Sidewalks
to Sexual Violence Prevention

A Guide to Social Inclusion with Adults with Cognitive and Developmental Disabilities

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INDIANA COALITION AGAINST DOMESTIC VIOLENCE

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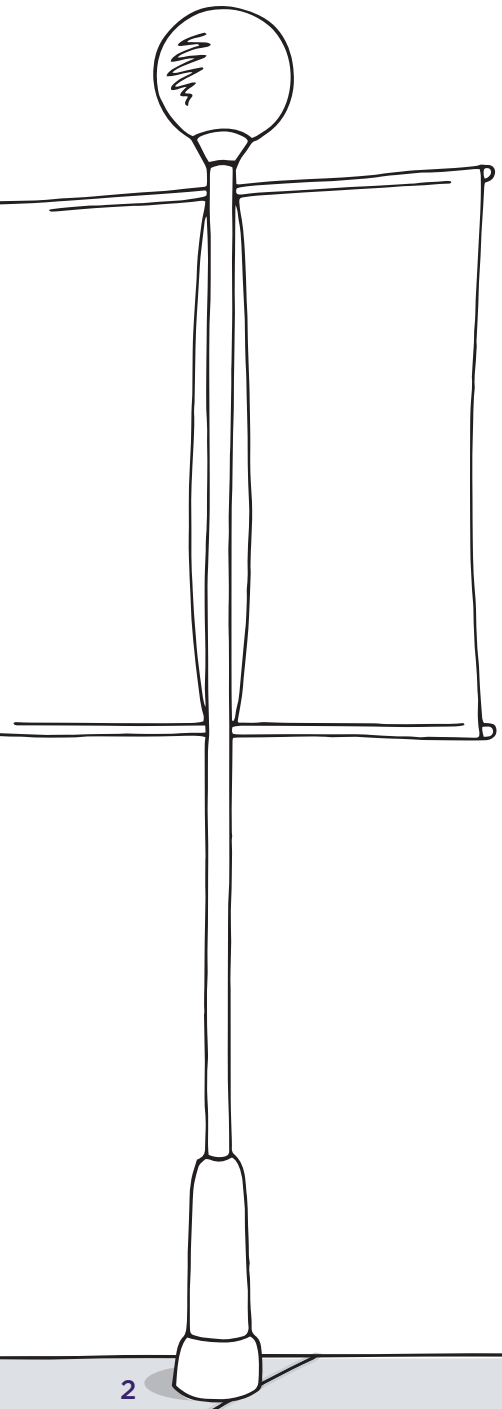

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About the Author

Cierra Olivia Thomas-Williams, MA (ney ee or she/her/hers) is a Prevention Specialist at Indiana Coalition Against Domestic Violence (ICADV) whose work focuses on advancing disability justice through the primary prevention of violence. Ney ee is a fat, queer, thoyewa (Disabled), Nisenan Miwok assa (woman), named after her homelands in now-California. Cierra is a survivor of poly violence. After 17 years as a victim's advocate who also coordinated prevention efforts for local shelters in Oregon and Indiana, Cierra joined the ICADV prevention team in 2015. Ms. Thomas-Williams works collaboratively with the ICADV prevention team to develop, implement, evaluate, and report on strategies supporting Indiana's sexual violence prevention plan. In 2018, Cierra co-founded and co-leads Indiana Disability Justice (IDJ) along with six other neurodivergent and Disabled people, and people with disabilities. IDJ provides training and technical assistance across the country to advocates and preventionists interested in exploring the intersection of disability and violence prevention. In 2022, Indiana Coalition to End Sexual Assault and Human Trafficking recognized Cierra's outstanding prevention services at the ICESAHT statewide conference. Cierra is an avid flower gardener and a Pearl Jam superfan who has attended every tour possible for the last 30 years.

For more free 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.

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 the Art

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 in the project.

Art in this image created by Stone Belt stakeholders in collaboration with Van Go Mobile Art Studio, January 28, 2017.

Project Partners

The Bloomington INclusion Collaborative Stakeholders 2015-2017

Indiana Coalition Against Domestic Violence
Cierra Olivia Thomas-Williams, Prevention Specialist

Stone Belt Arc
Leslie Green
Tiba Walter
Nathan Gilbert
People of the Bouncing Back Support Group
People of the Moving Forward Classroom
Jim Wiltz
Susan Russ
Eric Ford

Rural Transit
Amy Leyenbeck

Bloomington Transit Corporation
Eli McCormick

Monroe County Public Library
Chris Jackson

Van Go Mobile Art Studio
Ellen Bergan

City of Bloomington, Safe and Civil City
Rafi Hassan

Area 10 Agency on Aging
Barbara Salisbury

Family Voices Indiana
Heather Dane
Cyndi Johnson

Indiana Institute on Disability and Community
Jennie Todd

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Middle Way House
Sam Harrell
Evelyn G. Smith

Council on Domestic Abuse
Suzanne Gillies-Smith

"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

SL
American Sign Language

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

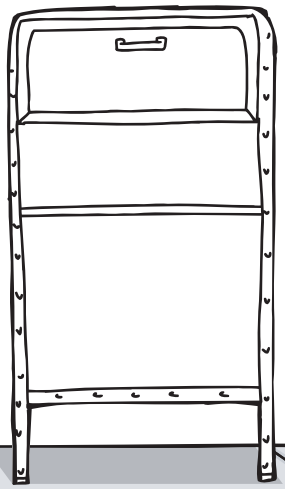
SEM
Social-Ecological Model

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."

