1950 by parents and family members of people with disabilities. The language of the
time is considered discriminatory today (Association for Retarded Citizens), so The Arc is referred to using the acronym preceded by the word “the”.

YRBS: Youth Risk Behavior Surveillance Survey

Date Night, painted January 28, 2017 by a young woman with disabilities who very much enjoys spending time with her boyfriend at restaurants eating their favorite food, pizza.

Introduction

The Bloomington Inclusion Collaborative formed in 2015 with the financial support of the Indiana State Department of Health Rape Prevention and Education grant to collaboratively develop community-wide solutions to increase inclusion based upon unique barriers found in Bloomington, Indiana. Adults with developmental and intellectual disabilities along with eleven cross-sector partners engaged in participatory social mapping to assess barriers to inclusion in neighborhoods, public spaces and businesses. In 2016, the data about barriers to inclusion specific to Bloomington were prioritized for solutions-advocacy and implementation. By sharing the tools developed over the course of the project along with the lessons learned, the Bloomington Inclusion Collaborative encourages others to engage with people with disabilities to examine factors that reduce sexual violence risks specific to their communities and implement practice-based solutions to increase inclusion, which is protective across all aspects of human life.
Love was painted during an art session exploring the multiple meanings of community with Van Go Mobile Art Studio. The young blind woman who painted this shared that her pets help her to feel connected, like she belongs, and they also help her to cope with a very loud world.

Measuring Inclusion
Community support and connectedness are protective factors against child maltreatment, youth violence, intimate partner violence, sexual violence, elder abuse and suicide. Because the protections of community support and connectedness span physical spaces, the invisible landscape of laws, rules and norms and internal psychic spaces of thoughts and feelings, social inclusion (the protective factor explored through this project) is a particularly strong health index to track. People with intellectual and/or developmental disabilities have been isolated from gainful employment, comprehensive integrated education, including sexuality education, and often do not have access to a range and variety of experiences and relationships, including consensual sexual ones. Transportation is essential to accessing support and facilitating connection; however, even these systems present barriers and risks for people with disabilities. Because people with a variety of disabilities are isolated across systems and are dependent upon certain forms of assistance, they are far more vulnerable to multiple forms of violence than “mainstream” populations.

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When I feel sad I tell someone. It makes me feel better I sit in a different room. It brings tears to my eyes. It feels good to cry. I feel a lot better. It makes me keep going.- a young woman with multiple disabilities wrote during a writing session with Women Writing for Change

Social isolation emerges or is expressed through inequitable access and opportunity across the structures and systems that support human life, including transportation, employment, education, health care and increased risks for perpetration and victimization of multiple forms of violence across the lifespan.² There is not a great deal of literature published about protective factors (see table of risk and protective factors below); however, there is strong evidence that social inclusion through community support and connectedness has the potential to increase protections in the form of increasing the number of safe, stable, nurturing environments and relationships around everyone (see table 1 below).

Research shows that safe, stable and nurturing relationships and environments support child development and have the potential to reduce child abuse and other forms of violence, which fosters resilience among youth who have experienced trauma³.

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² The World Health Organization defines “social exclusion as consisting of dynamic, multidimensional processes driven by unequal power relationships interacting across four main dimensions – economic, political, social and cultural – and at different levels including individual, household, group, community, country and global. It results in a continuum of inclusion/exclusion characterised by unequal access to resources, capabilities and rights which leads to health inequalities.” Jennie Popay, Sarah Escorel, Mario Hernández, Heidi Johnston, Jane Mathieson, Laetitia Rispel (February 2008). Final Report to the WHO Commission on Social Determinants of Health On behalf of the WHO Social Exclusion Knowledge Network. Available http://www.who.int/social_determinants/knowledge_networks/final_reports/sekn_final%20report_042008.pdf

Safety, stability and nurturing are key to quality of life for people with disabilities, their family and staff, but finding this place of balance between providing the best care and quality of life and the realities of workplace violence in the form of challenging behaviors that may or may not be related to trauma.

<table>
<thead>
<tr>
<th>Table 1 Safe, Stable, Nurturing Environments and Relationships</th>
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<tbody>
<tr>
<td><strong>Safety</strong> means that we create families and communities where children grow up free from fear, and secure from physical or psychological harm.</td>
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<tr>
<td>- For families, this means protecting our kids from experiencing or witnessing violence.</td>
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<tr>
<td>- For communities, this means addressing safety in all of the places where our children are living, learning, playing and growing. Communities can work to ensure safe childcare and educational settings, neighborhoods that are free from discrimination and healthy environmental conditions with safe housing, clean air and water.</td>
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<tr>
<td><strong>Stability</strong> describes the degree of predictability and consistency in a child’s social, emotional and physical environment.</td>
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<tr>
<td>- Within families, stability comes from the presence of reliable caregivers, regular routines, and consistent disciplinary consequences.</td>
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<tr>
<td>- Within the community, stability relies on the availability of affordable housing, dependable transportation, food security and sustainable employment opportunities.</td>
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<tr>
<td><strong>Nurturing</strong> describes the extent to which a parent or caregiver is available and able to sensitively and consistently respond to and meet the needs of their child.</td>
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<tr>
<td>- For families, this means that children receive and witness nurturing behaviors among parents, caregivers, family members and peers.</td>
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<td>- Community members can help to support children and families by participating in the belief that we all contribute to the wellbeing of youth by advocating for public investment in quality childcare, great schools, and youth programs.</td>
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©ICADV 2016, “What are safe, stable and nurturing relationships and environments?” from the #smallmoments go a long way to prevent violence social media campaign. More information, community examples and promotional materials available at: [http://icadv5.wixsite.com/smallmoments](http://icadv5.wixsite.com/smallmoments)

For many people in America, disability is not a consequence of violence, instead disability derives from human variation, genetics or some other form of trauma, such as job-related injury, alcohol and drug addiction, and poverty or other environmental factors. 14% of Indiana’s total population lives with varying degrees of disability; 14.3% of females of all ages and 13.8% of males of all ages in Indiana report a disability and
5% of this population also have cognitive disabilities. While 86% of Hoosiers (Indiana residents) who have disabilities are covered by health insurance, 65% are on Medicaid or Medicare (American Community Survey) and are, therefore, in low-income earners likely experiencing poverty. In 2015, the poverty rate of working-age people with disabilities in Indiana was 26.3% (American Community Survey).

People in poverty are at higher risk of violence across the lifespan; however, data collected about violence, such as the youth risk behavior surveillance survey (YRBS) or the National Intimate Partner and Sexual Violence Survey (NISVS), does not include people on the margins who may not speak English or be at the required literacy level to take such a survey. People who communicate using ASL, a computer device or other means such as pointing, nodding, and shaking one’s head are left out of these surveys.

When I am sad, I like to go somewhere. I like to get in a restaurant. I love Bob Evans. I don’t feel sad much. I’m mad at Stone Belt all the time. I go for a walk to feel better and I listen to music. I calm down when I watch TV. I walk outside. I see trees and sky that calms me down. -written by a young man who is a Stone Belt Stakeholder in collaboration with community partners from Women Writing for a Change, 2017.

In a simple search of the latest NISVS (2010) the word disability appears twice in sentences referring to the outcome of sexual and domestic violence and zero times in YRBS results published in 2016. The rate of all violent crimes against people with

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5 Centers for Disease Control and Prevention (2015). Sexual Identity, Sex of Sexual Contacts, and Health-Related Behaviors Among Students in Grades 9–12 — United States and Selected Sites, 2015. Surveillance Summaries. August 12, 2016. 65(9);1–202. Available online: [https://www.cdc.gov/mmwr/volumes/65/ss/ss6509a1.htm?s_cid=ss6509_w](https://www.cdc.gov/mmwr/volumes/65/ss/ss6509a1.htm?s_cid=ss6509_w); Centers for Disease Control and
cognitive disabilities is 63%. Sexual violence prevalence rates for people who have intellectual or developmental disabilities is estimated to be as low as 65% and high as 98% of the population over the course of a lifetime. There is no agreement on the prevalence rates, because statistics about people who have disabilities are largely not collected or reported to shared databases. Poverty, diminished economic opportunities, high unemployment rates, and weak health laws are not only determinants of long term poor health outcomes (such as disease, addiction), but these also increase risk for perpetration and victimization of domestic and sexual violence. All of these barriers and data suggests inclusion cannot be achieved without data on and the perspectives of those who are “left out,” since a society that is inclusive of the “least of us” will be one that fosters the lives of everyone.

“I have a lot of people that keep me from being alone. These people are my family, friends, my boyfriend, my staff and my Stone Belt. The reason why these are important is because they will not let me be alone and they are always there when I need someone to talk to.” – Written by a woman with physical and developmental disabilities in collaboration with Women Writing for a Change, January 2017.


Social inclusion is a vast category that spans across internal thoughts and feelings to the external behaviors and the systems that either foster equity or increase disparities. In their 2014 review, Baumgartner and Burns examined social inclusion projects on a global scale and found five tools commonly used, though the scales are not adapted for populations with varying levels of English literacy. Each stakeholder on the Bloomington Inclusion Collaborative has a different manner of communication. Some people are conversant about their lives using verbal English while others use American Sign Language, a computerized keyboard, or gestures and sounds. Because communication styles are unique, it takes time to understand. The Prevention Specialist modified a tool called “The Social Network Map: Assessing Social Support in 7 Domains of Life” (see appendix mapping tools, Tracey-Social Network Map), however, even a modified version of this instrument would be insufficient for use with some participants.9

Roses are red violets are blue each minute I’ve spent here with you is magical . . . as in memories!
Art beside and poem by “Jenny Quantum Physics,” self-identified optimist

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10 Pseudonym created by the person who wrote the poem in collaboration with Women Writing for a Change, January 2017. For a variety of reasons, Ms. Quantum Physics is restricted to the Stone Belt day program building, however, she served as the house illustrator for the project from 2015-2017.
Recruit Across Lifespan and “Sectors”

Building partnerships outside of one’s comfort zone and intentionally across sectors (transportation, housing, education, health care, government, business, etc.) helps to address not only sexual violence, but multiple forms of violence, in an efficient and effective way. Strategically seeking partnerships with agency stakeholders whose services reach a spectrum of ages (early childhood to elders) allows for a fertile prevention landscape that fosters connectedness and inclusion between people, among service agencies and in the environment. Collaborating around shared risk factors for sexual violence brings together partners with diverse interests, assets and unique challenges to focus on strengthening social support and connectedness. Community connectedness is a protective factor against youth violence, teen dating and sexual violence, bullying and suicide.11 Using this methodology—the public health approach—to sexual violence prevention allows stakeholders to maintain a connection to their social service, such as transportation or education; however, energy is focused on identifying the conditions that allow for violence to occur in their specific sector and building community-specific solutions that reduce or eliminate those shared risks. Social inclusion is a productive strategy that builds connections across sectors around shared risk factors benefiting all populations, not just the vulnerable. Increasing connectedness using inclusion strategies, therefore, builds protections against a lifetime of trauma and violence.

The Prevention Specialist (PS) developed a list of possible collaborative partners beginning with suggestions from the main stakeholder group, people with disabilities who use day program services at Stone Belt, Arc, including staff and administrative

11 Wilkins et. al., 2014, p. 9.
leadership. The PS conducted brief interviews to identify potential partners already connected to Stone Belt, Arc in some way and those on a “wish list” for community engagement. From these brief interviews, the PS created a list of agencies and people in them to contact and invite to the project. During those in-person meetings other partners were identified until the PS recruited cross-sector working professionals from government, public/private and community-service sectors offering services to children, adolescents and elders with a variety of disabilities. The 2015-2016 Bloomington Inclusion Collaborative (a nickname for the project) was comprised of people from nine agencies, including Family Voices Indiana and Indiana Coalition Against Domestic Violence (state level agencies) and Stone Belt, Arc and six other local agencies.12

Recruitment Process Checklist (printable version included in the appendix):

☐ Call, email, or in-person communication to introduce idea and ask if potential partner they would like more information;
☐ Executive summary provided including:
  o Timeline of project;
  o Time commitment expected;
  o Benefits or outcomes expected; and
  o Contact information.
☐ Request in-person meeting to go over project requirements and answer any questions.
☐ Memorandum of Understanding (MOU) to follow commitment
  o This document describes the roles of each agency in the project and includes the timeline and expectations.
  o Provide city departments with two originals, because they need to retain an original signed document.
  o Email with follow up deadline for MOU to be completed and preferred method of return to you (email, mail, etc.)
☐ Before work of any kind begins, obtain informed consent from all project participants.
  o May require guardian signatures for some participants with developmental and intellectual disabilities (see appendix for informed consent documents for all participants).

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12 The collaborative could have become much larger, because agencies were excited to participate and often suggested other agencies to invite to the process. The PS made the decision to stop the recruitment process once eight agencies were committed to work together for a period of one year (the duration of the grant funding for years 2015-2016).
After recruitment, in March of 2015 cross-sector collaborators included Indiana Coalition Against Domestic Violence, Stone Belt, Arc, City of Bloomington, Monroe County Public Library, Bloomington Transit, Rural Transit, Area 10 Agency on Aging.

