# Sidewalks to Sexual Violence Prevention: A Guide to Exploring Social Inclusion with People with Developmental Disabilities

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Photography, creative writing and other art forms give voice to perspectives that are misunderstood, discounted or simply not verbal. Art and reflective writing 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 and are included throughout with permission though no names will be shared to protect the anonymity of participants. Art in the following images created by Stone Belt stakeholders (who are people with developmental and intellectual disabilities) in collaboration with Van Go Mobile Art Studio, June 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. - *This was written in collaboration with Women Writing for a Change by a woman with multiple disabilities.*

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Susan Russ
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**Rural Transit**
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## Acronyms

ASL: American Sign Language

ARC: Name of national association for disability advocacy (it has disassociated from its original referent Association for Retarded Citizens and is now referred to by the acronym)

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

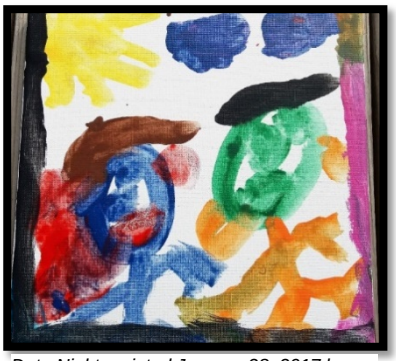
SEM: Social-Ecological Model

SB: Stone Belt

YRBS: Youth Risk Behavior Surveillance

## Introduction

Sexual violence (SV) is a preventable social problem that requires innovative collaboration between community members, including people made vulnerable by health inequities, key decision makers and stakeholders across sectors and generations. The Bloomington Inclusion Collaborative project goal was to build community protections through increasing inclusion at the individual, organizational and community levels of the social ecological model[1]. The intention of this guide is to aid project planners, preventionists, advocates and community organizers in the exploration of the idea of increasing the protective factor of social support (experienced as inclusion) for and with people with developmental disabilities as a means to reduce and end sexual violence. Ending sexual violence requires culture change, a purpose that necessitates work across the human lifespan and one that will unfold over many generations. Preventionists and other professionals can share in the extensive and long term work to end violence by focusing energy on prevention efforts that address shared risk and protective factors for perpetration and victimization in communities, while managing with intention the ways in which power is used and reproduced within the project. Sexual violence is a form of taking power over another—one (or more) individuals against another. The systems inequity that creates social isolation throughout the contexts of the lives of people with disabilities and care givers structures and heavily limits individual experience and opportunity: power over exerted at a much greater scale. Therefore,



*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.*

> *"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 in Bloomington, Indiana, January 2017.

restructuring the ways in which power is used is required to reduce and eventually eliminate sexual violence.

This project brings previously unheard voices to the forefront of a SV prevention effort and can contribute to the small and growing body of practice and community-based evidence about protective factors against perpetration and victimization of SV. By including people with disabilities in the planning, development, implementation and assessment of prevention initiatives, people with disabilities can become empowered to participate in decisions that impact their lives. Sharing power in this manner is relevant to SV prevention across organizations and communities and is responsive to the systemic exclusion of people with developmental disabilities. Although public discourse about SV prevention has increased in the last few years, people with developmental and intellectual disabilities remain an underserved population contributing to the further invisibility of some of the highest risk populations in the nation. There is little research and writing about prevention efforts on behalf of or with underserved populations further silencing the unique needs of people who experience health inequity across the lifespan. By sharing the evaluation tools developed over the course of the Bloomington Inclusion Collaborative project along with the lessons learned, the project participants encourage other primary prevention professionals 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.

## Why Inclusion?

Community support and connectedness are protective factors against child maltreatment, youth violence, intimate partner violence, sexual violence, elder abuse and suicide[2]. 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 added 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.

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 increases risk for perpetration and victimization of multiple forms of violence across the lifespan.[3]

There is a dearth of literature published about protective factors (see Table 1) and there is strong evidence that social inclusion through community support and connectedness has the potential to increase protections in the form of safe, stable, nurturing environments and relationships around everyone. The data that are available about people with disabilities suggests a current landscape that is anything but safe, stable and nurturing. The rate of all violent crimes against people with cognitive disabilities is 63%.[4] Sexual violence prevalence rates for people who have intellectual or developmental disabilities is estimated to be as high as 65-98% of the population experiences victimization over the course of a lifetime.[5] There is no agreement on the prevalence rates, because statistics about people who have disabilities are largely not collected nor 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[6]. All of these barriers suggests inclusion cannot be achieved without data on and the perspectives of those who are "left out," because a society that is inclusive of the "least of us" will be one that fosters the lives of everyone. What exactly does a culture look like that is inclusive of the most vulnerable people, including people with disabilities?

