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Developing a Training Program for Omaha Metro Area Sexual Assault Nurse Examiners Caring for Individuals with Developmental Disabilities

Emily Blanchard
University of Nebraska Medical Center

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Emily Blanchard, Maternal Child Health

University of Nebraska Medical Center

College of Public Health

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Capstone Committee:

- Chair: Dr Shannon Maloney, PhD
- Dr Shireen S. Rajaram, PhD
- Anne Woodruff Jameson, PT, DPT at the Munroe-Meyer Institute

Table of Contents

Abstract

Individuals with developmental disabilities experience many barriers to healthcare and are at a substantially higher risk for sexual assault and trauma. There is a need for more inclusive and collaborative healthcare policies, practices, and education to guide healthcare providers during their encounters with individuals with developmental disabilities as patients, especially during forensic examinations following sexual assault and trauma. In the Omaha metro area, physical therapists at the Munroe-Meyer institute provide clinical services in a transdisciplinary program that refer victims of sexual violence to local health systems' Sexual Health Nurse Examiners (SANEs).

There is an existing service gap for individuals with developmental disabilities in accessing and receiving individualized, evidence-based sexual healthcare. Addressing the service gap in this population's sexual healthcare requires a plan to increase communication amongst healthcare teams and ensuring both patients and providers have support and education. Starting with an investigation of community needs and available resources, this research plans a training program for a comprehensive, patient centered training program for SANEs providing care and forensic examinations for individuals with developmental disabilities .

Chapter 1

Background and Review of Literature

Sexual violence and intimate partner violence impacting individuals with developmental disabilities

Sexual violence and intimate partner violence are significant public health problems. The most recent national surveys indicate that one in three women and one in six men will experience some form of sexual violence in their lives (Smith et al, 2017). Sexual violence is defined by the Center for Disease Control and Prevention as an individual being forced or manipulated into unwanted sexual activity without their consent, and includes rape, sexual assault, incest, unwanted sexual contact or touching, sexual harassment, sexual exploitation, and sexual exposure without consent (National Sexual Violence Resource Center, 2010). One in five women and one in 73 men will be raped in their lifetime (Black et al, 2011). These are broadly manifested public health concerns, affecting not only the victim but their family, the offender, and the surrounding community as well (National Sexual Violence Resource Center, 2011). The effects of this violence on those impacted are wide ranging, from emotion and psychological trauma to grievous physical injuries and death (Tjaden & Thoeness, 2000).

Responses, reactions, and coping strategies to the trauma of sexual violence are complex and unique to each individual impacted (Yuan, Koss, & Stone, 2006). For individuals with developmental disabilities, experiencing the trauma of sexual and/or intimate partner violence is potentially compounded by other life challenges, such as disparities in accessing needed medical care and treatment following the assault, or knowledge deficits regarding consent and autonomy. There are population-specific characteristics and common experiences that may increase

vulnerability and potential for manipulation (Ryan, Salbenblatt, Schiappacasse, & Maly, 2001), such as dependence on others, desires to be compliant and accepted, and difficulties with cognition and information or sensory processing.

Research into developmental disabilities and trauma related fields has been recent and increasingly expanded, looking into areas such as adverse childhood events and complex grief. Of particular importance is the evidence that this population is experiencing significantly higher rates of abuse, maltreatment, and neglect than their non-disabled peers (Sullivan & Knutson, 2000). Emerging data shows that individuals with developmental disabilities are experiencing sexual violence at more than 7 times the rate of individuals without disabilities (Bureau of Justice Statistics, 2017). Individuals with developmental disabilities are at higher risk for sexual assualt, rape, and physical trauma because they may be easy for their offender to manipulate or physically overpowerer; they may even be reliant in some way on the person who assaults them (Martin et al, 2006). Difficulties with speech or verbalizing their needs, cognition and information or sensory processing disorders, compliance or obedience to caregivers and authority figures from early childhood, and decreased perceived credibility due to an intellectual disability may increase their vulnerability and potential for manipulation (Ryan, Salbenblatt, Schiappacasse, & Maly, 2001; Shapiro, 2018).

As healthcare professionals provide care and treatment for individuals with developmental disabilities who have been impacted by the trauma of sexual and intimate partner violence, they are guided within their legal and ethical responsibilities to identify and provide the best care possible for the patients they serve (Upshaw Downs & Swienton, 2012). Trauma informed care, a systems-level service delivery model, recognizes and acknowledges both the

prevalence and impact of trauma. In his call for the integration of trauma informed care into disability organizations' framework, author John Kessler describes this model as providing "a culture of safety, trustworthiness, choice, collaboration, and empowerment" (Kessler, 2014). Educating healthcare providers is a necessary component in a healthcare training program for success and sustainability as providers address the barriers this population experience in accessing and receiving the best possible care (Shakespeare & Klein, 2015), and work to close the gap in services tailored to the needs of each individual with developmental disabilities (McConkey & Truesdale, 2000).