Table 2: Known Risk & Protective Factors for Sexual Violence Perpetration

<table>
<thead>
<tr>
<th>Protective Factors for Sexual Violence Perpetration</th>
<th>Risk Factors for Sexual Violence Perpetration</th>
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<tbody>
<tr>
<td><strong>Individual level</strong></td>
<td></td>
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<tr>
<td>Emotional health and connectedness</td>
<td>Poverty</td>
</tr>
<tr>
<td>Academic achievement</td>
<td>Lack of employment opportunities</td>
</tr>
<tr>
<td>Empathy and concern for how one's actions affect other</td>
<td>Weak community sanctions against sexual violence perpetrators</td>
</tr>
<tr>
<td>Parental use of reasoning to resolve family conflict</td>
<td>General tolerance of sexual violence within the community</td>
</tr>
<tr>
<td>Academic Achievement</td>
<td>Lack of institutional support from police and judicial system</td>
</tr>
<tr>
<td><strong>Community level</strong></td>
<td>Societal level</td>
</tr>
<tr>
<td>Poverty</td>
<td>Societal norms that support sexual violence</td>
</tr>
<tr>
<td>Lack of employment opportunities</td>
<td>Societal norms that maintain women's inferiority and sexual submissiveness</td>
</tr>
<tr>
<td>Weak community sanctions against sexual violence perpetrators</td>
<td>Weak laws and policies related to sexual violence and gender equity</td>
</tr>
<tr>
<td>General tolerance of sexual violence within the community</td>
<td>High levels of crime and other forms of violence</td>
</tr>
<tr>
<td>Lack of institutional support from police and judicial system</td>
<td>Societal norms that support male superiority and sexual entitlement</td>
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Family Voices Indiana, Middle Way House, Inc., and Indiana Institute on Disability and Community. Working professionals from each of these agencies paired with Stone Belt stakeholders (adults who receive services, staff and leadership) to engage in participatory social mapping with Stone Belt stakeholders with disabilities. In 2016, the project experienced attrition when Area 10 Agency on Aging, Indiana Institute for Disability and Community, the City of Bloomington and Rural Transit ended their

\(^{13}\) The social-ecological model is a framework used in primary prevention to examine human beings and their choices and behavior as always already bound by the normative preference for power over and the influence of such power in the environment, including relationships, organizations humans interact with and in, and the communities in which people live, work and play and the differential expressions of such people, places and things.
participation. The reasons for the changes in participation include funding losses in programs, working professionals moving to different jobs, or becoming too busy in their current positions. One partner simply did not agree with the utility of the strategy to increase inclusion and chose not to continue into the second year of the project.

Women Writing for a Change and Van Go Mobile Art Studio joined the project in 2016 to engage all Stone Belt stakeholders and working professionals in telling stories about the importance of community and inclusion in Bloomington, Indiana using the mediums of art and creative writing.

Staff and resident art work produced with Ellen Bergan and Van Go Mobile Art Studio

Gather Community Specific Data

The Centers for Disease Control and Prevention have identified shared risk and protective factors for sexual violence (see Table 2); however, the ways in which these factors manifest is specific to communities and even within populations. The Center for Health and Human Services Social and Community Health Indicators mapping project\(^\text{14}\) indicates there is “inadequate social support” (defined as “social-emotional” support) in Monroe County, which ranks 16\(^{th}\) worse of 20 in a scaled comparison of peer counties ranging from “better” to “moderate” to “worse.” People with disabilities experience social isolation across all determinants of health (housing, transportation, education, employment, health care, etc.) in general. To determine what the community specific

\(^{14}\) The data are taken from the Behavioral Risk Factor Surveillance System (BRFSS).
barriers are in Bloomington, Indiana, the teams of working professionals and people with a variety of disabilities engaged in eight months of primary data collection using a several evaluation methods.

Bloomington specific barriers to inclusion were determined in 2015 using five different assessment methods:

- pre/post-test for cross-sector working professionals (see questions and results in appendix document entitled “2015Yr.End.Report.final.deidentified-rev”);
- circle of support social network maps with people with a variety of disabilities (see appendix documents entitled “2015Yr.End.Report.final.deidentified-rev” for adapted tools and the original tool “Tracy-Social Network Map Tool rev”);
- focus groups with people with a variety of disabilities (see appendix evaluation tools “Matson.FocusGroup.Protocol” focus group protocol);
- key informant interviews with care givers (see appendix evaluation tools for “Matson.Interview.Protocol” for key informant interview protocol);
- participatory social mapping of Bloomington neighborhoods, public spaces and businesses (see appendix Mapping Tools for original and adapted mapping protocols including a tool to use in service agencies to help determine accessibility).
Social Network and Participatory Social Mapping

Because the desired outcome of the Bloomington Inclusion collaborative is connectedness and social (relationship/community), systematic (law/policy), and structural (built environment) inclusion for and with people with developmental or intellectual disabilities, the PS tried to establish a baseline understanding of the support landscape of project stakeholders with a variety of disabilities. No single tool will work to get information from participants due to the varied degrees and types of communication and support or lack of support for the differing communication needs among participants. Instead, the following section includes examples of social and environmental network mapping used to gather data about the barriers to inclusion in Bloomington, Indiana. The appendix contains word and pdf documents of all tools developed during the project.

Circle of Support (Social Network Maps)

An elder man drew a heart surrounded by empty circles of support in 2015. When the PS asked the man why he did not fill in his circles, he stated “I don’t have any friends.” The heart is

In 2017, the names of two people appear among many other things that matter very much to this elder man (name redacted) including pool, hunting, and hiking in warm weather. During a creative writing session with Women Writing for a Change he shared “My dream. I work in nature fighting fire, cleaning up. I would be a park ranger.” He is 66 and when given opportunities for inclusive creative writing, a chair with arms and patient
Because art is a tool that does not require spoken communication, the Prevention Specialist used a self-assessment called the “Circle of Support” (pictured below) which would allow for writing, drawing, painting, or doodling. The network map uses four inset circles to demonstrate broad categories across a person's life, intimacy, friendship and social environment. The innermost circle (circle 1) represents the self/intimacy; the circle around the self (circle 2) is considered to be made up of friends or people the individual taking the assessment sees regularly; circle 3, which surrounds the self and friends, is called the “circle of participation” which identifies organizations in the person’s life; and finally, circle 4 is the “circle of exchange” where the participant lists paid activities such as shopping, attending movies. Participants are invited in a group setting to share their social lives and using markers, pens, and pencils to “map” their network on to the circle.

The Prevention Specialist used this tool before the project, at Midway (1 year in) and upon project completion (2 years later). In comparing the “circles of support” over the course of two years, the PS noted the contents of the social networks in the “close to my heart” tool often reflected activities the participants engaged in that day; the tool did not capture an abstraction of the people who fit in the greater context of stakeholder’s lives. The data from the circle of support taken with paintings, conversations, creative writing and participatory social mapping activities during the project allowed Stone Belt participants with disabilities to share their experiences in a variety of ways. The social networks of some of the Stone Belt participants grew
through participation in the project; however, project participants were interested in identifying and eliminating barriers to inclusion in the community.

Art created with stakeholders with disabilities. The middle piece is by Ellen Bergan, artist and entrepreneur, Van Go Mobile Art Studio

**Participatory Social Mapping**

**Barriers to Inclusion in Public Spaces, Businesses and Neighborhoods**

This is just one example of the nine outings stakeholder teams completed during 2015 participatory social mapping. The PS created a protocol for the process then met with working professionals to review and discuss the process of mapping. Stone Belt, Arc staff in collaboration with stakeholders who receive day program services adapted the tool, which was used for all excursions to collect data (see [appendix](#), Mapping Tools for the original and adapted mapping protocols).

This excursion includes a bus ride to and from the mall and trips to Target and Macy’s. Stakeholders on this trip included two people with disabilities, two Stone Belt staff, and two working professionals from Bloomington Transit and Rural Transit.
The distance from the Stone Belt day program (where the excursion began) to College Mall only 1.1 miles away. Because the 1.1 mile was not paved with connected sidewalks in 2015, bus travel was preferred. Google estimates travel time by bus is 12 minutes, only 4 minutes of which are actually spent riding the bus. The walk/roll from Stone Belt to the nearest bus stop for this journey included many barriers, such as no or narrow sidewalks and spans of muddy paths on a busy road. It took more than 15 minutes to traverse the walking path to the bus stop through the mud. The landing pad concrete was broken and muddy when the team arrived (see illustration).

**Stone Belt stakeholders with disabilities learned how and where to advocate for sidewalk repairs on the city website using a form submission (requires a computer with internet access) and their photovoice images. The repairs to sidewalks benefit everyone in Bloomington.**

The landing pad has since been re-paved and the sidewalk extends nearly all the way to Stone Belt. In 2017, the muddy path is still the only way to get to the new sidewalk from Stone Belt. The illustrations for this excursion are created by project illustrator Jenny Quan (one of her pseudonyms). Jenny was unable to attend the excursions, but was happy to contribute her skills in other ways. Jenny depicts the team waiting for the bus and again when the auto-open mechanism (ADA requirement) was inoperable.

Jenny’s illustrations depict the lack of access to the mall (left) and the return to the mall after the “access button” on the door was finally repaired (right). *It took six letters, three visits and eight months for the mall to repair the door.*
Using Google maps, Stone Belt stakeholder Mr. Ely (below) used the online tool to plot the locations that were mapped by teams and labelled the various barriers found throughout Bloomington.

This free Google map is useful tool for advocacy. Mr. Ely used Photovoice images captions to populate the map and symbols to indicate what barrier was encountered there.

Advocate for Changes

The Collective gathered pages of physical, policy, and emotional barriers during 2015 participatory mapping. The PS and consultant Maggie Matson, MPH organized the data collected from all five of the evaluation methods into categories using qualitative data analysis coding for broad themes (see appendix Evaluation Tools “2015.Barriers.All.Data” for list of barriers and themes). In early 2016 with renewed funding, the PS met with Stone Belt stakeholders to discuss findings and determine priority areas for solutions-advocacy. The PS met with participating cross-sector collaborators separately to discuss the list of barriers. The PS merged the ideas from both groups into short term (to be completed within the grant year), intermediate and long term solutions-advocacy. The following two lists comprise the prioritized barriers slated for solutions advocacy in 2016.

15 The map can be found by Googling “Bloomington Inclusion Collaborative Map or by clicking https://drive.google.com/open?id=1J6rrCf3CSOKJiMj59SZcKb18X7k&usp=sharing
Transportation and Mobility
- Policy (long term)
- Bus Stops (long/intermediate)
- Library access & safety (short term)
- Sidewalk connectivity (long/intermediate)

Self-Efficacy
- Checking in with others and calling out inappropriate behavior of staff and peers (short/long term)
- Increase cultural competency among professionals (long term)
- Increase use of public transportation (long/intermediate)
- Reading a map (intermediate)

PhotoVoice Images with captions from a participatory social mapping excursion to the IU Museum of Art (Public Space)

I can't even see it. – A young artist who often experiences seizures said of her excursion to see ancient Egyptian art at IU Museum. Staff support did not mind being physically tethered to the young woman for her safety while they walked to explore the museum; the safety tethers the young woman to a staff member who prevents the young woman from hitting her head if she falls.

“My neighborhood has roads like that. It’s dangerous for me. [inaudible] I can’t, like, I will trip over those.” - a 22 year old woman who experiences what she has named “brain drain” (seizures).

“You know one thing, they decide, on that street down there, if we could get a contract to build them sidewalks and fix them safe for the wheelchairs and everything, well there might be more revenue there to Bloomington.” – 66 year old man who works at and receives services at Stone Belt day program.
The Prevention Specialist engaged project participants in advocacy opportunities throughout 2016. On most occasions, lack of transportation or staff prevented Stone Belt stakeholders with disabilities from attending local advocacy opportunities. The Prevention Specialist used the data collected in 2015, images, and art to advocate for the elimination of barriers at city meetings, conference sessions, and other community events and encouraged other members of the collaborative to do the same. Working professionals were provided with PowerPoints with data collected, elevator speeches and encouragement to advocate for sidewalk connectivity, and more paved and covered bus stops (all goals prioritized by the collaborative). Working professionals were encouraged to take advantage of opportunities to build cultural competency by visiting at Stone Belt or by scheduling trainings about people with disabilities offered by Family Voices Indiana or Stone Belt.

The advocacy activities reported during the grant year include stakeholders from Stone Belt (including people with disabilities, staff and leadership) attending numerous meetings of the Monroe County Coalition on Access and Mobility (MCCAM) to share about how county/city zoning\textsuperscript{16} prevents some people with disabilities who receive Stone Belt services and live independently from being able to spontaneously easily come and go from their neighborhoods. Public transportation busses serve the public within Bloomington city limits, however, some group homes and individual residences served by Stone Belt are outside the city limits (revealed during participatory social

\textsuperscript{16} The public transportation budget gets only a small portion of funding from property taxes, which comes from property taxes within the Bloomington City limits. The largest portion of the budget is from federal funding, then state and Indiana University. The Bloomington Transit budget is available: \url{http://bloomingtontransit.com/wp-content/uploads/2016/08/2017-Proposed-Budget.pdf}
mapping by the “neighborhoods” team). Other transportation opportunities using BT Access or Rural Transit are sometimes available to people with disabilities, however, these benefits do not extend to staff.

One Stone Belt stakeholder shared during a MCCAM public meeting that the transportation barriers caused by zoning limitations cuts both ways. One woman with disabilities reported findings from the participatory social mapping of her neighborhood and told MCCAM she cannot easily or safely leave her neighborhood (as it is just over a 1 mile walk on I46 to the nearest bus stop). She added only people with cars can be staff for her neighborhood—“otherwise how would they get to work?” Not only are Stone Belt stakeholders interested in equitable access to public transportation options, but they are also deeply concerned with low wages provided to caregivers through Medicaid reimbursements. In an excerpt from a recent public advocacy video (not created for this project), a Stone Belt, Arc staff member states:

“We generally work eight-hour shifts, or 12-hour shifts or sometimes even 16-hour shifts. If someone calls in sick, staffing tries to find someone else, to come in or they will ask if I will stay longer . . . The clients are never left alone. How the staffing crisis affects me is that I have to work more hours to make sure the clients are cared for and it also affects the clients because they struggle with getting to know people. . . . I have second job that I do, plus I work extra hours at being a DSP [direct support professional] to make my ends meet. I would say I work at my retail job around 20 hours a week, so a total, an average of 90 to 100 hours a week of working both jobs.”

Working 100 hours per week leaves direct support professionals just under ten hours per day to sleep, bathe, eat, provide self or family care and travel to/from work—an isolating schedule.

17 Stone Belt, Arc. (January 27, 2017) Direct support professional wages need to increase, https://www.youtube.com/watch?v=wbXEJPL_I_Y
The narrative above describes a typical situation in disability services agencies across the United States. Stone Belt’s leadership reports high rates of turnover and sixty or more unfilled positions at any given time. DSPs generally work for $8-$11 per hour and provide care for vulnerable people who sometimes express themselves in ways that are challenging. When there are not enough staff to cover shifts, everyone’s stress increases and rare opportunities for community engagement (or even mundane errands or doctor appointments) become even more limited. People who are served by Stone Belt can and often do miss out on opportunities to leave the house or day program due to shortages; staff are tired, emotionally exhausted and far more likely to enact situational retaliation (a terse response or glare or unkind “handling”) that could cause harm.