*Table 1 2017 list of known risk and protective factors for sexual violence.*[7]

| **Protective Factors for Sexual Violence Perpetration** | **Known Risk and Factors for Perpetration** | |
|---|---|---|
| ***Individual level*** | ***Community level*** | ***Societal level*** |
| Emotional health and connectedness | Poverty | Societal norms that support sexual violence |
| Academic achievement | Lack of employment opportunities; Lack of institutional support from police and judicial system | Societal norms that maintain women's inferiority and sexual submissiveness; Societal norms that support male superiority and sexual entitlement |
| Empathy and concern for how one's actions affect other | Weak community sanctions against sexual violence perpetrators | Weak laws and policies related to sexual violence and gender equity |
| Parental use of reasoning to resolve family conflict | General tolerance of sexual violence within the community | High levels of crime and other forms of violence |

## Theory of Change for Social Inclusion

A theory of change serves the purpose of identifying long terms goals and requires mapping the necessary preconditions that must occur before that goal is met. Project planning from the outcome backward helps to identify appropriate programmatic approaches that are specific to the desired outcome. Rather than beginning a project with an evidence-based approach in which impact is tied to fidelity (meaning the program must be implemented in a specific way often by a specific person), a project based upon a theory of change using formative evaluation will allow participants to identify the appropriate vehicles for change as the project unfolds. A theory of change is a project road map that allows for innovation of strategy. Community partners identify indicators for success along the way and evaluation occurs throughout the process, making the project iterative and responsive to the unique needs of its participants.

*This heart 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 loud world.*

The theory of change developed by the Indiana Coalition Against Domestic Violence Prevention Specialist (PS), Cierra Olivia Thomas-Williams, and Empowerment Evaluator Marie Kelleman began with the idea that (Figure 1) that achieving social support/inclusion for people with developmental disabilities means they feel valued and part of the community. People with developmental disabilities who are included will share the experience of an increase in the range and depth of relationships. Having relationships with more people will allow people with developmental disabilities to increase knowledge of positive/negative interactions between people. Because people with disabilities are included and valued, there will be more people in their lives to talk with about the quality of relationships in their lives and more people who can identify abusive behavior if it happens. People who feel valued are empowered to value themselves, increasing the expectation of equitable treatment by others and reducing victimization. Empowered individuals do not need to exert power over others to feel valued, decreasing perpetration.