YRBSS
Youth Risk Behavior Surveillance System

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 cognitive 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. Previous versions of this publication used the phrase "intellectual and developmental disabilities" or IDD. In the 2023 revision, the author removed references to intellectual disability unless the phrase is used in cited sources. Categorizing people according to a perceived level of intelligence is a tactic of ableism developed during the era of scientific racism to oppress and devalue people of color and people with disabilities. Unfortunately, the phrase is still widely used today. This publication uses the phrases cognitive disabilities and developmental disabilities to address the full spectrum of neurodivergence and cognitive disabilities (mental health disorders, and traumatic brain injury), and developmental disabilities (cerebral palsy, autism spectrum, dyslexia, attention deficit, learning and processing disorders), visual, and auditory disabilities.

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.

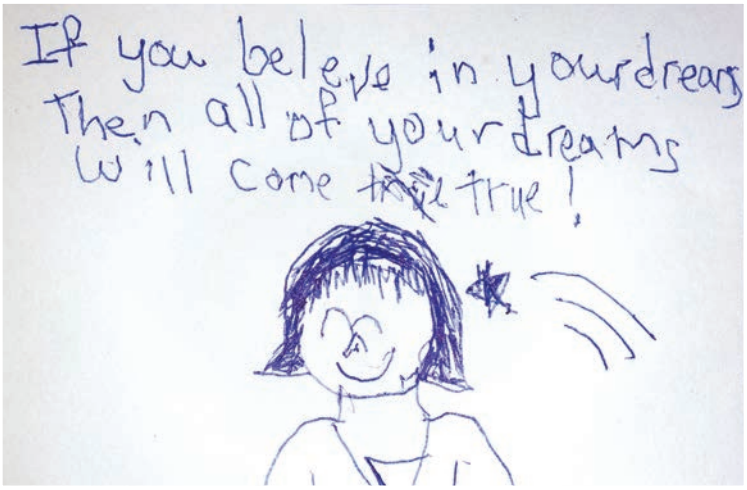
Measuring Inclusion

Community support and connectedness are protective factors against child maltreatment, youth violence, intimate partner violence, sexual violence, elder abuse, and suicide.[1] 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 cognitive 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.

Social isolation emerges or is expressed through inequitable access and opportunity across the structures and systems that support human life, including transportation, employment, education, and health care. Isolation and lack of access increases the risks for perpetration and victimization of multiple forms of violence across the lifespan.[2] There is not a lot of literature published about protective factors (see Table 1); 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.

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 trauma.[3] Safety, stability and



"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.

1 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. www.cdc.gov/violenceprevention/pdf/connecting_the_dots-a.pdf

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 characterized 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 www.who.int/publications/i/item/9789241563703

3 The 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. www.cdc.gov/violenceprevention/pdf/essentials-for-childhood-framework508.pdf

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 moments that may or may not be related to trauma.

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.[4] 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 (YRBSS) 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 reading level to take such a survey. People who communicate using American Sign Language, a computer device or other means such as pointing, nodding, and shaking one's head are left out of these surveys.

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 YRBSS results published in 2016.[5] The rate of all violent crimes against people with cognitive disabilities is

"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.

"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.

4 Statistics about intersex individuals is not tracked. Erickson, W., Lee, C., & von Schrader, S. (2016). "2014 Disability Status Report: Indiana." Ithaca, NY: Cornell University Yang Tan Institute on Employment and Disability (YTI). Accessed online November 11, 2016 at: www.disabilitystatistics.org/StatusReports/2014-PDF/2014-StatusReport_IN.pdf; and Erickson, W., Lee, C., von Schrader, S. (2016). "Disability Statistics from the 2014 American Community Survey (ACS)." Ithaca, NY: Cornell University Employment and Disability Institute (EDI). Accessed online April 1, 2016: www.disabilitystatistics.org.