A Stone Belt stakeholder with disabilities shared in the Women Writing for Change circle that after the project ended he testified in a February 2017 legislative committee hearing to demand an increase in wages paid to DSPs from Medicaid. He was very proud to have experienced speaking out for better pay. The stakeholder is an active member of self-advocates of Monroe County and had experience advocating at the state level prior to the Bloomington Inclusion Collaborative. His advocacy is not attributable to the project, but is mentioned to demonstrate the wide range of issues and barriers facing people with disabilities and their staff. Poverty, diminished economic opportunities, high unemployment rates, and weak health laws—all disproportionately impacting people with disabilities—increase risk for perpetration and victimization of sexual violence.\(^{18}\)

\(^{18}\) Wilkins et al., p. 8.
Outcomes

The gains from the advocacy and mapping efforts of the collaboration include accessible computers for patrons who are blind at Monroe County Public Library. The library also increased the number of books and DVDs for patrons interested in exploring disability cultural competency. Because the library took advantage of cross-agency trainings, the staff increased their cultural competency and communication skills with patrons with developmental disabilities (see appendix “2015Yr.End.Report.final.deidentified-rev” for evaluation report). Near Stone Belt there is increased sidewalk continuity and a safer, cleaner bus stop landing in an area identified as a barrier to inclusion on a 2015 excursion to the mall. The collaboration is likely not responsible for the repairs to the area, because the repairs to the bus stop began too quickly after reporting the problems via the city website. However, stakeholders did advocate for repairs to these areas through the proper city channels.

Stone Belt stakeholder’s social network maps grew after two years collaborating with the PS on the project. The recorded growth in Stone Belt stakeholder’s social networks attributed to the increase in familiarity with and communication skills between the PS and stakeholders. For example, some participants with disabilities indicated no support during the classroom activity, however, details about the individual’s lives are revealed through painting with Ellen Bergan of Van Go Mobile Art Studio or through creative writing with Women Writing for Change. One measurable increase by Stone Belt stakeholders with disabilities is the increased use of public transportation. Though the collaboration has concluded the inclusion work, the art and creative writing will continue to be used to advocate for inclusion through pop-up neighborhood art exhibits,
and transportation-access and wage-increase advocacy at the statehouse in Indianapolis.

Table 3 Inclusion Outcomes

<table>
<thead>
<tr>
<th>Inclusion Outcomes</th>
<th>Individual</th>
<th>Relationship</th>
<th>Organizational</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>•People with disabilities voice their concerns and see results moving toward self-advocacy and independence.</td>
<td>•People experience a sense of responsibility for health and safety of community members.</td>
<td>•Increase # of MCPL resources about people with disabilities.</td>
<td>•Increase # paved bus stop landing pads.</td>
<td></td>
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<tr>
<td></td>
<td>•Increase in use of mass transportation systems = increase in spontaneity by Stone Belt stakeholders.</td>
<td>•Increase # of accessible computers for blind patrons available at MCPL.</td>
<td>•Increase # of connected sidewalks and curb cuts.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>•Increase in cultural competency about disability for collaborators who used cross-agency training opportunities.</td>
<td>•Increase # people with disabilities participating in transportation-advocacy forums.</td>
<td>•Opportunity to interact with and hear from people who are not usually present at community meetings.</td>
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<tr>
<td></td>
<td></td>
<td>•Increase textural differences on floor leading to stairs (signaling to blind patrons that stairs are ahead)</td>
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<tr>
<td></td>
<td></td>
<td>•Increase # of acoustics in environment to aid in navigation for blind patrons.</td>
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</tbody>
</table>

MCPL is Monroe County Public Library.
Lessons Learned and Next Steps

The Bloomington Inclusion Collaborative had a very difficult time finding a good balance between project “business” time and relationship building. The project was on an accelerated timeline due to year to year funding structures and would have benefitted from more togetherness for togetherness sake. Creative engagement sessions facilitated by outside (not Stone Belt or Indiana Coalition Against Domestic Violence) partners brought people from the community in to Stone Belt locations to explore the meaning of community and inclusion using paint, photography or creative writing. No matter what the topic of the session, these works of art illustrate rich networks of support and love, but also deeply felt desires for more. Looking back, perhaps these activities should have been used early on to foster relationships and grow trust.

Day programs, should these become the site for collaboration, are against multiple systems level barriers that prevent easy or smooth engagement with the communities around them (i.e., low staffing radiates out to reduce other options, transportation access is limited, Medicaid Waiver does not allow for it). Transportation issues and staffing retention were the two largest barriers to Stone Belt stakeholders engaging with the community. Because staffing is consistently low, the stress on employees and clients increases at every site, thereby increasing risks for perpetration of multiple forms of violence across the organization. Employee retention is a structural barrier resulting in part from the way in which disability service agencies receive funding for services provided to their communities—they are consistently underfunded. When staffing is low the effects ripple outward, reducing staff’s ability to
take people into the community. Sometimes there are just enough people present in day program or at the group home to cover legal staff to client ratio requirements. Staff cannot accompany or drive the person with disabilities into the community, because there are not enough people to provide coverage in the home; therefore, people receiving services cannot leave the home without other transportation options. These other transportation options are restricted by funders such as Medicaid to day programs, medical and employment use only—all of which are necessary, but do reduce spontaneity. It is important for project coordinators to understand the challenges are multiple and beyond any one day program—they are systemic and require legislative intervention—however it is always possible and important to determine and address localized risk and protective factors toward the goal of eliminating sexual and other forms of violence across the lifespan.

In terms of data gathering, the excursions were difficult with only one level of observation for barriers from the perspective of stakeholders with disabilities using the adapted mapping protocol. The stakeholders with disabilities recorded barriers to inclusion and things that made connecting easier. The project would have benefitted from a second level of observation from collaborative partners who represented cross-sector working professionals who accompanied people with disabilities on the excursions. The Prevention Specialist noticed instances when stakeholders with disabilities did not record or experience something as a barrier during the excursion, though it impeded our progress. More than once, doors that did not have auto-open devices required the excursion group to wait outside or inside a building by until someone eventually opened the door for us. The person leading the expedition does not
use his arms to open doors, so those of us on the expedition also refrained from doing so. When the Prevention Specialist asked the expedition leader, a young man with disabilities, why the waiting around was not recorded as a barrier he replied “that’s life.” Waiting for doors, for people, for staff is part of his every day and he does not experience it as a barrier. Of course, most people experience their own circumstances differently than others. While this stakeholder did not mind waiting, the Prevention Specialist noted the doors were not compliant with the American’s with Disabilities Act of 1990. (This realization requires extensive analysis, but not in this project replication guide.) Rather than just one person with a clipboard recording barriers from their own singular perspective, all participants who can ought to collect observational data about barriers and protections.

Perhaps the greatest lesson learned through this process is the importance of relationship building and “total immersion” in disability services and advocacy for the project coordinator or prevention specialist working with people with disabilities19. One time classroom activities cannot reveal a person’s social network—though the activities engaged in during the project provided a beginning glimpse into stakeholder’s lives. It takes time and willingness to learn the innumerable and unique ways of communicating with the many stakeholders on the collaboration—including people who participated and did not identify as having a disability. With the passing of time and with practice with individuals, communication can become less of a barrier. There is no universal way to communicate with the adults with developmental or intellectual disabilities. Stakeholders

19 The phrasing “total immersion” comes from Meg Stone, IMPACT:Ability Executive Director and Keith Jones’s presentation on September 1, 2016 at the National Sexual Assault Conference on their work “Collaborating with the Disability System to Prevention Sexual Assault and to Support Survivors with Disabilities.” Ms. Stone introduced this term as a suggestion to preventionists who work on sexual violence prevention for people with disabilities. Please see the section entitled “Sexual Violence and Disability Resource for Prevention and Advocacy for contact information for Impact:Ability.
communicated using devices, such as computers and keyboards, by writing words, drawing pictures, using sign language, using spoken language, pointing, making happy or sad faces, turning away, leaning toward, smiling, saying no, giving hugs, pushing away and many other methods to indicate thoughts and feelings. Every person has their own way of communicating with others and it is worth every moment to figure it out together. Communication enables people to advocate for themselves and moves service providers toward more equitable client-directed service model.

The Prevention Specialist’s perception of the problem of sexual violence for people with developmental disabilities has dramatically shifted since 2015. In 2015, the PS had a narrow perspective on how perpetration might occur in such a vulnerable population. The literature and data sources indicate sexual violence happens with normative regularity for people with developmental disabilities and that perpetrators are by and large care givers. In 2017, the PS understands that social isolation from relationships systems and services does not only happen for the person with a disability, but it also occurs across the spectrum of human life for the people who also give care and their families. This project alone cannot change a culture that so thoroughly ensures isolation for people with disabilities and the people who care about and for them; however, it does address localized risk and protective factors for sexual violence. The Prevention Specialist is looking forward to turning inward toward these barriers to assist with the many solutions Stone Belt, Inc. puts in place to address emergent and continual issues both in the agency and in the culture at large. The Prevention Specialist and Stone Belt, Inc. are collaborating to pilot a culturally appropriate trauma-informed care initiative designed to intervene and prevent toxic
stress (a risk for violence). Family Voices Indiana and the PS are collaborating to increase organizational support for people with developmental disabilities to have safe, healthy sexuality and will work with and learn from Boston’s Impact:Ability (see next section for more information) to include organizational level sexual violence prevention policies, such as a healthy sexuality policy for group home and supported living environments.

Throughout the course of the project at meetings, gatherings, and presentations, members of the Bloomington Inclusion Collaborative were challenged with questions about how increasing the number of sidewalks or bus stops would help to decrease sexual violence. The project sought barriers to inclusion in order to address issues of isolation, which increases risks for perpetration and victimization. The solution to decreasing risk for perpetration and victimization of sexual violence is increasing connections across all aspects of human life. Sidewalks were identified by numerous stakeholders and key to the process of inclusion. Sidewalks provide the safest means of traversing neighborhoods and city streets for all members of society. Though, many people are isolated from transportation services through zoning (bus services stop at city border), increasing the number of sidewalks means an increase in the number of ways in which vulnerable stakeholders can safely connect with doctors, supermarkets, jobs and day programs. Physical infrastructure is important to increase social connections, so too are people. Social connections offer the opportunity for people to “check in” with others in their lives and allows for those people to “call out” unacceptable behaviors (or provide support); the more social inclusion and connectedness a person experiences, the better protected that person is from silence—one of social norms that
allows sexual violence to continue. Sexual violence is normative in America and no single program or initiative can end sexual violence in its entirety. It is the Bloomington Inclusion Collaborative’s greatest hope that these tools and lessons can benefit others in their endeavors to address risk and protective factors in their journey to change culture.

Afterward: Sexual Violence and Disability Resources for Prevention and Advocacy

Professionals working to end sexual violence can benefit from access to free information and resources about sexual violence that directly relates to and addresses the needs of people with a variety of disabilities. Advocates, primary prevention practitioners and other working professionals can use the below resources to gain insight on background of the American’s with Disabilities Act, definitions and information about specific disabilities, leads to academic resources including the different methods used to measure social inclusion and suggestions for communities and organizations to create better access within agencies to engage with and serve people with disabilities. The list is presented in alphabetical order.

California Coalition Against Sexual Assault


This special information packet by CALCASA provides an excellent overview of ableism, legal rights, and prevalence of sexual violence of people with disabilities. Not only does the tool provide suggestions for outreach and engagement, it provides a comprehensive list of physical accessibility improvement suggestions and list of
disabilities with definitions and disability support agencies in California. The packet includes primary prevention strategies, including suggestions to increasing community inclusion for people with disabilities.

**Disability Rights Ohio**


The document includes examines Ohio’s contributing factors for sexual violence (isolation for example), support services, and gaps in the criminal justice system for people with disabilities. The free download contains examples and recommendations for improvements to support systems for people with disabilities and is recommended reading to understand the depth and breadth of the problem of sexual violence for people with disabilities.

**IMPACT:Ability**

IMPACT:Ability 2017
[www.impactboston.org](http://www.impactboston.org)
Meg Stone, Executive Director
781-321-3900
mstone@impactboston.org

IMPACT:Ability brings together a sexual violence prevention program with a Boston disability services agency. Together, they worked to create culture change supportive of equitable practices and multiple forms of relationships for people with disabilities. Meg Stone, IMPACT:Ability Executive Director and Keith Jones presented September 1, 2016 at the National Sexual Assault Conference on their work “Collaborating with the Disability System to Prevention Sexual Assault and to Support
Survivors with Disabilities.” IMPACT implemented policies that support the ethical and equitable treatment of people who receive services at a disability services day program in Boston. Using a variety of evaluation methods, Ms. Stone reported most non-managerial staff could not correctly identify proper reporting protocol in 2012 before her intervention. In 2014, post-intervention evaluations demonstrated most staff could correctly identify reporting protocols and were more likely to report caregiver abuse of a client with disabilities.

IMPACT:Ability is an evidence-based program that uses a three pronged approach to:

- build capacity within agencies to support and report abuse using model policies and procedures;
- empower people with disabilities with relationship skills necessary to pursue safe, healthy, and consensual interactions with others; and
- provide organizational consulting and consent training, including sexual violence prevention model policies (code of ethics, mandated reporter of abuse, participant-on-participant abuse, whistleblower, abuse disclosure checklist, residential sexuality).

Indiana Coalition Against Domestic Violence

Indiana Coalition Against Domestic Violence in partnership with Stone Belt, Arc (2016). The Prevention Specialist participated in a national conversation with CALCASA and PreventConnect about emergent inclusion efforts in sexual violence prevention and in research using the data and efforts of the Bloomington Inclusion Collaborative. The project was followed through to a session at the 2016 National Sexual Assault Conference, which co-presented by two project stakeholders. The session was recorded and it is available below.