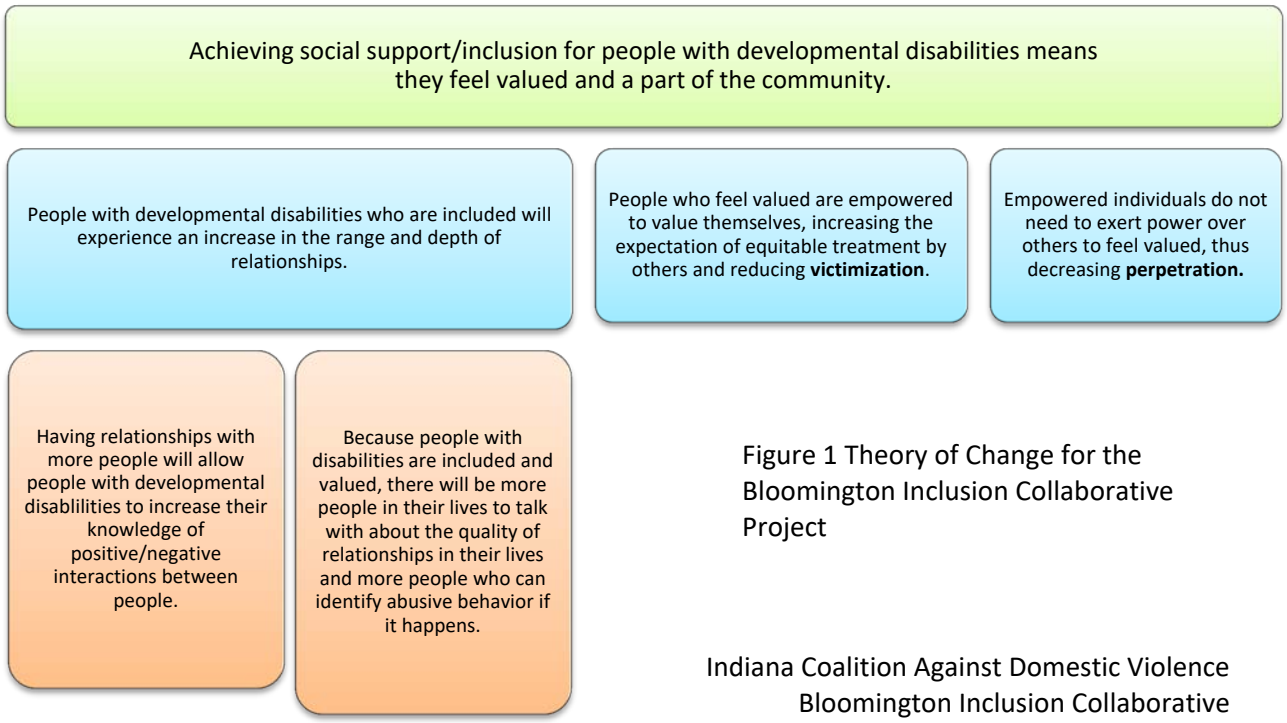



Figure 1 Theory of Change for the Bloomington Inclusion Collaborative Project

*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 with disabilities in collaboration with community partners from Women Writing for a Change, 2017.

The theory of change requires people with disabilities be exposed to a range and depth of human experience and requires attention to the way in which power is used to reduce and eliminate risk for victimization and perpetration. The remainder of this document describes the process project participants engaged in with the goal of increasing the protections of social support and inclusion for people with developmental and intellectual disabilities and provides references, tools, and protocols the participants used to gather local data to drive community-based sexual violence prevention initiatives.

## Step 1: 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.[8] Using the public health approach (see glossary) to sexual violence prevention allows stakeholders to maintain a connection to their

> ***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***.- Written by a young woman with disabilities wrote during a writing session with Women Writing for Change.

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 work builds connections across sectors around shared risk factors benefiting all populations, not just the vulnerable. Increasing connectedness using inclusion strategies, therefore, have the potential to build protections against a lifetime protecting against trauma and violence.

## Step 2: Using Data to Guide Action

The Centers for Disease Control and Prevention have identified shared risk and protective factors for sexual violence (see figure below), 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 indicates there is "inadequate social support" (defined as "social-emotional" support) in Monroe County, which ranks 16th-worse of 20 in a scaled comparison of peer counties ranging from "better" to "moderate" to "worse."[9] 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 barriers are in Bloomington, Indiana, teams of working professionals and people with a variety of disabilities engaged in eight months of primary data collection using a several evaluation methods.

The Bloomington Inclusion Collaborative project used evaluation methods—like participatory social mapping and photo voice—and designed sexual violence prevention initiatives from 2015-2017 based upon known risk and protective factors (Table 1) in collaboration with adult individuals with developmental, intellectual and often also physical

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## 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.

Photovoice image captured in November 2015 by community partner Amy Leyenbeck, Rural Transit Manager, during participatory social mapping of Indiana University Museum, a public space in Bloomington, Indiana with Stone Belt Stakeholders, staff and Heather Dane from Family Voices Indiana.

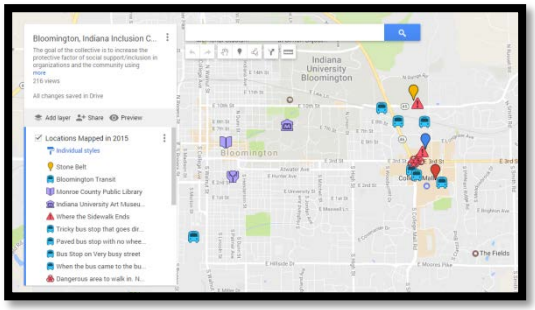
***"My neighborhood has roads like that. It's dangerous for me. [inaudible] I can't, like, I will trip over those."*** **- a 22 year old woman who experiences what she has named "brain drain" (seizures).**

***"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.**

Photovoice image captured in November 2015 by a young man with disabilities, during participatory social mapping of Barnes and Nobles, a public space in Bloomington, Indiana with Stone Belt Stakeholders and Middle Way House.

disabilities.