Forensic nursing services and sexual assault nursing examinations

In healthcare systems with established Sexual Assault Nurse Examiner/Sexual Assault Response Team (SANE/SART), the individuals who experience sexual violence or intimate partner violence either present themselves or are referred to emergency services to be assessed by forensic nursing services. Forensic examinations are performed to gather a focused medical history and physical, collect forensic evidence, treat injuries, and provide prophylactic medications while maintaining a chain of custody of the collected evidence for law enforcement purposes. Sexual Assault Nurse Examiner (SANE) services are also requested to provide crisis intervention and psychological support, resources and information, and education (Upshaw Downs & Swienton, 2012). These nurses may be required to provide legal testimony and be called in court as experts in their field (Humphreys & Campbell, 2011).

SANE examinations are thorough, head-to-toe, in-depth nursing assessments and event documention that require ongoing informed consent and collaboration with each patient (Upshaw Downs & Swienton, 2012). Forensic nursing services can involve an interview, evidence

collection and documentation, photographs of injuries, a physical examination, or any combination of these. Individuals, their guardians, and their caregivers can refuse any portion of the exam at any time, can choose to report a crime to the police or not, and can receive or refuse prophylactic medications for sexually transmitted diseases. In the event that the individual or their caregiver chooses to report the event to the police, the collected evidence kit will be signed over and given to the accepting officer. (National Center on Domestic and Sexual Violence, 2016) . This chain of custody, with collected evidence kept in the presence of the individual responsible for its integrity, is important and maintained for legal purposes. The forensic assessment and documentation, as well as any photographs collected, are stored and kept private by the healthcare system providing the forensic nursing services in accordance with healthcare information privacy laws, and provided to legal services only upon authorized request (National Center on Domestic and Sexual Violence, 2016).

Building a training program for SANEs: rationale and reasoning

Sexual assault nurse examiners have unique interactions with patients with developmental disabilities, due to the intimacy of their examinations and assessments, the need for ongoing consent and communication throughout their entire time providing care, the potential for involvement of legal services, social work, victim advocates, and multidisciplinary plans of care, and increased time spent with each individual (Upshaw Downs & Swienton, 2012; Humphreys & Campbell, 2011). SANEs and victim advocates provide acute trauma services in emotionally charged situations, and are at high risk for provider burnout and turnover. It is imperative to provide them with the ongoing education, resources, and support they need to

provide the best possible care to their vulnerable patient population. The Department of Justice's Office on Violence Against Women states:

> Providing trauma-informed services for survivors highlights the closely related issue of vicarious trauma experienced by many service providers, law enforcement personnel, and others who work with victims and survivors of violence. Vicarious trauma, sometimes called 'provider fatigue,' 'compassion fatigue,' or 'secondary trauma,' has been described as the "experience of having exhausted hearts, minds, bodies, and souls from helping survivors through their painful experiences" (Department of Justice, 2014, para 6).

Educational interventions are proven routes to increasing support, awareness, knowledge, and positive attitudes in the healthcare community towards individuals with developmental disabilities (Shakespeare & Klein, 2013). Providing healthcare professionals with opportunities to increase their knowledge, awareness, and interactions with this population have been shown to be well received by both students and experienced providers (Crotty, Finucane, & Ahern, 2000). Successfully received programs are inclusive and use multidisciplinary communication, incorporating nursing and allied health staff and advocates as well as drawing from the needs, wants, concerns, and advice of individuals with developmental disabilities and their caregivers (Zwarenstein, Goldman, & Reeves, 2009). Methods of disseminating information and education range from traditional lectures and presentations, to utilizing mobile training modules, to providing interactions with individuals with developmental disabilities. Higher levels of retention and success have been associated with teaching strategies that incorporate self reflection and information processing (Duggan, Bradshaw, Carroll, Rattigan, & Altman, 2009);

those on the receiving end of the training or education are given time to examine their own attitudes, experiences, and emotions regarding developmental disability. Additionally, increased knowledge and retention is found when participants are given time and opportunity to self-reflect and self examine as well (Gitlow & Flecky, 2005). Healthcare professionals who receive this training are able to build and incorporate a variety of new, innovative, and multidisciplinary pathways and strategies for providing care and treatments.

Individuals with developmental disabilities are deserving of quality healthcare, both for ongoing conditions and for new or unanticipated health events (Shakespeare, 2012). Developmentally disabled individuals are more likely than non disabled individuals to feel they are not listened to, respected, or involved in their healthcare and health education (Smith, 2009). Healthcare professionals, as the providers of this care and education, are in unique positions to understand and stay informed on both the rights and needs that individuals with developmental disabilities have (Shakespeare & Klein, 2013).