Handouts from the project including participant interviews, tools and PowerPoints are available online at http://www.nsvrc.org/nsac2016/handouts

Inclusion Appendix with pdf tools referred to within this document are available on PreventConnect at this url: http://www.preventconnect.org/wp-content/uploads/2017/07/Inclusion-Appendix.pdf

National Sexual Assault Resource Center (NSVRC) podcast “Mapping Prevention” about using PhotoVoice as needs assessment available online at https://www.nsvrc.org/blogs/preventionista/mapping-prevention

Cierra Olivia Thomas-Williams, M.A. (she/her/hers pronouns), Prevention Specialist, 1915 W. 18th Street, Suite B, Indianapolis, IN 46202, Phone: 317.917.3685, Cell: 812.219.8545, Toll free: 800.538.3393, cwilliams@icadvinc.org

Resources Cited


Centers for Disease Control and Prevention (2015). Sexual Identity, Sex of Sexual Contacts, and Health-Related Behaviors Among Students in Grades 9–12 — United States and Selected Sites, 2015. Surveillance Summaries. August 12,


Glossary

**Adverse Childhood Experiences (ACEs)** evolved out of a long term study that links early childhood trauma and negative health outcomes later in life, including poor quality of life, certain illnesses and death. Researchers developed a tool that counselors and other trained professionals use to “score” childhood trauma (called an ACE score), which is useful to determine the proper interventions and to provide services. The ACEs that are tested for in the tool are considered risk factors for long term negative health outcomes, which necessitate trauma informed practices (see trauma informed care). ACES connect to primary prevention through the presence of risk factors for disease and for multiple forms of violence across the lifespan. Research points to the presence of trauma in early childhood as an indicator for diminished life opportunity across the context of where people live, work and play. This understanding is essential to shift the narrative that contributes to upholding social norms that blaming individuals for poverty, addiction, victimization or mental illness to addressing the context of people’s lives—where they live work and play (Metzler, Marilyn, et al. (2017). *Adverse childhood experiences and life opportunities: Shifting the narrative*. *Children and Youth Services Review*, Volume 72, January 2017, Pages 141–149, [http://www.sciencedirect.com/science/article/pii/S0190740916303449](http://www.sciencedirect.com/science/article/pii/S0190740916303449). For more information including readings, podcasts, and the ACEs scoring mechanism, please visit: [http://www.acestudy.org/yahoo_site_admin/assets/docs/ACE_Calculator-English.127143712.pdf](http://www.acestudy.org/yahoo_site_admin/assets/docs/ACE_Calculator-English.127143712.pdf) (ACE quiz in English), [http://www.acestudy.org/](http://www.acestudy.org/) and [http://www.cdc.gov/violenceprevention/acestudy/](http://www.cdc.gov/violenceprevention/acestudy/)

**Community Needs Assessment (CNA):** A process used to identify the priority needs in any given community. Many forms of violence are interconnected and share the same root causes (see *Connecting the Dots*). In short, the CNA process includes gathering
local data in order to understand the problems unique to that locale, identifying gaps between needs and resources that address those needs, determining risk factors in the community and sharing the information with key stakeholders. Forms, resources, and suggestions about how to conduct a CNA in your community are free and can be found at Community Toolbox http://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources

Crime Prevention Through Environmental Design (CPTED): A multidisciplinary method that emerges from the study of criminology, CPTED focuses on elements of the built environment. Crowe (2000) argues “CPTED attempts to reduce or eliminate opportunities [for crime] by using elements of the environment to (1) control access; (2) provide opportunities to see and be seen; and (3) define ownership and encourage the maintenance of territory.” Environmental conditions and the opportunities they offer have the added benefit of increased community health and relate very closely to the ideas presented in Essentials for Childhood, because CPTED is a means to achieve safe, stable and nurturing environments (see SSNERS). Ultimately, Crowe argues “proper design and effective use of the built environment can lead to a reduction in fear and incidence of crime, and an improvement in the quality of life” (2000, p6).


Determinants of Health (SDOH): The conditions in which people are born, grow, live, work and age that influence their opportunities for a healthy, productive life. These circumstances are shaped by access to money, power and resources at global, national and local levels. The determinants of health contribute to health inequities—the unfair and avoidable differences in health status seen within and between countries. These factors include internal and external conditions that contribute to long term health outcomes. The CDC in its definition identifies factors, such as “biology and genetics (sex and age), individual behavior (alcohol/drug abuse, smoking, etc.), social environment (discrimination, income and gender), physical environment (where a person lives, crowded conditions, and health services (access to quality health care, having/not having health insurance)” as DOH (CDC, 2015). The DOH are usually preceded by the terms social or structural as in “social determinates of health” or “structural determinates of health” resulting in the acronym SDOH. The two phrases are often used interchangeably, however, the Jones, et. al. (2009) article on the cliff analogy provides a nuanced discussion of the difference (see further reading for citation). Definitions from the CDC at http://www.cdc.gov/socialdeterminants/Definitions.html. For a short easily accessible article about the ten greatest determinates according to the

**Developmental Assets**: A tool that helps youth workers identify and develop the internal and external assets of youth they work with. The strengths based approach includes attention to the development of skills, experiences, relationships and behaviors that help young people become “successful contributing adults.” The Search Institute created an instrument called “The 40 Developmental Assets,” a list derived from research, of the assets necessary for youth to thrive. This tool is a fantastic way to develop curricula and programs to address and intervene in ACEs. The tools and companion interventions are online and available for purchase at: http://www.search-institute.org/research/developmental-assets and http://www.search-institute.org/content/40-developmental-assets-adolescents-ages-12-18

**Empowerment Evaluation**: "Empowerment evaluation places an explicit emphasis on building the evaluation capacity of individuals and organizations so that evaluation is integrated into the organization’s day-to-day management processes… Empowerment evaluators coach individuals and organizations through an evaluation of their own strategies by providing them with the knowledge, skills, and resources they need to conduct just such an evaluation." Definition from Centers for Disease Control and Prevention: http://www.cdc.gov/violenceprevention/deltafocus/

**E4 Violence Prevention Strategy Selection Framework**: a tool that asks practitioners to centralize how power is operating in the decision-making process. (See next page for framework.)
**Is it effective?** What evidence makes us believe that this strategy will work? Research, practice-based and community-based knowledge are each valid forms of evidence in making this determination.

**Is it ethical?** Does this strategy place the burden of responsibility on the shoulders of those with the power/responsibility to create change? This does not mean that members of traditionally marginalized communities should not lead these efforts rather it means that our strategies should not require vulnerable communities and populations to change their behavior, or to do more, in order to try to safely navigate the inequitably distributed risks that they face. Rather, privileged individuals, programs and systems should work in collaboration with diverse leaders to reduce risks and to ensure that opportunities to safely thrive are available for all community members.

**Is it efficient?** Does this strategy have the potential to impact broad populations and/or multiple social problems? With consideration of our limited resources and the overlap in risk and protective factors between multiple social problems, it is in our strategic interest to maximize our impact by working at the intersections.

**Is it equitable?** Does this strategy center the voices, needs, interests and strengths of traditionally marginalized populations? We will not introduce or invest in prevention strategies that result in increased health and safety disparities between privileged and marginalized populations.
**Equity** is a complex process that requires the distribution of resources according to their need and demands a shift in thinking that blames people for circumstances like poverty or addiction. The pursuit of equity situates individuals within larger systems that unjustly distribute resources and opportunity over the course of the lifetime, where one’s behavior and choices are heavily influenced by advantages or disadvantages that are outside of individual control. Rather than blaming people for poor choices, this shift in thinking demands action to create an equitable society in which all people can participate and prosper. Just and fair inclusion is a means to create conditions that allow people to use the assets they have to the best of their potential. Visual metaphors such as the one included here by Matt Kinsella and featured in the blog *Cultural Organizing* are helpful tools to help guide one’s understanding of complex social issues: [http://culturalorganizing.org/the-problem-with-that-equity-vs-equality-graphic/](http://culturalorganizing.org/the-problem-with-that-equity-vs-equality-graphic/). To read about how adversity—such as inequity—is linked to reduced opportunities over the lifespan, please read Metzler, et al., (2017), “Adverse childhood experiences and life opportunities: Shifting the narrative,” [http://www.sciencedirect.com/science/article/pii/S0190740916303449#](http://www.sciencedirect.com/science/article/pii/S0190740916303449#).

**Health:** A state of complete physical, mental, and social well-being and not just the absence of sickness (W.H.O. 2003).

**Health Disparity:** A type of difference in health that is closely linked with social or economic disadvantage.

**Health Equity:** Health equity is a focused effort to address disparities in population health that can be traced to unequal economic and social conditions that are systemic yet avoidable. Health equity is achieved when all people have “the opportunity to ‘attain their full health potential’ and no one is ‘disadvantaged from achieving this potential because of their social position or other socially determined circumstance’” such as poverty, family violence, poor work environment, lack of healthcare, etc. (W.H.O., 2003).

**Health Impact Pyramid:** A five-tier pyramid that demonstrates the importance of attending to the structural determinants of health as a baseline for sustainable primary prevention efforts. The base of the pyramid indicates “interventions with the greatest potential impact” on the population, because they address “socioeconomic determinants of health” that change the “context to make individuals’ default decisions healthy” (p. 590). Friedan argues structural changes are the most politically charged and difficult prevention interventions, because they directly address power differentials, however, they are more efficient than individual efforts to educate people to change their behavior and more likely to have a sustainable impact. From Thomas R. Friedan’s free online article: “A Framework for Public Health Action: The Health Impact Pyramid” (2010) *American Journal of Public Health*. 2010 April; 100(4): 590–595 at [http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2836340/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2836340/)

**Primary Prevention:** A systematic process/practice that promotes safe and healthy
environments and behaviors that may reduce the likelihood or risk of the perpetration or victimization of violence. Two particularly helpful documents that clearly communicate what primary prevention is and what programs and practices maximize impact across the social ecology the CDC’s 2014 Connecting the Dots: an Overview of the Links Among Multiple Forms of Violence http://www.sciencedirect.com/science/article/pii/S0190740916303449# and the CDC’s 2016 Preventing Multiple Forms of Violence: A Strategic Vision for Connecting the Dots: https://www.cdc.gov/violenceprevention/pdf/strategic_vision.pdf. For more details on violence specific strategies, approaches ad evidence, please review Technical Packages for Violence Prevention: Using Evidence-based Strategies in Your Violence Prevention Effort on the CDC website at: https://www.cdc.gov/violenceprevention/pub/technical-packages.html

The following are the available violence-specific technical packages as of July 2017:

|-------------------|-------------------------------------------------------------------------------------------------------------------------------|

**Protective Factors**: Circumstances that correlate with protection and are associated with the absence of perpetration or victimization. These factors reduce risks for multiple forms of violence (incident, injury or disease) across the lifespan. See Connecting the Dots for more information: http://www.cdc.gov/violenceprevention/pdf/connecting_the_dots-a.pdf

**Public health approach to population level problems**: The focus of public health is on the health, safety and well-being of entire populations. Rooted in the scientific method and grounded in data, public health "strives to provide the maximum benefit for the largest number of people" (CDC, 2015). The four steps to this process are:

1. Define and monitor the health problem.
2. Identify risk and protective factors associated with the problem.
3. Develop and test prevention strategies to control or prevent the cause or the problem.
4. Ensure widespread adoption.

See CDC for more information: http://www.cdc.gov/violenceprevention/overview/publichealthapproach.html
Risk Factors: Circumstances and conditions associated with an increased likelihood of perpetration or victimization. These factors increase the risk for incident, injury or disease. See Connecting the Dots for more information: http://www.cdc.gov/violenceprevention/pdf/connecting_the_dots-a.pdf

Safe, Stable Nurturing Relationships and Environments (SSNREs): The conditions necessary to collaboratively create and sustain protective health promotional practices that prevent child maltreatment and build healthy communities.
- Safety: the extent a child is free from fear and secure from physical/psychological harm within their environment.
- Stability: degree of predictability and consistency in a child’s social, emotional and physical environment.
- Nurturing: the extent to which a caregiver is sensitive and consistently available to respond to the needs of the child.

The presence of each of these conditions is necessary to prevent child maltreatment to assure children reach their full potential, to provide a buffer against the effects of stressors, and ultimately they are fundamental to healthy brain development. See Essentials for Childhood for more information: http://www.cdc.gov/violenceprevention/pdf/essentials_for_childhood_framework.pdf

Social Ecological Model (SEM) is a framework for understanding that effective, efficient and sustainable primary prevention efforts include addressing risk and protective factors across an entire social ecology. This framework situates individuals within a larger ecology that encompasses not only individuals’ knowledge, skills and behaviors, but the interpersonal relationships they exercise them in, organizational structures they work in, communities they play in and the public policies, which inform all of the preceding levels. To read a history of sexual violence prevention that explains the importance of using SEM, please see Centers for Disease Control and Prevention (2004). Sexual violence prevention: beginning the dialogue. Available online at: http://www.cdc.gov/violenceprevention/pdf/svprevention-a.pdf

Social Inclusion: Equitable access to tangible and intangible resources (social capital/emotional support, meaningful paid employment, love, justice, services, healthcare, etc.) This means that power is examined, re-distributed and/or made available to all people. Social inclusion is both an outcome and a process of improving the cultural conditions in which people live. To learn more about social inclusion theory and find free tools to gather data about inclusion, please visit Prevent Connect to listen to a webinar called “What About Power and Patriarchy? Examining Social Cohesion Strategies to Prevent Sexual and Domestic Violence” and get access to ICADV social Inclusion tools at http://www.preventconnect.org/2016/06/what-about-power-and-patriarchy-examining-social-cohesion-strategies-to-prevent-sexual-and-domestic-violence/.

Social Norms: The shared beliefs, standards and social mores that shape behavior within a given community or society. The five social norms that contribute to sexual violence as identified by Prevention Institute and the
CDC are:
1. Limited roles for femininity and women (gender);
2. Limited roles for masculinity and men (gender);
3. Privacy & Silence;
4. Power (over others); and the

More readings about social norms and a how-to guide to the methodology for use in your work, please read the following:


**Spectrum of Prevention**: A model that “identifies multiple levels of intervention to encourage people to move beyond the perception that prevention is about teaching healthy behaviors.” Its comprehensive approach to addressing primary prevention uses six levels that build on each other and interact, including strengthening individual knowledge and skills, promoting community education, educating providers, fostering networks and coalitions, changing organizational practices, and influencing policy and legislation. More information at Prevention Institute online: [http://preventioninstitute.org/component/jlibrary/article/id-105/127.html](http://preventioninstitute.org/component/jlibrary/article/id-105/127.html)

**Trauma Informed Care (TIC)** is a systemic approach to human services derived from the understanding that most people in America have experienced at least one of the ACEs in their lifetime (VetoViolence, 2015) and that these traumatic events can have a significant negative impact on the health outcomes of the individual who suffered trauma. Providers who are **Trauma Responsive** understand that “traumatic events can impact people’s behaviors, perceptions, cognitions and productivity,” thus interactions between service providers and people in need are sensitive to triggers and as a result are empathetic and compassionate ([Trauma Matters KC](http://www.tacommunityhealth.com)), 2015). **Trauma Sensitive Practices** require providers to work with (rather than on behalf of) an individual to collaboratively develop a service plan all the while acknowledging a person’s experiences (should they disclose trauma) and supporting them throughout the process. One of the most common ways of explaining this model of care is the movement away from posing the question “what’s wrong with you?” and instead asking “what happened to you?” then designing a care plan from a place of compassion. For more information about the impact of trauma on people and society take a look at the VetoViolence infographic about the ACES available online:: [vetoviolence.cdc.gov/apps/phl/images/ACE_Accessible.pdf](http://vetoviolence.cdc.gov/apps/phl/images/ACE_Accessible.pdf).
Recommended further reading about primary prevention:


20 Unfortunately this reading list does not directly address disability—most primary prevention work does not. It is on us, practitioners, to change that.