The Bloomington Inclusion Collaborative spent approximately one year developing relationships and collecting local data about barriers to social support and inclusion. The data collection methods used to determine local barriers to inclusion include focus groups with people with developmental disabilities, key informant interviews with care givers, and participatory mapping of public spaces, businesses, and neighborhoods in Bloomington to develop a prioritized list of solutions to barriers (all tools are provided for use in Inclusion Appendices). In project year two, stakeholders selected barriers to collaboratively address during systems advocacy in year two (see 2015.AllBarriers.Data.pdf for the full list of environmental data collected).




**This free Google map is useful tool for advocacy. A project stakeholder with disabilities used Photovoice images and captions to populate the map and symbols to indicate what barrier was encountered there.**

Over the years 2016-2017 stakeholders worked together to achieve changes in problematic environments identified through participatory social mapping (a formative assessment method and tool included in Inclusion Appendix). The following lists the prioritized barriers for solutions advocacy that project participants prioritized and pursued from 2016-2017. These goals shaped the work of project year two in pursuit of increasing social inclusion with people with developmental disabilities.

**Transportation and Mobility:**

- Bus Stops (long/intermediate);
- Library access & safety (short term);
- Sidewalk connectivity (long/intermediate).

**Self-Efficacy:**

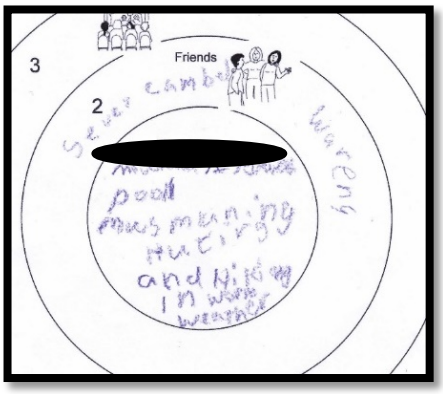
- Checking in with others and calling out inappropriate behavior of staff and peers (short/long term);
- Increase cultural competency among professionals (long term).

## Step 3: Advocating for Outcomes

The gains from the advocacy and mapping efforts of the Bloomington Inclusion 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 Inclusion Appendix for evaluation report and assessment tools used). 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. Stone Belt stakeholder's social network maps grew after two years collaborating with the PS on the

### Circle of Support (Social Network Map) Example

An elder man drew a heart surrounded by empty circles of support in 2015. When the Prevention Specialist asked the man why he did not fill in his circles, he stated "I don't have any friends." The heart is green, because he says nature is never far from his thoughts.




In 2017, the names of two people appear among many other things that matter very much to the 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 reflection time he writes down the recipes for the foods he made with this mother growing up; so far there are 33 different meals in his journal.

project. Another 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 transportation-access and wage-increase advocacy locally.

**Table 2 Inclusion Outcomes at each level of the SEM**

| Individual | Relationship | Organizational | Community |
|---|---|---|---|
| •People with disabilities voice their concerns and see results moving toward self-advocacy and independence. | •People experience a sense of responsibility for health and safety of community members.<br><br>•Increase in use of mass transportation systems = increase in spontaneity by Stone Belt stakeholders.<br><br>•Increase in cultural competency about disability for collaborators who used cross-agency training opportunities. | •Increase # of Monroe County Public Library resources about people with disabilities.<br><br>•Accessible computers for blind patrons available at MCPL.<br><br>•Increase # people with disabilities participating in transportation-advocacy forums through Monroe County Council on Accessibility and Mobility.<br><br>•Increase # of outreach programs, including creative writing, which bring community members from Women Writing for a Change to Stone Belt Day Program. | •Increase # paved bus stop landing pads.<br><br>•Increase # of connected sidewalks and curb cuts.<br><br>• Increase # opportunities to interact with and hear from people who are not usually present at public forums and community meetings. |

## Lessons Learned

### Slowing Down

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, and 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.

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

*A lovingly rendered portrait of a young woman who is the fiancé of a young man with disabilities during art work with Ellen Bergan and Van Go Mobile Art Studio*

### Managing Expectations

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 issues and staffing retention were the two principal barriers to Stone Belt stakeholders engaging with the community. Staffing is consistently low, increasing stress on employees and clients, thus increasing risk for 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 ratios requirements. Staff cannot leave, because there are not enough people to jump in and help, therefore, clients cannot leave without other transportation options. These other transportation options are restricted by funders such as Medicaid to day program, 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.