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: www.cdc.gov/mmwr/volumes/65/ss/ss6509a1.htm?s_cid=ss6509_w; Centers for Disease Control and Prevention (2015). Youth Risk Behavior Surveillance Survey United States 2015. Surveillance Summaries. June 10, 2016. 65(6);1–174. Available online: www.cdc.gov/mmwr/volumes/65/ss/ss6506a1.htm?s_cid=ss6506_w and www.in.gov/isdh/files/4_2015INH_Summary_Tables.pdf ; Black, M.C., Basile, K.C., Breiding, M.J., Smith, S.G., Walters, M.L., Merrick, M.T., Chen, J., & Stevens, M.R. (2011). The National Intimate Partner and Sexual Violence Survey (NISVS): 2010 Summary Report. Atlanta, GA: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention. www.cdc.gov/violenceprevention/nisvs/summaryreports.html or www.cdc.gov/violenceprevention/pdf/NISVS_Report2010-a.pdf

6 The Arc's National Center on Criminal Justice and Disability (NCCJD) (2015). Violence, Abuse and Bullying Affecting People with Intellectual/Developmental Disabilities. Washington, D.C.: The Arc.

63%.[6] Sexual violence prevalence rates for people who have cognitive or developmental disabilities is estimated to be as low as 65% and high as 98% of the population over the course of a lifetime.[7] 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 the risks for perpetration and victimization of domestic and sexual violence.[8] All 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.

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 and poem by "Jenny Quantum Physics,"[10] self-identified optimist

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

8 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. www.cdc.gov/violenceprevention/pdf/connecting_the_dots-a.pdf

9 Tracy, E.M. & Whittaker, J.K. (1990). The Social Network Map: Assessing social support in clinical social work practice. Families in Society, 71(8), 461-470; Tracy, E.M. 2000. Assessing Informal and Formal Networks. Accessed online on April 13, 2015 at: www.dhs.vic.gov.au/__data/assets/pdf_file/0010/449173/assessing-informal-and-formal-networks-2000.pdf

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 communities. 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 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

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:
  - Timeline of project.
  - Time commitment expected.
  - Benefits or outcomes expected; and
  - Contact information.
- ☐ Request in-person meeting to go over project requirements and answer any questions.
- ☐ Memorandum of Understanding (MOU) to follow commitment.
  - This document describes the roles of each agency in the project and includes the timeline and expectations.
  - Provide city departments with two originals, because they need to retain an original signed document.
  - 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.
  - May require guardian signatures for some participants with developmental and cognitive disabilities (see appendix for informed consent documents for all participants).

11 Wilkins et al., 2014, p. 9.

agencies) and Stone Belt, Arc and six other local agencies.[12]

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, 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 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.

Table 1: As of February 2023, these are the only known protective factors against perpetration-little has changed since the original CDC publication of risk factors in 2016. The Bloomington Inclusion Collaborative project seeks to build community protections through increasing inclusion at the individual, organizational and community levels of the social ecological model.[13]

Table 1: Known Risk & Protective Factors for Sexual Violence Perpetration

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

Table source: Centers for Disease Control and Prevention (2017). Sexual Violence Risk and Protective Factors. Available online at: 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. Available online at: www.cdc.gov/violenceprevention/pdf/sv-prevention-technical-package.pdf

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).

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. This includes 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.

Gather Community Specific Data

The Centers for Disease Control and Prevention have identified shared risk and protective factors for sexual violence (see Table 1); 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[14] indicates there is "inadequate social support" (defined as "social-emotional" support) in Monroe County. Monroe County ranks 16th worse of 20 in a scaled comparison of peer counties ranging from "better" to "moderate" to "worse" in Indiana. 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, 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.

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

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

- Pre/post-test for cross-sector working professionals[15]
- Circle of support social network maps with people with a variety of disabilities[16]
- Focus groups with people with a variety of disabilities[17]
- Key informant interviews with care givers[18]
- Participatory social mapping of Bloomington neighborhoods, public spaces, and businesses[19]

Staff artwork with Ellen Bergan and Van Go Mobile Art Studio

14 The data are taken from the Behavioral Risk Factor Surveillance System (BRFSS).

15 Questions and results in appendix document entitled "2015Yr.End.Report.final.deidentified-rev."

16 Adapted tools and the original tool in appendix documents entitled "2015Yr.End.Report.final.deidentified-rev," and "Tracy-Social Network Map Tool rev."

17 Focus group protocols are available in appendix evaluation tools "Matson.FocusGroup.Protocol."

18 Key informant interview protocol is available in appendix evaluation tools called "Matson.Interview.Protocol."

19 Mapping Tools for original and adapted mapping protocols including a tool to use in service agencies to help determine accessibility are available in the appendix.

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 cognitive 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.

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

Circle of Support
(Social Network Maps)