Appendix


For more information, training and technical assistance on Primary Prevention, please contact the prevention team at Indiana Coalition Against Domestic Violence via email at icadv@icadvinc.org.

Funding for this publication was made possible by the Centers for Disease Control and Prevention and the Indiana State Department of Health. The views expressed in written conference materials or publications and by speakers and moderators do not necessarily reflect the official policies of the Department of Health and Human Services, nor does the mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government.
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Informed Consent (for Consultant)

**Informed Consent**

**Purpose:** You have been invited to participate as a member of ICADV/Stone Belt collaboration. The purpose of this project is to guide the development of a shared definition of social inclusion to enhance and promote respectful, safe, healthy relationships in Monroe County for self-advocates. We will discover together where self-advocates feel excluded and together with other community partners develop solutions to those identified problems. ICADV Rape Prevention and Education Consultant, Maggie Matson, would like to record any discussions about exclusion/inclusion to accurately collect information, thoughts and feelings. Maggie will transcribe the tapes herself and then she will delete the recordings. Additionally, to assure confidentiality of participants, no names will be included in the transcripts.

We recognize that this subject sometimes requires us to think about the abusive behaviors that self-advocates are experiencing, like social exclusion. We know that this can be tough. Ultimately, we won't ask you to stick with the project if your participation is causing you any discomfort. You have the right to withdraw at any time; please just let us know, or else we will worry. We believe that this will be an exciting, productive and empowering experience; thanks for being part of it.

**Responsibilities:** Responsibilities include honestly sharing your ideas and feelings and communicating with other members.

**Benefits:** We believe that participation on this project will strengthen your leadership and advocacy skills and help build a more inclusive Bloomington. We know that your expert opinions will contribute to the success of ICADV’s work to prevent violence.

**Risks:** We believe that the risks of participation are minimal. Our focus will be on strategy for fostering healthy, safe, fair, respectful relationships, but we recognize that this will also mean sometimes thinking about abusive behaviors. We recognize that survivors of violence may feel discomfort when talking about violence prevention. ICADV and Stone Belt staff will be available to help process our conversations and experiences, and we will offer additional resource numbers where you can seek info and advocacy services should you need them.

I have read the informed consent document and I understand my rights and responsibilities as a member of this collaborative process. I consent to being recorded, however, during any session, I may request that the recorder be turned off if I am not comfortable with that topic or subject and want to share.

<table>
<thead>
<tr>
<th>Name</th>
<th>Signature</th>
<th>Date</th>
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<tbody>
<tr>
<td>ICADV Staff</td>
<td>Signature</td>
<td>Date</td>
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Recruitment Process Checklist:

☐ Call, email, or in-person communication to introduce idea and ask if potential partner they would like more information;

☐ Executive summary provided including:
  o Timeline of project;
  o Time commitment expected;
  o Benefits or outcomes expected; and
  o Contact information.

☐ Request in-person meeting to go over project requirements and answer any questions.

☐ Memorandum of Understanding (MOU) to follow commitment
  o This document describes the roles of each agency in the project and includes the timeline and expectations.
  o Provide city departments with two originals, because they need to retain an original signed document.
  o Email with follow up deadline for MOU to be completed and preferred method of return to you (email, mail, etc.)

☐ Before work of any kind begins, obtain informed consent from all project participants.
  o May require guardian signatures for some participants with developmental and intellectual disabilities.
Participatory social mapping: individuals, businesses, neighborhoods, public spaces
Original protocol for social network mapping

The Social Network Map: Assessing Social Support

7 Domains of Life

Formal Services (including Transportation)
Household
Other Family
Work/School
Clubs/Organizations/Church
Friends
Neighbors

Prevention Specialist will measure the following functions across the 8 domains (Tracy, 1990, p. 464):

1. Network Size: total number of people identified in the network
2. Domain size: total number/proportions of people in each of the seven domains
3. Perceived availability of emotional, concrete, and informational support
4. Criticalness: proportion of network perceived as “almost always” critical of the individual
5. Closeness: proportion of network perceived to be “very close”
6. Reciprocity: proportion of network relationship in which help goes “both ways”
7. Directionality: proportion of network relationships in which help goes primarily from client to network and proportion of network relationships in which help goes primarily from network to client
8. Stability: length of relationships (how long known)
9. Frequency: frequency of contact (how often seen)

We will use the steps outlined in Tracy and Whittaker (1990, 464-467) to deliver the Social Networking Map assessment; however, as the authors suggest we will modify the delivery to suit the needs of the people we are surveying.

I will ask self-advocates I interview to name the people in their lives in each of the 7 domains. I will put the names given by self-advocates in the grid below (first column) and seek detailed information about each of the people who were names. This gives us a great baseline as to the breadth and depth of social support and inclusion prior to any interventions through the project.
### Social Network Grid

<table>
<thead>
<tr>
<th>Name</th>
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Adapted from:


Original protocol for environmental mapping
Bloomingon, IN Group Mapping Exercise
Goal: complete mapping excursions by August 31, 2015

<table>
<thead>
<tr>
<th>Team 1</th>
<th>Team 2</th>
<th>Team 3</th>
<th>Team 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barbara Salisbury</td>
<td>Chris Jackson</td>
<td>Rafi Hasan, II</td>
<td>Eli McCormick</td>
</tr>
<tr>
<td>Heather Dane</td>
<td>Evelyn G. Smith</td>
<td>Amy Leyenbeck</td>
<td>Jennifer Burch</td>
</tr>
<tr>
<td>Leslie Green</td>
<td>Jennie Todd</td>
<td>Allison Pack</td>
<td>Susan Russ</td>
</tr>
<tr>
<td>Self-Advocate</td>
<td>Support Person?</td>
<td>Self-Advocate</td>
<td>Self-Advocate</td>
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Neighborhoods

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</thead>
<tbody>
<tr>
<td>Group Home Neighborhood 1</td>
</tr>
<tr>
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<tr>
<td>Group Home Neighborhood 3</td>
</tr>
<tr>
<td>TBD?</td>
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Public Places

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<tr>
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<td>MCPL</td>
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<tr>
<td>PARK(?)</td>
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<tr>
<td>BT/RT</td>
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</tbody>
</table>

Original Version - Community Windshield/Walking/Rolling Survey

Purposes (to collect data):
1) What attracts you to this space or helps you feel included here?
2) What are the barriers to inclusion in this space?

Directions:
While driving, walking or rolling around complete a questionnaire together about the location using the Community Windshield survey especially important in the neighborhoods. Drive, walk or roll around the area selected (using the map as a reference). Using the guiding questions below, make observations, take pictures of barriers to inclusion and things that foster inclusion, draw on the maps (can we also indicate red/yellow/green rated for inclusion?), and discuss your findings as you drive/walk/roll around. Possibilities for coding include self-advocates using red/yellow/green markers or smiley/frowny to code maps for inclusion/exclusion. For example, if a bus stop makes a person
feel unsafe, he or she circles that place on the map in red. Working professionals are asked to follow up and ask for details about locations mapped to gather narrative stories as we go.

Materials Provided:
- Disposable camera(s);
- Map(s);
- Pads of paper;
- Pens/markers (or faces);
- Clipboard(s); and
- Windshield/walking/rolling survey packets with probing questions.

The Necessary Roles:
1. Self-advocates who assess barriers to or places of inclusion using a map and red/yellow/green markers to code areas of the map.
2. Assistant to make note of the specific attractions/barriers on a map—circle them on map or write in barriers/attractions and be sure pictures are taken of attractions/barriers.
3. One/two people to record thoughts self-advocates share during excursion.
4. A person in charge of asking questions and writing answers to before and after-mapping survey questions.

The Mapping Process:
While walking, rolling or driving please make a note of the specific attractions (green/smile) or barriers (red/frown) on the map:
- Circle or mark them in the appropriate color,
- Take a picture of the attraction(s) or barrier(s),
- Elicit a story or explanation about the attraction or barrier from self-advocates if possible.

Please be sure to record all information in some way, whether it is through notes or other means. These stories, descriptions and explanations will be juxtaposed with map imagery, drawings and photos for the final product.

Probing questions to ask during mapping are:
- What is your overall impression of the space?
- What attracts you to this place or helps you feel included here?
  - Another way to ask this: What helps you feel good/safe/secure about this space?
- Do you feel safe or welcome here?
  - Why or why not? (indicate these feelings on the map using yellow, or green or faces)
- What barriers for access, use, and or inclusion do you encounter?
  - If there are emotional barriers, draw the route that you would prefer to take.
  - If the barrier is physical, try to find the nearest accessible route that you can take and note that on the map.

After Mapping:
Follow up reflections for group brainstorming on the ride back (someone please ask these questions and take notes of the answers):
- What are the areas/spaces with some of the strongest visceral (bodily/emotional) reactions?
- What are some of the most important or pressing land or physical issues identified?
- What did you enjoy about the process of participatory social mapping?
- What challenges to the process of participatory social mapping did you encounter aside from the barriers you were tracking?
When:
Groups are assigned and once logistics can be worked out with Stone Belt, trips should occur any

time after the third meeting with professionals up until the end of September. Groups should get

started as soon as possible, but it would be fun to coordinate a meet up with a common departure
time set for a specific day or over a weekend. We could then gather after to de brief, celebrate and
tell stories.

All materials must be returned to Cierra by September 1, 2015.
Dear community member:

Please use this survey to guide your conversation and observations during this adventure to a Bloomington neighborhood and park called Bryan Park. You will accompany and Nathan Gilbert, Stone Belt staff on this journey into Bloomington. Please use this survey to guide your interview and add your own observations, however, please distinguish your comments from experiences. Feel free to go off-script to collect information about barriers to inclusion (emotional and physical) and please also note situations where inclusion is encouraged or felt by the adventurees! Take copious notes!

The Mapping Process: While walking, rolling or driving please make a note of the specific attractions or barriers on a map (back of survey) at the site:
- Circle or mark them.
- Take a picture of the attraction(s) or barrier(s),
- Elicit a story or explanation about the attraction or barrier from Michelle if possible.
Please be sure to record all information in some way, whether it is through notes or other means. These stories, descriptions and explanations will be juxtaposed with map imagery, drawings and photos for the final product.

Please leave the survey and camera with Nathan, Stone Belt staff, who will return it to Cierra.

Destination: Bryan Park Bloomington Neighborhood

Who are you? 
Who are you interviewing? 

Is there a bus stop in or near the neighborhood? 

The bus stop features: (i.e., cleanliness) 

Is the location conveniently located (why/why not)? 

What are the features of the landing (area where stop is located)? (i.e., in the grass, concrete, no curb cut)
Are there any obstacles that would limit the mobility of a wheelchair? If yes, what?

**BEFORE**

Have you been here before?

What do you remember about this place?

If you haven’t been here before what do you expect it will be like?

Do you like coming here? WHY or WHY not.

Why haven’t you been here before?

Is there a park or somewhere you like to hang out in this neighborhood? IF SO, where? IF NOT, why not?

What’s the first thing you think/feel/hear when you see in your neighborhood? (for those who can see/hear)

What are your favorite features of the neighborhood?

What don’t you like about your neighborhood?

What do you think about what you see around the neighborhood?

What do you hear?

Any other thoughts?

**Staff or Community member: Also consider how the clients LOOK, their affect, do they look worried, happy, sad excited?**

Do you feel safe? WHY or WHY not.

Do you feel like you are welcome here, do they want us to be here? WHY or WHY not.
Would you hang out in your neighborhood (or a park in the neighborhood) alone? WHY or WHY not.
Would you come here with friends or staff?
What would you change about this place to make it better?
What do you like about this place the best?
What is hard about visiting this place?

Also revisit some of the questions AFTER the trip

Participatory Social Mapping in Your Own Agency

Evelyn Smith, Prevention Coordinator at Middle Way House, Inc., a domestic violence and rape crisis shelter serving five Indiana counties, created participatory mapping tools to be used within her agency. Participatory social mapping is a great method to collect data about spaces, the way they are used, and the way spaces effect the people who use them. It is an interactive process that allows for localized source of knowledge. The process was used in the Bloomington Inclusion Project to map neighborhoods, public spaces
and businesses. Evelyn Smith, Prevention Coordinator used the method to gather data from the women who use Middle Way House’s public shelter spaces to make trauma-informed changes to the spaces when residents interact (such as re-arranging spaces to support desired behaviors). For example, rather than have signs posted that prohibit children from wandering, Ms. Smith created an open play area where children can color on the wall while families wait for case management services!

Gathering data about the way in which the space was being used, how shelter residents wanted to use the space, and how rules were being enforced within the agency allowed Evelyn to reduce or eliminate re-traumatizing vulnerable people. Resident’s knowledge and locally sourced experiences are used to effect positive changes within the agency. Using this data, an interesting discrepancy was discovered. Staff all reported the resident exercise equipment was broken—this information is passed on in volunteer orientations. Residents reported enjoying the equipment and appreciating its availability whether the resident used it or not. This equipment was not “broken,” rather residents used it and felt it helped support healthy environments. While, MWH staff interpreted the room as useless, MWH residents viewed the room with exercise equipment in it as a nice amenity not usually available.

Evelyn used two methods to gather data about how people were using MWH shelter space:

- Ask staff to use the Mapping/Assessment Tool (next page) to use within their offices. Special attention is focused on three key details: structural space (physical things), sensory spaces (noises and lights), and social spaces (how many posters with people who look like me?).
- Give participants a blank map, clip board and pen to write their responses directly on the map (see example below);
- Give participants post it notes, assign an area, have them respond to space usage in the area. For analysis, be sure to specify on the post it note which area it was found in before removing them (or take pictures to record data before you remove the post-its).