### Relationship Building

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 PS working with people with disabilities[10]. 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 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.

## Next Steps

The PS'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. By the end of the project, the PS understood that social isolation from relationships, systems, and services does not only happen for the client or person with a disability, but it also occurs across the spectrum of human life for their families and caregivers. 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 PS 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 PS (PS) 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) and increase the quality of job satisfaction for staff. In order to support the sustainability of trauma-informed care and practices, the PS is working with stakeholders to increase organizational support for people with developmental disabilities to have safe, healthy sexuality. In 2017-2018, the PS, Stone Belt, Arc will implement trauma informed care training supported by organizational level sexual violence prevention policies, such as a healthy sexuality policy for group home and supported living environments.

## Afterward

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 risk of 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, as they 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, because it provides for the ease and safety of travel and opportunity to connect with other people. Increasing the number of people available to “check in” with and who can in turn “call out” unacceptable behaviors (or provide support) the better protected a person is

from silence—one of social norms that allows sexual violence to continue. Sexual violence is normative in America and no one program or initiative can end sexual violence in its entirety. It is the Bloomington Inclusion Collaborative's greatest hope that these tools and lessons learned can benefit others in their endeavors to address risk and protective factors in their journey to change culture.

## 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 following resources to gain insight on the American's with Disabilities Act, definitions and information about specific disabilities, 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

CALCASA (2010). Creating Access: Supporting Survivors of Sexual Assault with Disabilities. California Coalition Against Sexual Assault.
http://www.evawintl.org/library/DocumentLibraryHandler.ashx?id=493

This special information packet by CALCASA provides an 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

Disability Rights Ohio (2015). Sexual Abuse of Individuals with Developmental Disabilities: Analysis and Recommendations for Ohio.
http://www.disabilityrightsohio.org/assets/documents/dro_sexual_abuse_combined_report.pdf

The Ohio document examines 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
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 PS 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.

- Podcast, "National Sexual Assault Workshop Preview," Podcast with Ashleigh Klein, PreventConnect, Prevention Institute guest, July 22, 2016.
- "What About Power and Patriarchy? Examining Social Cohesion Strategies to Prevent Sexual and Domestic Violence," PreventConnect guest, July 13, 2016.
- "Mapping for Social Inclusion," National Sexual Assault Conference (NSAC), Washington D.C., August 29-September 2, 2016; and "Social Inclusion as Sexual Violence Prevention Strategy," National Sexual Violence Resource Center in Partnership with PreventConnect October 2016 Newsletter video-recording of NSAC 2016 http://www.preventconnect.org/2016/10/social-inclusion-as-sexual-violence-prevention-strategy
- Handouts from the project including participant interviews, tools and PowerPoints are available online at http://www.nsvrc.org/nsac2016/handouts

## Recommended primer reading on primary prevention[1]:

- American Public Health Association (March 2015). *Better Health through Equity: Case Studies in Reframing Public Health*. https://www.apha.org/~/media/files/pdf/topics/equity/equity_stories.ashx

- Berkowitz, Alan (2012). *A Grassroots' Guide to Fostering Healthy Norms to Reduce Violence in our Communities: Social Norms Toolkit*. Mt. Shasta, CA. http://www.alanberkowitz.com/Social_Norms_Violence_Prevention_Toolkit.pdf

- Centers for Disease Control and Prevention (2014). *Building Community Commitment for Safe, Stable, Nurturing Relationships and Environments*. http://www.cdc.gov/violenceprevention/pdf/efc-building-community-commitment.pdf.pdf

- Centers for Disease Control and Prevention (2014). *Essentials for Childhood: Steps to Create Safe, Stable, Nurturing Relationships and Environments for all Children*. http://www.cdc.gov/violenceprevention/pdf/essentials_for_childhood_framework.pdf

- Centers for Disease Control and Prevention (2014). *Promoting Positive Community Norms*. http://www.cdc.gov/violenceprevention/pdf/efc-promoting-positive-community-norms.pdf.pdf

- Centers for Disease Control and Prevention (2004). *Sexual Violence Prevention: Beginning the Dialogue*. Atlanta, GA: Centers for Disease Control and Prevention. http://www.cdc.gov/violenceprevention/pdf/svprevention-a.pdf