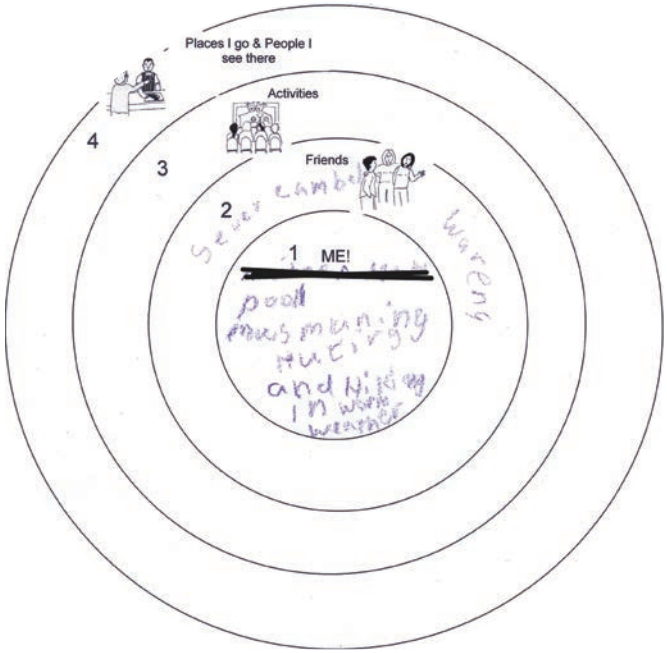
Because art is a tool that does not require spoken communication, the Prevention Specialist used a self-assessment called the "Circle of Support" (following page) which would allow for writing, drawing, painting, or doodling. The network map uses four inset circles to demonstrate broad categories across 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.

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 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 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 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.

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 is only 1.1 miles away. Because the 1.1 miles were 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).

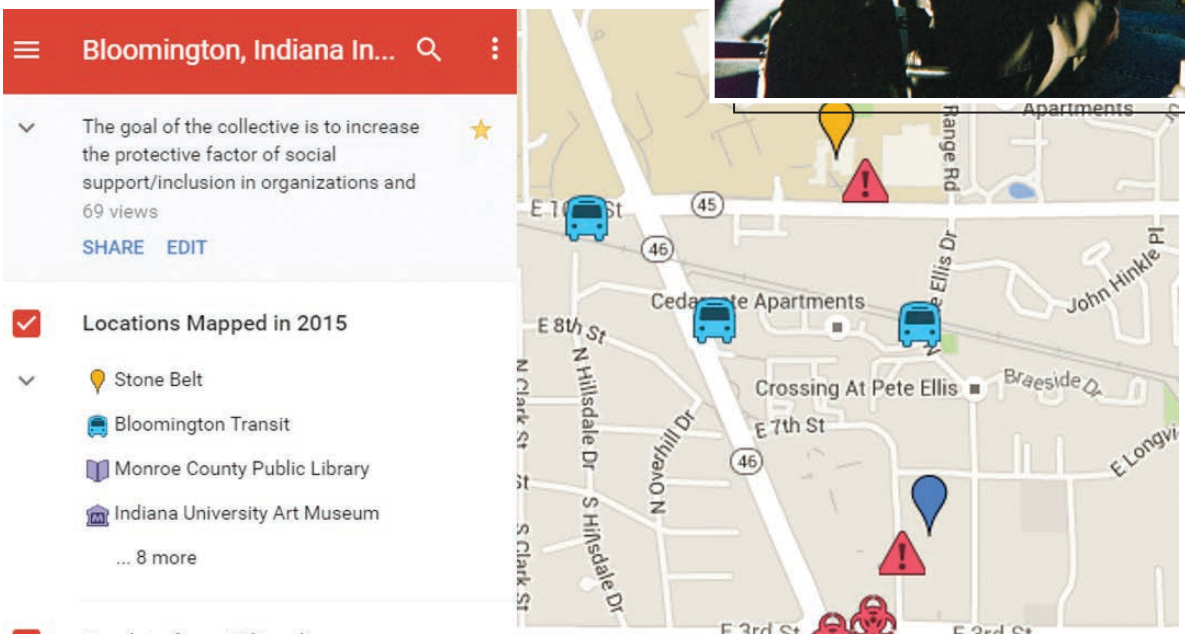
Stone Belt stakeholders with disabilities learned how and where to advocate for sidewalk repairs on the city website using a form submission (requires a computer with internet access) and their PhotoVoice images. The repairs to sidewalks benefit everyone in Bloomington.

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 (right) used the online tool to plot the locations that were mapped by teams and labeled the various barriers found throughout Bloomington.

This free Google map is useful tool for advocacy.[20] Mr. Ely used PhotoVoice images captions to populate the map and symbols to indicate what barrier was encountered there.



20 The map can be found by Googling "Bloomington Inclusion Collaborative Map" or by clicking drive.google.com/open?id=1J6rrCf3CSOKJiMj59SZcKb18X7k&usp=sharing

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.

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)

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[21] 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 buses 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 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.

21 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: bloomingtontransit.com/wp-content/uploads/2016/08/2017-Proposed-Budget.pdf

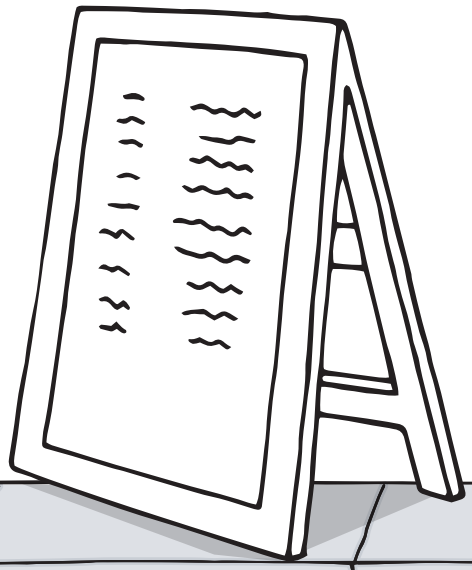
One Stone Belt stakeholder shared during a MCCAM public meeting that the transportation barriers caused by zoning limitations cuts both ways. One woman with disabilities reported findings from the participatory social mapping of her neighborhood and told MCCAM she cannot easily or safely leave her neighborhood (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 care givers 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."[23]

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.