For more information about these tools, contact:

Evelyn G. Smith  
Volunteer and Community Engagement Coordinator  
Middle Way House, Inc. & The Rise  
volunteer@middlewayhouse.org

812-333-7404

**Organizational Mapping/Assessment Tool**

<table>
<thead>
<tr>
<th>Space</th>
<th>Structural Space</th>
<th>Sensory Space</th>
<th>Social Space</th>
</tr>
</thead>
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Appendices 12
<table>
<thead>
<tr>
<th>Sample Questions: Is this space navigable if you are in a wheelchair/on crutches/use a cane/use a walker? How do you know how to navigate it? Does this space share a floor plan with other spaces? How is seating arranged? Where are exits/entrances?</th>
<th>Sample Questions: Is this space navigable if you cannot see/hear? Are there cues that are only visual/aural? Is this space potentially overwhelming visually/aurally? What are the acoustics of this space like? Are senses other than sight/hearing engaged/necessary and how?</th>
<th>Sample Questions: What kinds of relationships dominate this space? What kinds of power dynamics dominate this space? Who is represented in this space? What would this space look like if you were unfamiliar with the inhabitants? How are people represented in art or via other materials available?</th>
</tr>
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<tbody>
<tr>
<td>Space 1</td>
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<td>Space 2</td>
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De-escalation is the process of bringing an individual from a state of agitation or increased arousal back to or closer to, their baseline emotional state. De-escalation is not about reasoning with someone or trying to convince them of anything. A person who is involved in an altercation is not generally capable of making informed decisions. Your only goal is to bring them back to a baseline emotional state.

Strategies for De-escalation

**Attitude**
- Act calm, relaxed, and self-assured. Fake it if you have to. Your anxiety or fear can trigger the same emotions in the people around you, including the person you are engaging with.
- Don’t become defensive. The issue at hand is probably not you. Avoid situations where it is.
- Maintain a low, calm, monotone voice. Demonstrate engagement in ways other than intonation.
- Be respectful but firm when setting limits, calling for help, or disengaging. Communicate your respect for the person you are conversing with even when ending the conversation or taking other action.
- Don’t try to speak over someone who is yelling or speaking loudly. Wait for them to breathe.

**Physical Presence**
- *Never turn your back on someone.* It makes you vulnerable and communicates disrespect.
- Maintain the same eye level, whether that means sitting or standing.
- Give them more space than you think they need (about 4 times the usual amount: 4-8 feet).
- Do not stand toe-to-toe or full-front to the person you are with. People often interpret this as threatening or combative. Instead, stand at an angle, shoulder forward.
- Do not maintain constant eye contact. Let others choose where and when to make eye contact.
- Keep your hands out of your pockets, up, and open (not balled into fists). This demonstrates that you are not physically threatening or hiding anything. Also avoid pointing or “finger wagging.”
- Avoid smiling. Smiling is often interpreted as condescending or dismissive.

**The Conversation**
- Remember: **You are there to help the other person reach a state where they are capable of stating their needs and safely moving towards meeting them. Until they reach that state, they are very vulnerable and most likely not able to make informed decisions.**
- Respond to questions for information, even if those questions are worded rudely or are accusatory (“Why the hell do I have to fill out these forms?”). **Do not** respond to questions that are solely abusive (“Why is everyone here such a jerk?”).
- Setting limits and boundaries is good. Ultimatums are not. Give people real choices where both options are safe. (“Can we continue this meeting calmly, or would you prefer to come back tomorrow when we can both be more relaxed?”)
- Express empathy for feelings, if not behaviors. (“I understand you have every right to be frustrated, but it’s not okay to threaten staff like that.”)
- Engage cognitive, teaching processes. A person who is teaching you something they want you to know will usually feel better about the situation. (“Please help me understand what you’re saying to me.”)
- Do not position yourself as an external controller. (“I can’t let you do that.”) Discuss external controls as structural or institutional. (“That is against XYZ Company’s policy.”)
Inclusive Changes to Structures
(some cheap or low cost solutions)

Children/Parents
- If children are likely to be bored, provide non-disruptive activities for them.
- If they are likely to be anxious, provide activities for coping (stuffed animals, drawing supplies, etc.).
- If this is a shared space, provide clearly labeled storage for toys to make cleanup easy.

People of Size
- Provide chairs without armrests, and tables as well as desks/auditorium seating.

People Who Are Blind/Have Low Vision
- Maintain consistent furniture arrangement within/across rooms.
- Provide auditory/tactile cues for environmental changes (such as auditory notifications for elevators or textured floors to warn of elevation changes).

People Who Are Deaf/Hard of Hearing
- Provide visual cues for environmental obstacles/changes (i.e. blinking lights for doorbells or empty/occupied signs for restrooms).
- For DV/SV shelters, please consider using signage near your “audio box” so that deaf patrons can communicate with people inside the shelter.

People with Wheelchairs/Walkers/Canes/Other Mobility Aids
- Provide curb cuts to ease navigating roads and sidewalks.
- Provide mobility assistance no-questions-asked (i.e. generally accessible elevators instead of keyed ones to which access must be requested).
- Maintain unobstructed roads and pedestrian paths/report issues for repair promptly and insistently.

People with Limited Literacy/English Proficiency
- Provide pictographic/multilingual signage and documentation.

People Who Are Queer, Trans, and/or Gender-Nonconforming
- Provide gender neutral restrooms. Bathrooms can be converted with a sign. One example is to put a sign on the door not with gendered stick figures, but list the amenities, such as stalls, menstrual products, urinals, etc. Or just put a picture of a toilet on the door.
- Offer non-gender-specific titles for forms and documentation. (Mx.)
- Put pronouns on employee IDs or badges

People with Anxiety
- Provide quiet, low-activity areas for recovery from social exhaustion/panic attacks/agoraphobia/clausrophobia.
- Provide multiple avenues for social interaction (email, mailboxes, person to person).

Quick Facts About the Americans With Disabilities Act
• Provisions cover: employment issues, public services, privately-operated public accommodations and services, and telecommunications networks
• Variously regulated and enforced by the DOJ, EEOC, FCC
• Generally defines disability as: “[Having] a physical or mental impairment that substantially limits one or more major life activities; [Having] a record of such impairment; or [Being] regarded as having such an impairment”
• Generally requires “reasonable accommodation” made for qualified individuals
• Examples: making sign language interpreters available for interviews; giving individuals with diabetes regular breaks for monitoring/adjusting blood sugar
• Also stipulates requirements for built environments
• Examples: Bathrooms in public spaces must have at least one “accessible” stall with 60” diameter turning space; light switches in public spaces must be between 15” and 48” from the ground
• (Some) Conditions covered by the ADA: Limited mobility conditions, intellectual disabilities/delays, cancer, HIV seropositivity, PTSD, autism, schizophrenia
• (Some) Conditions exempted from ADA coverage: homosexuality/bisexuality, gender dysphoria/”transexualism”, pedophilia, obesity, pregnancy

Defining “Accessibility”

Accessibility: the design of products, services, and environments to ensure both direct access (via unassisted access) and indirect access (via compatibility with assistive technology) for people with disabilities

Usability: the degree to which a specified audience can use a specified product, service, or environment to achieve a specified outcome with efficiency, efficacy, and satisfaction

Universal Design: the design of products, services, and environments to be aesthetic and usable by as many people as possible, regardless of age, ability, or status in life
Focus Group Protocols

Focus Group Protocol for Rape Prevention and Education (RPE) Project
Maggie Matson
Indiana Coalition Against Domestic Violence

Protocol for Focus Groups

Recruitment:
Stone Belt staff and ICADV staff will assist with recruiting and setting up focus groups once protocol is finalized.

Location:
Focus groups will be held in a quiet room, free of distraction, at Stone Belt or a community venue.

Things to Bring:
- Name tags
- Consent forms (see Appendix A)
- Pens
- Audio recorder
- Refreshments (lemonade and/or water)
- Snacks (check with Stone Belt staff regarding specific dietary needs or restrictions of volunteers beforehand to determine best food options)
- Poster board with rules (see Appendix B)
- Photos (see Appendix C)
- Flip chart (see Appendix D)
- List of questions
- Resource card w/ contact information (Katie’s or Cierra’s business cards)
- Poster to hang in front of room for list activity (bringing more than one is optional)
- Smaller blank pieces of paper and markers/crayons (optional)
- Traffic light symbol
- Sheets of paper with images of activity options (Appendix E)
- Self-Advocate Acting Worksheets (Appendix F)
- Sign-up Sheet (Appendix G)

Other Information:
- **Focus group facilitator:** Maggie Matson
- **Advocacy staff:** ICADV and Stone Belt staff will be available to help process self-advocates conversations and experiences.
  - **Co-facilitator:** ICADV staff (Kate, Cierra, or Marie) to help take notes and operate audio recorder.
  - **Support staff:** Stone Belt staff to assist self-advocates if needed.

Focus Group Questions

Rapport building
- What is something nice that happened to you this past week?

Activity to introduce idea of social inclusion
- How would you describe this picture? (ask for each picture shown)
  - What do you see? (probe)
• Where is the person in the picture? (probe)
• What is the person in the picture doing? (probe)
• How is the person in the picture feeling? (probe)
• How does this picture relate to your own experiences? (ask for each picture shown)
  o How is this picture similar to your own experiences? (probe)
  o How is this picture different to your own experiences? (probe)

Discussion questions
• What are some of the activities you enjoy doing or would enjoy doing near where you live?
  o Why is this? (probe)
• What helps you get involved in these activities?
• How can the staff and the service manager help you do more activities you enjoy?

Activities to identify factors that limit or promote social inclusion
• What are things that stop you from doing community activities in Bloomington, Indiana?
  o Why is this? (probe)
• What changes need to be made in the community in order to address each thing that stops you from doing community activities in Bloomington, Indiana? (Ask for each thing mentioned through activity).
  o Why is this? (probe)
• If you could change one thing in Bloomington, Indiana, to make it easier to do the community activities you enjoy or would enjoy doing, what would that one thing be?

Probing (Optional)
• If someone mentions anything related to something in the community that helps them get involved in these activities, I will follow up with this. “You mentioned X, tell me more about that.”
• Probe: If no one mentions anything other than staff (or parents) as barriers to social inclusion, then I will ask “other than Stone Belt staff (or parents), what helps you get involved in these activities?”
  o How do you find out about these activities?
  o How or where do you get money to pay for these activities?
  o How do you travel to the place where these activities are located?
  o How does the space or people where the activity takes place help you get involved?

Focus Group Script

1. Welcome/Introductions:
   a. Hello! We are so glad you volunteered to join us today. My name is Maggie and I am going to be the group’s facilitator. This is [note-taker’s name], she is going to listen and take notes during today’s discussion. [Introduce anyone else present during or assisting with the focus group].
2. Introduce focus group topic:
   a. The main reason we are here today is to talk about the things you feel stop you and other self-advocates from doing community activities in Bloomington, Indiana. We will also discuss what you think needs to change in Bloomington the in order to make it easier to do community activities.
3. Consent
   a. [Hand out one copy of the consent form to each self-advocate (see Appendix A for Consent Form)].
   b. The papers I just handed out are consent forms, which we will go over together. The consent form explains the purpose of our project and the potential benefits and risks of volunteering for the focus group. Please feel free to ask questions as we go over the consent form together.
   c. Would anyone like to read the consent form out loud to the group? [Wait 30 seconds].
     i. If someone volunteers: Thank you so much for volunteering to read, [Name of first person to volunteer].
     ii. If no one volunteers: If there are no volunteers, I will read the consent form out loud and we can go through it together. Please feel free to interrupt me if you have any questions along the way [Pause at the end of each paragraph/section to ask if there are any questions from the group].
d. Are there any questions?

e. I would also like to mention that [note-takers name] will be taking notes about what is said, but will not write down any names or identifying information next to what is said during the discussion.

f. You may leave for any reason and at any time before or during the discussion if you no longer want to be a part of the focus group.

g. I have more copies of the consent form if you want to keep an unsigned copy for yourself. Please let me know if you would like one. Once I collect all of your signed consent forms, we will go over some guidelines for the discussion.

h. [Collect signed consent forms].

4. Focus group guidelines

a. Now let’s go over a few guidelines. [Go over rules written on poster and leave on display for group to see (See Focus Group Appendix B)].

i. Remember everyone’s opinion is important.

ii. There are not right or wrong answers to questions.

iii. We want to hear what everyone has to say. You do not have to just talk to me. We encourage you to discuss responses with one another and to take turns talking so that everyone can be heard.

iv. I may ask you to share your thoughts if you haven’t said much during the discussion, but it is your right to pass on any question if you do not wish to answer.

v. Being here is voluntary. You have the right to leave at any time and for any reason.

vi. Please do not share personal stories or the names of other group members with anyone outside of this room.

vii. And finally, have fun.

5. Ice breaker

a. Let’s take some time to get to know each other a little bit better. As we go around the room, say your first name and share something nice that happened to you this past week.

b. [Ask each person]

i. What is your first name?

ii. What is something nice that happened to you this past week?

6. Activity to introduce idea of social inclusion (Abbott and McConkey, 2006):

a. I am going to show pictures of people doing different community activities. For each picture I will ask you to describe the photograph and relate it to your own experiences [See Focus Group Appendix C for photographs].

i. Here is a picture [Show picture].

ii. Describe the picture.

1. What do you see? (probe)

2. Where is the person in the picture? (probe)

3. What is the person in the picture doing? (probe)

4. How is the person in the picture feeling? (probe)

iii. How does this picture relate to your own experiences?

1. How is this picture similar to your own experiences? (probe)

2. How is this picture different to your own experiences? (probe)

iv. [Repeat steps i. – iii. for each photo]

7. Ask questions (adapted from Abbott and McConkey, 2006):

a. What activities do you enjoy doing or would you enjoy doing near where you live?

i. Why is this?

b. What helps you get involved in these activities?

c. How can the staff and the service manager help you do more activities you enjoy?