- Centers for Disease Control and Prevention (2016). *Essentials for Childhood Framework: Steps to Create Safe, Stable, Nurturing Relationships and Environments for All Children*. National Center for Injury Prevention and Control, Division of Violence Prevention. https://www.cdc.gov/violenceprevention/childmaltreatment/essentials.html

- Department of Health and Human Services (2015). *Prevention Resource Guide: Making Meaningful Connections*. Available online at https://www.childwelfare.gov/pubpdfs/guide.pdf

- Friedan, Thomas R. (2010). "A Framework for Public Health Action: The Health Impact Pyramid." *American Journal of Public Health*. 2010 April; 100(4): 590–595 *at* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2836340/

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- World Health Organization (2003). *Social Determinates of Health: The Solid Facts, 2nd Edition*. Ed: Richard Wilkinson and Michael Mermot http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf

## Glossary of Prevention Terms

**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 ). 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 (ACE quiz in English**),** http://www.acestudy.org/ and 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). http://www.popcenter.org/tools/pdfs/cpted.pdf and http://www.portlandoregon.gov/oni/article/320548

**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 World Health Organization, please read *Social Determinates of Health: The Solid Facts, 2nd Edition* by the World Health Organization, http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf

**Equity**: An equitable society is one in which all people can participate and prosper; just and fair inclusion is a means to create conditions that allow people to fulfill their "potential" or to create capacity for success.

**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).*

**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. For more details on the different forms of violence prevention, visit: http://www.cdc.gov/violenceprevention/index.html

**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 Environments and Relationships (SSNERs):** 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.

**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
5. Normalization of Violence.

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

*A Grassroots' Guide to Fostering Healthy Norms to Reduce Violence in our Communities: Social Norms Toolkit*:
http://www.alanberkowitz.com/Social_Norms_Violence_Prevention_Toolkit.pdf

*Connecting the Dots: An Overview of the Links Among Multiple Forms of Violence*
http://www.cdc.gov/violenceprevention/pdf/connecting_the_dots-a.pdf

*Promoting Positive Community Norms*, a supplemental guide to *Essentials for Childhoo*d:
http://www.cdc.gov/violenceprevention/pdf/efc-promoting-positive-community-norms.pdf.pdf

**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

**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, 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 at: vetoviolence.cdc.gov/apps/phl/images/ACE_Accessible.pdf.

## Sources Cited:

[1] 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.

[2] Wilkins, N., Tsao, B., Hertz, M., Davis, R., Klevens, J. (2014). Connecting the Dots: An Overview of the Links Among Multiple Forms of Violence. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention Oakland, CA: Prevention Institute. https://www.cdc.gov/violenceprevention/pdf/connecting_the_dots-a.pdf

[3] 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

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[5] Elman, A (2005). "Confronting the sexual abuse of women with disabilities." *National Online Resource Center on Violence Against Women*. Retrieved October 9, 2014 from: http://www.vawnet.org/Assoc_Files_VAWnet/AR_SVDisability.pdf ; and Valenti-Hein, D. & Schwartz, L. (1995). *The Sexual Abuse Interview for Those with Developmental Disabilities.* Santa Barbara, CA: James Stanfield Company.

[6] Wilkins et al., p. 8. Wilkins, N., Tsao, B., Hertz, M., Davis, R., Klevens, J. (2014). Connecting the Dots: An Overview of the Links Among Multiple Forms of Violence. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention Oakland, CA: Prevention Institute. https://www.cdc.gov/violenceprevention/pdf/connecting_the_dots-a.pdf

[7] Table 1 Source: Centers for Disease Control and Prevention (2017). Sexual Violence Risk and Protective Factors. https://www.cdc.gov/violenceprevention/sexualviolence/riskprotectivefactors.html; and Basile, K.C., DeGue, S., Jones, K., Freire, K., Dills, J., Smith, S.G., Raiford, J.L. (2016). STOP SV: A Technical Package to Prevent Sexual Violence. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention. https://www.cdc.gov/violenceprevention/pdf/sv-prevention-technical-package.pdf

[8] Wilkins et. al., 2014, p. 9.

[9] *Centers for Disease Control and Prevention* (2017). Monroe County, Indiana data. Community Health Status Indicators, 2017. *Accessed online:* https://wwwn.cdc.gov/CommunityHealth/profile/currentprofile/IN/Monroe The data are taken from the Behavioral Risk Factor Surveillance System (BRFSS).

[10] 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.