The narrative above describes a typical situation in disability services agencies across the United States. Stone Belt's leadership reports high rates of turn over 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.



22 Stone Belt, Arc. (January 27, 2017) Direct support professional wages need to increase, www.youtube.com/watch?v=wbXEJPL_I_Y

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.

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.

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.

"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.

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 2: Inclusion Outcomes

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. • Increase in use of mass transportation systems = increase in spontaneity by Stone Belt stakeholders. • Increase in cultural competency about disability for collaborators who used cross-agency training opportunities.	• Increase # of MCPL* resources about people with disabilities. • Increase # of accessible computers for blind patrons available at MCPL. • Increase # people with disabilities participating in transportation-advocacy forums. • Increase textural differences on floor leading to stairs (signaling to blind patrons that stairs are ahead) • Increase # of acoustics in environment to aid in navigation for blind patrons.	• Increase # paved bus stop landing pads. • Increase # of connected sidewalks and curb cuts. • Opportunity to interact with and hear from people who are not usually present at community meetings.

*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 up 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

Art created with 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 disabilities.[23] 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 cognitive disabilities. Stakeholders communicated using devices, such as computers and keyboards, by writing words, drawing pictures, using sign

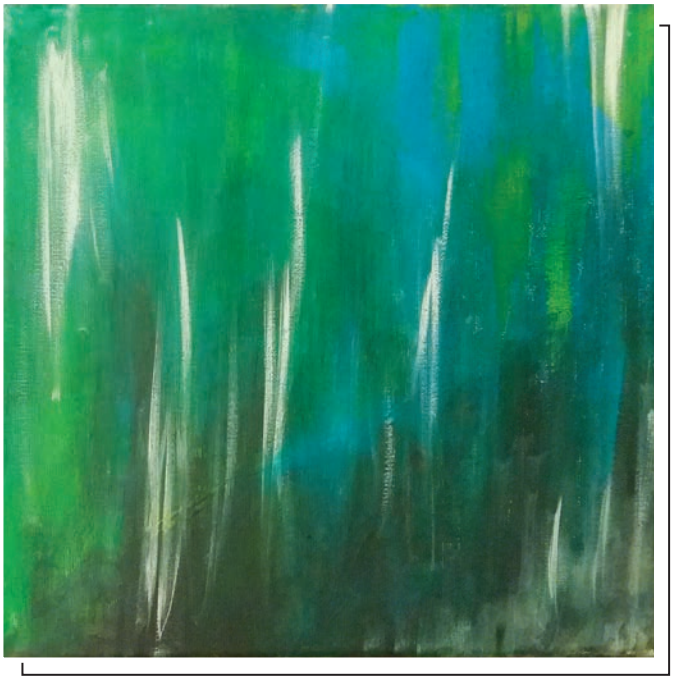
Art by Ellen Bergan, artist and entrepreneur, Van Go Mobile Art Studio

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 community. 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

23 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.

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



Art created with stakeholders with disabilities.

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 the risks 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 Americans 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

CALCASA (2010). Creating Access: Supporting Survivors of Sexual Assault with Disabilities. California Coalition Against Sexual Assault. www.calcasa.org/wp-content/uploads/2010/12/Disabilities-Info-Packet-Final-Upload-12.29.10.pdf

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, but it also 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. www.disabilityrightsohio.org/assets/documents/dro_sexual_abuse_combined_report.pdf

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
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 (ICADV) in partnership with Stone Belt, Arc (2016) participated in a national conversation with formerly CALCASA now VALORUS 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. Since 2016, the ICADV Prevention Specialist has expanded the collaborative work with PreventConnect to include the following learning resources:

- PreventConnect Podcast: Disability Justice and Primary Prevention Part 1: Moving at the Speed of Trust, www.preventconnect.org/2022/11/disability-justice-and-primary-prevention-part-1-i-moving-at-the-speed-of-trust/
- PreventConnect Podcast: Disability Justice and Primary Prevention Part 2: Resources for Practitioners, www.preventconnect.org/2022/12/disability-justice-and-primary-prevention-part-2/
- Health Equity Approaches to Preventing Sexual and Intimate Partner Violence Session 3: Partnering With Sectors and Movements, www.preventconnect.org/2022/11/health-equity-approaches-to-preventing-sexual-and-intimate-partner-violence-session-3-partnering-with-sectors-and-movements/
- Prevention Town Hall: Advancing, expanding, and sustaining primary prevention of sexual and intimate partner violence in the era of #MeToo and #TimesUp, www.preventconnect.org/2019/10/prevention-town-hall-advancing-expanding-and-sustaining-primary-prevention-of-sexual-and-intimate-partner-violence-in-the-era-of-metoo-and-timesup/
- Peer Learning Forum: Implementing Community-Level Strategies to Prevent Sexual and Domestic Violence, www.preventconnect.org/2017/09/peer-learning-forum-implementing-community-level-strategies-to-prevent-sexual-and-domestic-violence/
- Social Inclusion as Sexual Violence Prevention Strategy, www.preventconnect.org/2016/10/social-inclusion-as-sexual-violence-prevention-strategy/
- What About Power and Patriarchy? Examining Social Cohesion Strategies to Prevent Sexual and Domestic Violence, www.preventconnect.org/2016/06/what-about-power-and-patriarchy-examining-social-cohesion-strategies-to-prevent-sexual-and-domestic-violence/
- Inclusion Appendix with pdf tools referred to within this document are available on PreventConnect at this url: 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 www.nsvrc.org/blogs/preventionista/mapping-prevention

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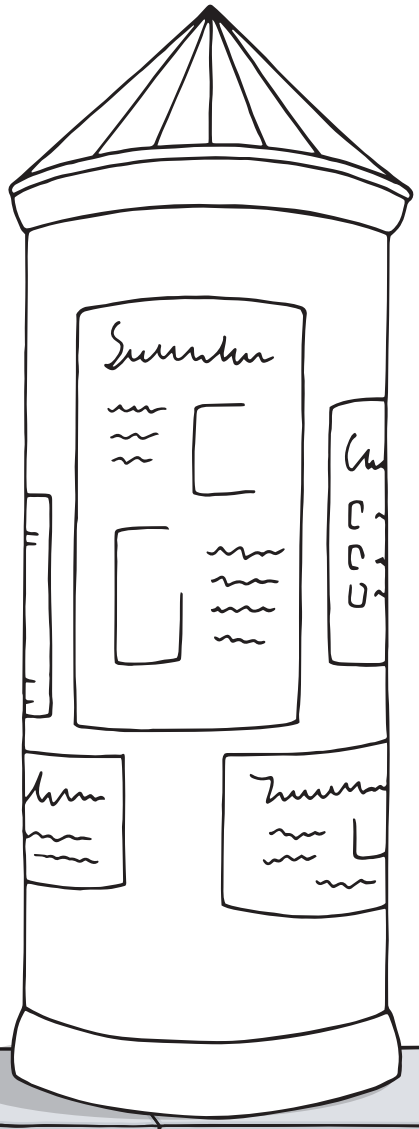
Art work produced with Van Go Mobile Art Studio



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, www.sciencedirect.com/science/article/pii/S0190740916303449). For more information please visit: www.cdc.gov/violenceprevention/aces/index.html

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 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 ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources

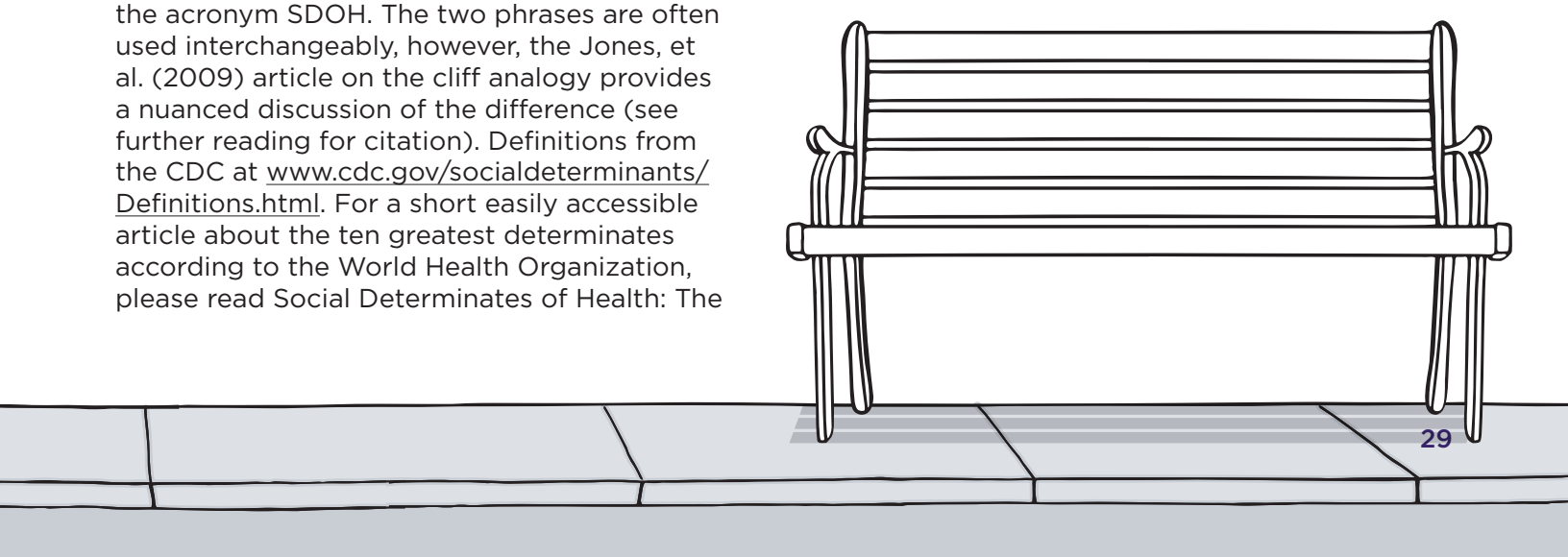
Crime Prevention Through Environmental Design (CPTED): A multidisciplinary method that emerges from the study of criminology, CPTED focuses on elements of the built environment. Crowe (2000) argues "CPTED attempts to reduce or eliminate opportunities [for crime] by