8. Options for activity to facilitate discussion about factors that limit or support social inclusion (bring materials for each activity; let group vote and decide on activity):

a. Alright now we are going to do an activity to talk about the things you feel stop you from doing community activities in Bloomington, Indiana. We will also discuss what you think needs to change in Bloomington the in order to make it easier to do community activities.
b. You are going to vote on which activity you would like to do by raising your hands. Only vote once for the activity you would like to do the most. There are three different choices for activities.

c. Your choices are to 1) make a list, 2) draw a picture, or 3) act out a story. You can only raise your hand to vote for one activity. [Use the three different sheets of paper with images of activities to show self-advocates to help them select the activity they would like to do.] [See Focus Group Appendix E].

d. [Hold up image] Raise your hand now if you would like to make a list.

e. [Hold up image] Raise your hand now if you would like to draw a picture.

f. [Hold up image] Raise your hand now if you would like to act out a story.

g. Alright, [insert activity that received the most votes] got the most votes, so we will be [insert activity that received the most votes].

h. Option 1: List generating activity

i. Next, I would like for you to think of things in that stop you from doing community activities in Bloomington, Indiana, and list as many things you can think of. Just name the thing out loud and say why it stops you from doing community activities to the rest of the group.

ii. I will add each thing mentioned to this list. [Hang poster board in front of room or group]. We can always add or make changes to the list if you think of something else later. [Stop adding to the list when self-advocates feel there is nothing more to add; probe specifically for information about barriers to social inclusion in the community].

iii. Next I will ask you to think of changes needing to be made in the community in order to address each thing that stops you from doing community activities in Bloomington, Indiana, and list as many ideas as you can think of. Just name the idea out loud and say why you think it will make it easier for you to do community activities in Bloomington, Indiana.

iv. I will add each idea mentioned to this list. [On another poster board hanging in front of the room or group]. [Stop adding to the list when self-advocates feels there is nothing more to add; probe specifically for information about changes to address barriers to social inclusion in the community].

i. Option 2: Drawing a picture

i. [Hand out sheets of paper, markers/crayons, and pencils].

ii. Next, I would like for you all to think of a situation or time when something stopped you from doing a community activity in Bloomington, Indiana, and draw a picture about it. Let’s take about 15 minutes to draw our pictures. Then we will take turns sharing and talking about your pictures together.

iii. Does anyone have any questions before we get started?

iv. It is okay if you do not finish the entire picture in 15 minutes, you will just use it to help tell your story about a time something stopped you from doing a community activity in Bloomington, Indiana.

v. I will use this traffic light to let everyone know when time is almost up and when it is time to stop working on our drawings. Green means there is still plenty of time left; yellow means you have five minutes left to work on your drawings, and red means there is no more time left. We will start our discussion again when the light is red.

1. [Use traffic light tool to facilitate transition].

2. [Wait ten minutes; give five minute warning; take off green sign].

3. [Wait five more minutes; then take off yellow sign].

4. [Display red sign to show there is no more time left].

vi. Alright, the traffic light is red, which means there is no more time left. We are going to stop working on our drawings and begin our discussion again. Let’s each go around the room and share our drawings with the rest of the group.

vii. Feel free to share if you have had similar experiences or are able to relate to someone else’s drawing after they are finished explaining it.

viii. Who would like to go first?
ix. [For each person in the group]
   1. Tell us about your drawing
   2. What are the things that stopped you from doing community activities in Bloomington, Indiana?
      a. Why is this? (probe)
   3. [To group] How is this drawing different or similar to everyone else’s experiences?
   4. [To group] What would you change in Bloomington to address the thing that stopped you from doing the community activity (shown in the drawing)?

j. Option 3: Acting out a scene
   i. Next, I would like for you all to choose a partner (there can be one group of three if there are five self-advocates) and think of a situation or time when something stopped you from doing a community activity in Bloomington, Indiana, and act the scene out together.
   ii. [Pass out self-advocate acting worksheets, see Focus Group Appendix F] I am passing out worksheets for your group to write down information about the characters, settings, and story for the scene.
   iii. Let’s take about fifteen minutes to get with a partner to plan out and practice the scene you are going to act out for the rest of the group. Then we will come back together as one big group and each team will take turns acting out their scene.
   iv. Does anyone have any questions before we get started?
   v. This activity will just help you tell a story about a time something stopped you from doing a community activity in Bloomington, Indiana. I will use this traffic light to let everyone know when time is almost up and when it is time to stop practicing your scene. Green means there is still plenty of time left; yellow means you have five minutes left to practice your scenes, and red means there is no more time left. We will start our discussion again when the light is red.
      1. [Use traffic light tool to facilitate transition].
      2. [Wait ten minutes; give five minute warning; take off green sign].
      3. [Wait five more minutes; then take off yellow sign].
      4. [Display red sign to show there is no more time left].
   vi. Alright, the traffic light is red, which means there is no more time left. We are going to stop practicing the scene with our partner(s) and begin our discussion again. Let’s each go around the room and act out your scene with the rest of the group.
   vii. Feel free to share if you have had similar experiences or are able to relate to another group’s story after they are finished acting out their scene.
   viii. Who would like to go first?
   ix. [For each group]
      1. Act out your story
      2. [After scene] In this story, what were the things that stopped you from doing community activities in Bloomington, Indiana?
         a. Why is this? (probe)
      3. [To group] How is this story different or similar to everyone else’s experiences?
      4. [To group] What would you change in Bloomington to address the thing that stopped you from doing the community activity (in the scene)?

9. Final Question and Close
   a. This is the last question for our discussion today, so feel free to share or talk about anything else you did not have the chance to discuss earlier.
   b. The last question is, if you could change one thing in Bloomington, Indiana, to make it easier to do the community activities you enjoy or would enjoy doing, what would that one thing be?
      a. Is there anything that anyone else would like to add to our discussion today? Feel free to share anything you think is important and you would like us to know.
      b. Thank you so much for volunteering and meeting today. ICADV staff and Stone Belt staff are here to help everyone process the discussion and experiences you had today, and will offer
c. Do you have any other questions before we wrap up our meeting?
d. Your opinions are really important for the project. **We will use the information from this group’s discussion and interviews with caregivers to make changes in Bloomington to make it easier for you to do community activities. Does anyone here want to be a part of the process of deciding on and making these changes in Bloomington? Here is a sign-up sheet if you are interested. ICADV staff will contact you about volunteering to be a part of this process in the future if you are interested.** You may write your name or ask me to write down your name down on the sign-up sheet if you are interested [See Focus Group Appendix G].
e. **Thanks again for volunteering, we are very glad we had the opportunity to meet with you and learn about your experiences. I will be here for a little while after the focus group if you have any other questions or comments.**

---

**Focus Group Appendix A**

**Informed Consent**

**Purpose:** You have been invited to participate as a member of ICADV/Stone Belt collaboration. The purpose of this project is to guide the development of a shared definition of social inclusion to enhance and promote respectful, safe, healthy relationships in Monroe County for self-advocates. We will discover together where self-advocates feel excluded and together with other community partners develop solutions to those identified problems. ICADV Rape Prevention and Education Consultant, Maggie Matson, would like to record any discussions about exclusion/inclusion to accurately collect information, thoughts and feelings. Maggie will transcribe the tapes herself and then she will delete the recordings. Additionally, to assure confidentiality of participants, no names will be included in the transcripts.

We recognize that this subject sometimes requires us to think about the abusive behaviors that self-advocates are experiencing, like social exclusion. We know that this can be tough. Ultimately, we won’t ask you to stick with the project if your participation is causing you any discomfort. You have the right to withdraw at any time; please just let us know, or else we will worry. We believe that this will be an exciting, productive and empowering experience; thanks for being part of it.

**Responsibilities:** Responsibilities include honestly sharing your ideas and feelings and communicating with other members.

**Benefits:** We believe that participation on this project will strengthen your leadership and advocacy skills and help build a more inclusive Bloomington. We know that your expert opinions will contribute to the success of ICADV’s work to prevent violence.

**Risks:** We believe that the risks of participation are minimal. Our focus will be on strategy for fostering healthy, safe, fair, respectful relationships, but we recognize that this will also mean sometimes thinking about abusive behaviors. We recognize that survivors of violence may feel discomfort when talking about violence prevention. ICADV and Stone Belt staff will be available to help process our conversations and experiences, and we will offer additional resource numbers where you can seek info and advocacy services should you need them.

I have read the informed consent document and I understand my rights and responsibilities as a member of this collaborative process. I consent to being recorded, however, during any session, I may request that the recorder be turned off if I am not comfortable with that topic or subject and want to share.
Focus Group Appendix B
Rules for Focus Group (Displayed on Poster Board)
1. Everyone’s opinion is important
2. No right or wrong answers
3. Take turns talking
4. You have the right to pass on any question
5. You have the right to leave at any time
6. Don’t share stories or identity of group members w/ anyone outside of the room.
7. Have fun

Focus Group Appendix C
http://www.vancouversun.com/health/Attitude+slowly+changing+toward+hiring+people+with+developmental+disabilities/9455948/story.html
(From http://www.paimn.org/programs-services/young-adults/community-exploration/)

(from http://turncommunityservices.org/)
Focus Group Appendix D
Flip Chart for Recording Responses (Introduction to Social Inclusion Activity)

<table>
<thead>
<tr>
<th>Photograph</th>
<th>Describe the photo.</th>
<th>How does the photograph relate to your own experiences?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coffee w/ friends (#1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping (#2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swimming (#3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other activities? (#4)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Focus Group Appendix E.

Appendices 29
Focus Group Appendix F.

Self-Advocate Acting Worksheet
Directions: Fill out information about the setting and story as a group here.

Setting (where and when the story takes place):
What is the main conflict of the play?
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________
______________________________________________________________________________

What happens at the beginning of the scene?
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

What is the first line of the scene?
________________________________________________________________________________________
________________________________________________________________________________________

What happens in the middle of the scene?
________________________________________________________________________________________
________________________________________________________________________________________

What happens at the end of the scene (how is the conflict resolved)?
________________________________________________________________________________________
________________________________________________________________________________________

Directions: Fill out information about the character each group member is playing.

**Group Member #1**
What character are you playing? Describe the character.
______________________________________________________________________________

What does your character want in the play?
________________________________________________________________________________________

What does your character do to try to get what they want?
________________________________________________________________________________________
________________________________________________________________________________________
__________________________________________________________

Does your character get what they want?
______________________________________________________________________________

**Group Member #2**
What character are you playing? Describe the character.
______________________________________________________________________________

What does your character want in the play?
________________________________________________________________________________________

What does your character do to try to get what they want?
________________________________________________________________________________________
________________________________________________________________________________________
__________________________________________________________

Does your character get what they want?
______________________________________________________________________________

**Group Member #3 (Optional)**
What character are you playing? Describe the character.
______________________________________________________________________________
What does your character want in the play?
________________________________________________________________________________________
________________________________________________________________________________________
What does your character do to try to get what they want?
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
Does your character get what they want?
________________________________________________________________________________________

Focus Group Appendix G.

Sign-Up Sheet

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

Key Informant Interviews

Key Informant Interview Protocol for Rape Prevention and Education (RPE) Project
Maggie Matson

Appendices 33
Indiana Coalition Against Domestic Violence

Protocol for Key Informant Interviews

Recruitment:
See Appendices A and B for a sample recruitment email and project information sheet.

Location:
Interviews will be held in a quiet room, free of distraction, at a location that is most convenient for the key informant.

Things to Bring:
- Project information sheet (see Appendix B)
- Consent forms (see Appendix C)
- Pens
- Audio recorder
- Refreshments (lemonade and/or water)
- Snacks
- Photos (see Appendix D)
- Blank sheets of paper
- Phone [if telephone interview and audio recorder hook up device]
- Resource card w/ contact information (Cierra’s or Katie’s)
- List of questions

List of Questions for Staff

Rapport building
- How is your day going?
- How long have you lived in Bloomington, Indiana, and worked at Stone Belt (or other service provider organization)?
- Tell me a little bit about your job and work with self-advocates at Stone Belt (or other service provider organization)?

Activity to introduce idea of social inclusion
- How would you describe this picture? (ask for each picture shown)
- How does this picture relate to the experiences of self-advocates? (ask for each picture shown)

Discussion questions
- What are some of the activities self-advocates that you work with enjoy doing or would enjoy doing near where they live?
  - Why is this? (probe)
- What helps self-advocates that you work with get involved in these activities?
- How can the staff and the service manager help self-advocates do more activities they enjoy?

Activities to identify factors that limit or promote social inclusion
- What are things that stop self-advocates from doing community activities in Bloomington, Indiana?
  - Why is this? (probe)
- What changes need to be made in the community in order to address each thing that stops self-advocates from doing community activities in Bloomington, Indiana? (Ask for each thing mentioned through activity).
  - Why is this? (probe)
- If you could change one thing in Bloomington, Indiana, to make it easier for self-advocates to do the community activities they enjoy or would enjoy doing, what would that one thing be?

Probing (Optional)
- If staff mentions anything related to something in the community that helps self-advocates get involved in these activities, I will follow up with this: “You mentioned X, tell me more about that.”
- Probe: If staff don’t mention anything other than themselves (or parents) as barriers to social inclusion, then I will ask “other than Stone Belt staff (or parents), what stops self-advocates from getting involved in these activities?”
How do self-advocates find out about community activities?
How or where do self-advocates get money to pay for these activities?
How do self-advocates travel to the place where these activities are located?
How does the space or people where the activity takes place help self-advocates get involved?

List of Questions for Parents

Rapport building
- How is your day going?
- How long have you and your family lived in Bloomington, Indiana?
- Tell me a little bit about your kids.

Activity to introduce idea of social inclusion
- How would you describe this picture? (ask for each picture shown)
- How does this picture relate to the experiences of self-advocates? (ask for each picture shown)

Discussion questions
- What are some of the activities your son or daughter (self-advocate) enjoys doing or would enjoy doing near where they live?
  - Why is this? (probe)
- What helps your son or daughter (self-advocate) get involved in these activities?
- How can the staff and the service manager help your son or daughter (self-advocates) do more activities they enjoy?

Activities to identify factors that limit or promote social inclusion
- What are things that stop your son or daughter (self-advocates) from doing community activities in Bloomington, Indiana?
  - Why is this? (probe)
- What changes need to be made in the community in order to address each thing that stops your son or daughter (self-advocates) from doing community activities in Bloomington, Indiana? (Ask for each thing mentioned through activity).
  - Why is this? (probe)
- If you could change one thing in Bloomington, Indiana, to make it easier for your son or daughter (self-advocates) to do the community activities they enjoy or would enjoy doing, what would that one thing be?

Probing (Optional)
- If parent mentions anything related to something in the community that helps self-advocates get involved in these activities, I will follow up with this: “You mentioned X, tell me more about that.”
- Probe: If parents don’t mention anything other than staff as barriers to social inclusion, then I will ask “other than Stone Belt staff (or parents), what stops self-advocates from getting involved in these activities?”
  - How do self-advocates find out about community activities?
  - How or where do self-advocates get money to pay for these activities?
  - How do self-advocates travel to the place where these activities are located?
  - How does the space or people where the activity takes place help self-advocates get involved?

Script for Key Informant Interviews

10. Introductions and consent:
   a. Hi, I’m Maggie, it’s nice to meet you [or see you again]. Thank you so much for meeting [or talking] with me today about your experiences as a caregiver. The purpose of the interview is to identify barriers that limit social inclusion for individuals with intellectual and developmental disabilities or self-advocates in Bloomington, Indiana.
   b. [Hand two copies of the consent form [or send via email and obtain informed consent for telephone interviews ahead of time] (see Appendix C for Consent Form)].
c. [If in-person meeting] This is a consent form, which explains the purpose of the project and the potential benefits and risks of volunteering as a key informant. Please feel free to ask questions about the information on the consent form as you read along. You may leave for any reason and at any time before or during the interview if you decide that you are no longer interested in volunteering as a key informant. I will not attach your name or any identifiable information to your responses to ensure confidentiality. I have provided you with an additional copy of the consent form if you would like to keep an unsigned copy for yourself.

d. [Give time to read over and sign consent form].
e. [Collect signed consent form].
f. Do you have any questions before we begin?

11. Rapport building questions:
   a. [I will start by asking some questions depending on whether or not the key informant is a parent of staff and chat with the key informant to build rapport before I asking other questions].
      i. [For staff ask]
         1. How is your day going?
         2. How long have you lived in Bloomington, Indiana, and worked at Stone Belt (or other service provider organization)?
         3. Tell me a little bit about your job and work with self-advocates at Stone Belt (or other service provider organization)?
      ii. [For parents ask]
         1. How is your day going?
         2. How long have you and your family lived in Bloomington, Indiana?
         3. Tell me a little bit about your kids.

12. Activity to introduce idea of social inclusion (Abbott and McConkey, 2006):
   a. I am going to show you some pictures of people doing different community activities. For each picture I will ask you to describe the photograph and relate it to the experiences of self-advocates [See Appendix D].
      i. Here is a picture [Show picture].
      ii. Please describe the picture.
      iii. How does this photograph relate to the experiences of self-advocates? [Repeat steps i. – iii. for each photo].

13. Ask interview questions (adapted from Abbott and McConkey, 2006)
   a. What are some of the activities self-advocates enjoy doing or would enjoy doing nearby where they live?
      i. Why is this?
   b. What helps self-advocates get involved in these activities?
   c. How can the staff and the service manager help self-advocates do more activities they enjoy?

14. List generating activity
   f. Next, I would like for you to think of barriers that limit social inclusion for self-advocates in Bloomington, Indiana, or things that stop them from doing community activities. Just say the barriers out loud and discuss why each barrier limits social inclusion for self-advocates or stops them from doing community activities. I will add each barrier mentioned to this list [Show sheet of paper to key informant]. We can always add or make changes to the list if you think of something else later. [Stop adding to the list when key informant feels there is nothing more to add; probe specifically for information about barriers in the community].
   g. One of the last things I will ask is for you to come up with some changes or ways to overcome barriers that limit social inclusion for self-advocates in Bloomington, Indiana, or things that stop them from doing community activities and list as many ideas as you can think of. Just say them out loud and discuss how that change will address a barrier that limits social support for self-advocates or stops them from doing community activities. I will add each idea mentioned to the list [Show sheet of paper to key informant]. [Stop adding to the list when key informant feels there is nothing more to add; probe specifically for information about changes to address barriers in the community].

Final Question and Close
a. This is the last question for our interview today, but feel free to share or talk about anything else you did not have the chance to discuss earlier.

b. If you could change one thing in Bloomington, Indiana, to make it easier for self-advocates to do the community activities they enjoy or would enjoy doing, what would that one thing be?

h. Is there anything else you would like to add to the discussion today? Feel free to share anything you think is important and would like us to know.

i. Thank you so much for your time and meeting with me today. If you have any other questions, concerns, or comments about the project, you may contact myself, Kate, or Cierra. Our contact information is listed on the project information sheet. Here is a copy in case you do not already have one. [Hand copy of project information sheet]. ICADV and Stone Belt staff will offer additional resource numbers where you can seek info and advocacy services should you need them [Hand Katie’s or Cierra’s business card w/ contact information].

j. Do you have any other questions before we wrap up our meeting?

k. Your insight is really important for the project. We will use the information from interviews with caregivers and focus groups with self-advocates to make changes in Bloomington to address barriers to social inclusion in the community. Would you like to be a part of the decision-making and implementation process for these changes? ICADV staff will contact you about volunteering to be a part of this process in the future if you are interested and choose to give us your contact information. You may ask me to tell Kate or Cierra if you are interested or you may contact them yourself if you would like to be a part of the process.

l. Thanks again for your time. I appreciated having the opportunity to meet with you!

Interview Appendix A
Sample recruitment email
Dear _____________,

Hello, my name is Maggie Matson and I am a consultant for the Indiana Coalition Against Domestic Violence. ICADV is currently working on a project to increase social support and inclusion for individuals with developmental and intellectual disabilities (self-advocates) in Bloomington, Indiana.

I am conducting interviews with caregivers (parents, direct support professionals, and other direct care staff) for the project. The purpose of the interview is to identify barriers that limit social support and inclusion for self-advocates in Bloomington, Indiana. We will use this information to implement strategies that will increase social inclusion and support for self advocates in this community.

I would like to interview you because of your knowledge and experiences as a caregiver. We are also talking with self advocates, but you bring a unique perspective and we want to know more about what you observe about the individuals you care for and their experiences in the community.

ICADV’s prevention focuses on structural-level changes within communities to help reduce the incidence of domestic and sexual violence. By addressing the root causes of these issues, we hope to not only prevent it from happening, but also make communities safer and happier places to live and grow. We hope you will join us in this endeavor – your experiences and thoughts matter, as you are a part of the solution!

My contact information is listed below. I have also attached a project information sheet and consent form to this email. Please let me know about the possibility of setting up a time to meet with you. I look forward to hearing from you!

Thank you,

Maggie Matson
Rape Prevention & Education (RPE) Consultant
mamatson@iupui.edu
Aim: To identify barriers that limit social inclusion for adults with developmental and intellectual disabilities (self-advocates) in Bloomington, Indiana.

Problem:
Inadequate social support, which increases the risk of sexual violence, was ranked as a worse problem in Monroe County compared to 19 other peer counties (Centers for Disease Control and Prevention, see http://wwwn.cdc.gov/CommunityHealth/profile/currentprofile/IN/Monroe).

Rationale:
This project will provide ICADV and collaborating organizations with:
- Additional information about barriers that limit social inclusion for self-advocates in Bloomington, Indiana.
- This information will help ICADV and collaborating organizations make structural-level changes in the community to enhance social inclusion for self-advocates and reduce the risk of sexual violence.

Questions:
The project will provide answers to the following questions:
1. What are barriers that limit social inclusion for self-advocates in Bloomington, Indiana?
2. What structural changes in the community will enhance social inclusion for self-advocates in Bloomington, Indiana?

Methods:
This project will use a mapping activity, key informant interviews, and focus groups. Focus groups will consist of self-advocates who currently live in Bloomington, Indiana. Key informant interviews will be conducted with caregivers in Bloomington, Indiana. Caregivers include parents, direct support professionals, and other direct service staff. The entire key informant interview process will last about 60 minutes. The interview will be audio recorded, and to assure confidentiality of participants, information will be de-identified and no names will be included in the transcripts.

Contact: If you have any comments, concerns, or questions about the project, please contact the individuals listed above.

Interview Appendix C
Informed Consent

Informed Consent

Purpose: You have been invited to participate as a member of ICADV/Stone Belt collaboration. The purpose of this project is to guide the development of a shared definition of social inclusion to enhance and promote respectful, safe, healthy relationships in Monroe County for self-advocates. We will discover together where self-advocates feel excluded and together with other community partners develop solutions to those identified problems. ICADV Rape Prevention and Education Consultant, Maggie Matson, would like to record any discussions about exclusion/inclusion to accurately collect information, thoughts and feelings. Maggie will transcribe the tapes herself and then she will delete the recordings. Additionally, to assure confidentiality of participants, no names will be included in the transcripts.

We recognize that this subject sometimes requires us to think about the abusive behaviors that self-advocates are experiencing, like social exclusion. We know that this can be tough. Ultimately, we won’t ask you to stick with the project if your participation is causing you any discomfort. You have the right to withdraw at any time; please just let us know, or else we will worry. We believe that this will be an exciting, productive and empowering experience; thanks for being part of it.

Responsibilities: Responsibilities include honestly sharing your ideas and feelings and communicating with other members.

Benefits: We believe that participation on this project will strengthen your leadership and advocacy skills and help build a more inclusive Bloomington. We know that your expert opinions will contribute to the success of ICADV’s work to prevent violence.

Risks: We believe that the risks of participation are minimal. Our focus will be on strategy for fostering healthy, safe, fair, respectful relationships, but we recognize that this will also mean sometimes thinking about abusive behaviors. We recognize that survivors of violence may feel discomfort when talking about violence prevention. ICADV and Stone Belt staff will be available to help process our conversations and experiences, and we will offer additional resource numbers where you can seek info and advocacy services should you need them.

I have read the informed consent document and I understand my rights and responsibilities as a member of this collaborative process. I consent to being recorded, however, during any session, I may request that the recorder be turned off if I am not comfortable with that topic or subject and want to share.

Name     Signature     Date
Interview Appendix D

http://www.vancouversun.com/health/Attitude+slowly+changing+toward+hiring+people+with+developmental+disabilities/9455948/story.html

(From http://www.paimn.org/programs-services/young-adults/community-exploration/)
Monroe County Public Library Cultural Competency Assessment

<table>
<thead>
<tr>
<th>Evaluation Question</th>
<th>Average/Percent Change</th>
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<tbody>
<tr>
<td>Rate your knowledge about managing a challenging behavioral situation. (1 being very low, 3 being moderate, 5 being Very High)</td>
<td>Before Program</td>
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<tr>
<td></td>
<td>2.4</td>
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<tr>
<td>Topic</td>
<td>Before Program</td>
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<tr>
<td>Rate your knowledge about managing a challenging behavioral situation. (1 being very low, 3 being moderate, 5 being Very High)</td>
<td>2.6</td>
</tr>
<tr>
<td>Rate your knowledge about the <strong>function of behaviors and mannerisms</strong> of patrons with disabilities. (1 being very low, 3 being moderate, 5 being Very High)</td>
<td></td>
</tr>
<tr>
<td>Rate your knowledge about the <strong>function of behaviors and mannerisms</strong> of patrons with disabilities. (1 being very low, 3 being moderate, 5 being Very High)</td>
<td></td>
</tr>
<tr>
<td>Rate your knowledge about <strong>person-first language</strong>. (1 being very low, 3 being moderate, 5 being Very High)</td>
<td>2.6</td>
</tr>
<tr>
<td>Rate your knowledge about <strong>person-first language</strong>. (1 being very low, 3 being moderate, 5 being Very High)</td>
<td></td>
</tr>
<tr>
<td>Rate the degree to which you agree: <strong>I have the skills I need</strong> to appropriately engage with patrons who have disabilities. (1 being strongly disagree, 5 being Strongly Agree)</td>
<td>3</td>
</tr>
<tr>
<td>Rate the degree to which you agree: <strong>I feel capable to assist</strong> patrons who have disabilities. (1 being strongly disagree, 5 being Strongly Agree)</td>
<td></td>
</tr>
<tr>
<td>Rate the degree to which you agree: I am <strong>comfortable engaging parents</strong> and caregivers of patrons who have disabilities. (1 being strongly disagree, 5 being Strongly Agree)</td>
<td>3.133333333</td>
</tr>
<tr>
<td>Rate the degree to which you agree: I am <strong>comfortable engaging parents</strong> and caregivers of patrons who have disabilities. (1 being strongly disagree, 5 being Strongly Agree)</td>
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<tr>
<td>Rate the degree to which you agree: <strong>I have the support I need</strong> from MCPL (staff and leadership) to engage with patrons who have disabilities. (1 being strongly disagree, 5 being Strongly Agree)</td>
<td>3.466666667</td>
</tr>
<tr>
<td>Rate the degree to which you agree: I have the support I need from MCPL (staff and leadership) to engage with patrons who have disabilities. (1 being strongly disagree, 5 being Strongly Agree)</td>
<td></td>
</tr>
</tbody>
</table>
As a result of this program, I will use techniques provided by the trainer to manage a challenging behavioral situation at work if necessary. (2 indicates maybe, 3 indicates Yes)

<table>
<thead>
<tr>
<th></th>
<th>Before the Training</th>
<th>After Training</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing a challenging behavioral situation.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>Person-first language.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>The function of behaviors or mannerisms of patrons with disabilities.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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</table>

MCPL Score Codes

<table>
<thead>
<tr>
<th></th>
<th>Very Low</th>
<th>Low 2</th>
<th>Moderate 3</th>
<th>High 4</th>
<th>Very High 5</th>
<th>Very Low</th>
<th>Low 2</th>
<th>Moderate 3</th>
<th>High 4</th>
<th>Very High 5</th>
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</thead>
<tbody>
<tr>
<td>I feel capable to assist patrons who have disabilities.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<td>I am comfortable engaging parents and caregivers of patrons who have disabilities.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>I have the support I need from MCPL (staff and leadership) to engage with patrons who have disabilities.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<tr>
<td>I have the skills I need to appropriately engage with patrons who have disabilities.</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
<td>1 2 3 4 5</td>
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<td>As a result of this program, do you intend to:</td>
<td>No</td>
<td>Maybe</td>
<td>Yes</td>
<td>Already doing this</td>
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<tr>
<td>Use person first language at work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Use techniques provided by the trainer to manage a challenging behavioral situation at work if necessary?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
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<td></td>
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<tr>
<td>Use person first language outside of work?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>Use techniques provided by the trainer to manage a challenging behavioral situation outside of work if necessary?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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