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). popcenter.asu.edu/content/using-cpted-problem-solving-2 and www.popcenter.org/sites/default/files/Responses/closing_streets/PDFs/Crowe_Zahm_1994.pdf

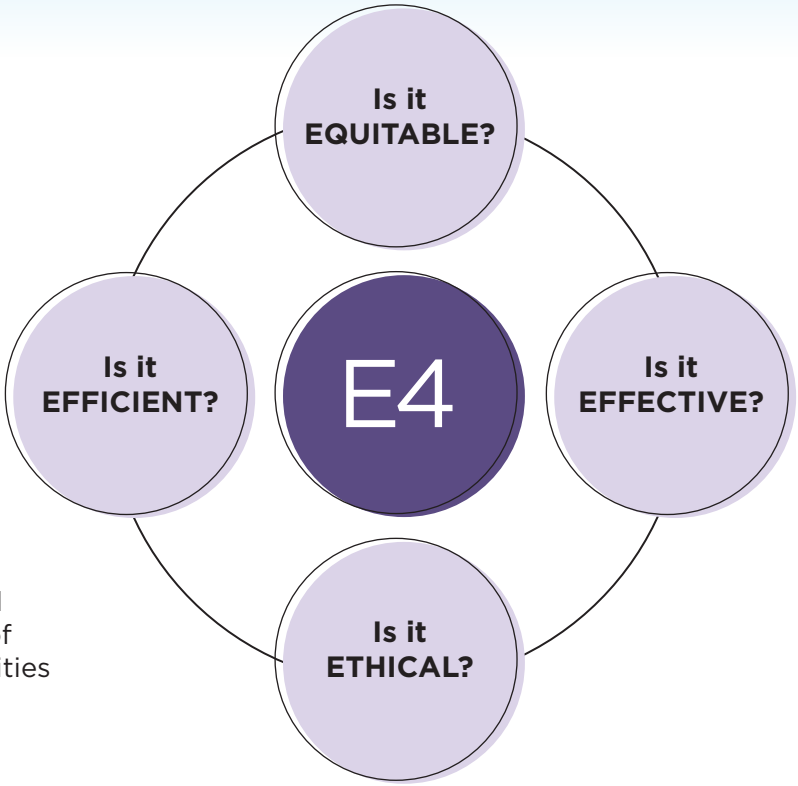
Determinants of Health (SDOH): The conditions in which people are born, grow, live, work and age that influence their opportunities for a healthy, productive life. These circumstances are shaped by access to money, power, and resources at global, national and local levels. The determinants of health 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 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, www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf

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: www.search-institute.org/research/developmental-assets and 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: 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.



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. Have the people most impacted by the problem had the lead in defining the problem and solutions? It is unlikely that efforts to retrofit prevention strategies developed by/for mainstream populations with the hope of expanding the reach or relevance to communities that have been marginalized will be effective. When the benefits/protections of prevention strategies fail to support communities that have been marginalized we contribute to the inequities in health and safety between advantaged and disadvantaged populations.

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.

Equity is a complex process that requires the redistribution 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 by Matt Kinshella are helpful tools to help guide one's understanding of complex social issues: www.ces101fall2018.wordpress.com/2018/09/10/equity-versus-equality-triple-participation/. 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," 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 (WHO, 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. (WHO, 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 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 www.sciencedirect.com/science/article/pii/S0190740916303449# and the CDC's 2016 Preventing Multiple Forms of Violence: A Strategic Vision for Connecting the Dots: www.cdc.gov/violenceprevention/pdf/strategic_vision.pdf. For more details on violence specific strategies, approaches and evidence, please review Technical Packages for Violence Prevention: Using Evidence-based Strategies in Your Violence Prevention Effort on the CDC website at: www.cdc.gov/violenceprevention/communicationresources/pub/technical-packages.html

The following are the available violence-specific technical packages as of February 2023:

- Adverse Childhood Experiences (ACEs)
  - Preventing Adverse Childhood Experiences (ACEs): Leveraging the Best Available Evidence (2019) www.cdc.gov/violenceprevention/pdf/preventingACES.pdf
- Child Abuse and Neglect
  - Preventing Child Abuse & Neglect: A Technical Package for Policy, Norm, and Programmatic Activities (2016) www.cdc.gov/violenceprevention/pdf/can-prevention-technical-package.pdf
  - Prevención del maltrato y abandono infantil: Paquete técnico para las actividades relacionadas con políticas, normas y programas www.cdc.gov/violenceprevention/pdf/CAN-Prevention-Technical-Package-spanish508.pdf
- Intimate Partner Violence
  - Preventing Intimate Partner Violence Across the Lifespan: A Technical Package of Programs, Policies, and Practices (2017) www.cdc.gov/violenceprevention/pdf/ipv-technicalpackages.pdf
- Sexual Violence
  - STOP SV: A Technical Package to Prevent Sexual Violence (2016) www.cdc.gov/violenceprevention/pdf/sv-prevention-technical-package.pdf
  - DETENGAMOS LA VS: Paquete técnico para prevenir la violencia sexual www.cdc.gov/violenceprevention/pdf/sv-prevention-technical-package-spanish508.pdf
  - "Sexual Violence on Campus: Strategies For Prevention (2016) www.cdc.gov/violenceprevention/pdf/campussvprevention.pdf

- Suicide
  - Preventing Suicide: A Technical Package of Policy, Programs, and Practices (2017) www.cdc.gov/violenceprevention/pdf/suicideTechnicalPackage.pdf
- Youth Violence
  - A Comprehensive Technical Package for the Prevention of Youth Violence and Associated Risk Behaviors www.cdc.gov/violenceprevention/pdf/yv-technicalpackage.pdf
  - Un paquete técnico integral para la prevención de la violencia juvenil y los comportamientos de riesgo asociados www.cdc.gov/violenceprevention/pdf/yv-technicalpackage-spanish.pdf

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: 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: www.cdc.gov/violenceprevention/about/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: 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: www.cdc.gov/violenceprevention/pdf/essentials-for-childhood-framework508.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 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: 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 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
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: www.alanberkowitz.com/articles/Social_Norms_Violence_Prevention_Toolkit.pdf
- Connecting the Dots: An Overview of the Links Among Multiple Forms of Violence www.cdc.gov/violenceprevention/pdf/connecting_the_dots-a.pdf
- Promoting Positive Community Norms, a supplemental guide to Essentials for Childhood: www.cdc.gov/violenceprevention/pdf/efc-promoting-positive-community-norms.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: 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 available online: vetoviolence.cdc.gov/apps/phl/images/ACE_Accessible.pdf.

Recommendations

Recommended further reading and listening about primary prevention:[24]

American Public Health Association (March 2015). *Better Health through Equity: Case Studies in Reframing Public Health.* Available online: 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. Available online: www.alanberkowitz.com/articles/Social_Norms_Violence_Prevention_Toolkit.pdf

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

Centers for Disease Control and Prevention (2014). *Essentials for Childhood: Steps to Create Safe, Stable, Nurturing Relationships and Environments for all Children*. Available online: www.cdc.gov/violenceprevention/pdf/essentials-for-childhood-framework508.pdf

Centers for Disease Control and Prevention (2014). *Promoting Positive Community Norms.* Available online: 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. Available online: 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. Available online: www.cdc.gov/violenceprevention/childabuseandneglect/essentials/about-essentials.html

Department of Health and Human Services (2015). *Prevention Resource Guide: Making Meaningful Connections.* Available online: 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 Available online: www.ncbi.nlm.nih.gov/pmc/articles/PMC2836340/

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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. Available online: www.cdc.gov/violenceprevention/pdf/connecting_the_dots-a.pdf

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

24 Unfortunately, this reading list largely does not directly address disability — the majority of primary prevention work does not. It is on us, practitioners, to change that.

Appendix

The Inclusion Appendix referred to within this document is available online at PreventConnect: https://www.preventconnect.org/wp-content/uploads/2017/07/Inclusion-Appendix.pdf?x47887.

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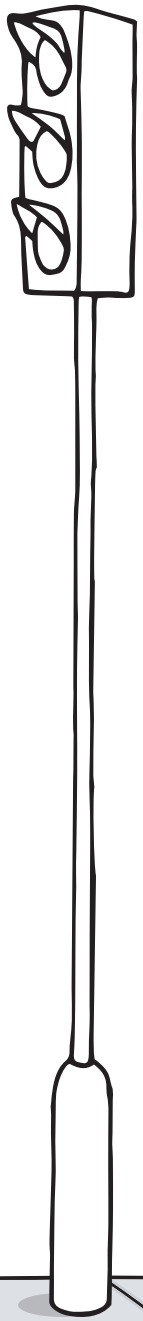

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