Disability is a complex topic, involving a wide range of topics and areas of focus; medical concerns are intertwined with social justice, respect and autonomy are intertwined with conversations about finances and insurance coverage. Therefore, to teach healthcare providers, and to provide continuing education all involved stakeholders, multifaceted approaches are utilized in the development of training programs and educational resources and materials. While significant improvements to both attitudes and knowledge levels can be gained with singular education opportunities, the best approach may be one known as the “spiral of learning” (Shakespeare & Klein, 2015). This longitudinal approach focuses on best outcomes by utilizing a range of strategies across a person’s learning lifespan to reinforce learning points. For example, a

curriculum that offer quarterly education modules such as clinical observations, relevant speakers, and school and community based experiences is preferable to a curriculum comprised of strictly monthly didactic lectures (Symons, McGuigan, & Akl, 2009). Both the variety of educational experiences and consistently available learning opportunities broaden the curriculum's impact and reinforce the skills and attitudinal shifts healthcare providers will need in their encounters with individuals with developmental disabilities.

Participating organizations and agencies

Program planning and topics for interdisciplinary education and communication were developed in coordination with Anne Woodruff Jameson (PT, DPT), a physical therapist with the Munroe-Meyer Institute at the University of Nebraska Medical Center in Omaha, Nebraska. The Munroe-Meyer Institute provides services and support for individuals with developmental disabilities and complex health needs (https://www.unmc.edu/mmi/). They are a federally designated University Center of Excellence for Developmental Disabilities education, research and service, and are currently building capacity for a transdisciplinary clinical program to address women's and sexual health for individuals with developmental disabilities. The goals of this program are to improve the quality of life for these individuals by ensuring successful comprehensive health screenings, and to identify community partners to build awareness and develop referral systems, including forensic nursing exams.

Within the Omaha metro area, there are various clinics, community health centers, emergency departments, and inpatient hospital units with forensically trained nurses. These nurses follow their state and professional guidelines as well as their institution's policies and procedures. In researching a cohesive, collaborative, and systemic approach to an education

training program, interviews were conducted with the Sexual Assault Nurse Examiner/Sexual Assault Response Team Coordinators from two Omaha metro area health systems, CHI Health and Methodist Health System. Interviews were also conducted with Victim Advocates and the Director of Prevention and Education at the Women's Center for Advancement.

- CHI Health (Forensic Nurse Examiner Program Supervisor: Jodi Hayes, RN, BC, SANE-A): CHI Health is a non-profit, faith based health system comprising 14 acute care hospitals, two behavioral health facilities, and over 150 physician practice locations (chihealth.com). Their six Omaha metro area hospitals receive 24/7 on call SANE/SART services. It is headquartered in Omaha, Nebraska.
- Methodist Health (Forensic Nurse Examiner Program Team Leader: Jen Tran, MSN, RN, SANE-A): Methodist Health System is a non-profit health system comprising four hospitals, over 20 clinics, and a health college (bestcare.org). Their three Omaha metro area hospitals receive 24/7 on call SANE/SART services. It is headquartered in Omaha, Nebraska.
- The Women's Center for Advancement (Director of Prevention and Education: Sara Eliason): The WCA is the designated direct service provider for victims of domestic violence and sexual assault in Douglas County (wcaomaha.org), and is located in Omaha, Nebraska. Their approach is multifaceted, focusing on advocacy, prevention, education, and victim services, including a crisis hotline, therapy, legal services, and classes in self sufficiency and career options.

Chapter 2

Specific Aims and Research Significance

Specific aims

1. An investigation of community needs and available resources for Omaha metro area Sexual Assault Nurse Examiners providing care and forensic examinations for Individuals with Developmental Disabilities.

The investigation of community needs and available resources will include interviews with Sexual Assault Nurse Examiner/Sexual Assault Response Team directors, staff at the Women's Center for Advancement, and physical therapists providing sexual healthcare and women's healthcare to individuals with developmental disabilities at the Munroe-Meyer Institute. Additional research will be through literature reviews and logic model compilation of current available community resources, both for the healthcare providers as they treat individuals with disabilities, and for the individuals seeking care.

2. Compilation of research from the planning investigation categorized and organized to plan a comprehensive, interdisciplinary training program for Sexual Assault Nurse Examiner/Sexual Assault Response Teams providing care and forensic examinations for individuals with developmental disabilities.

Utilizing knowledge from public health, nursing, and physical therapy, the plan for a comprehensive, interdisciplinary training program will be developed to assist Sexual Assault Nurse Examiners in providing care that is both individualized and evidence-based for individuals with developmental disabilities during forensic exams, facilitating communication with the MMI physical therapy team referring the individual with developmental disabilities for the exam and

ensuring both the healthcare staff and community advocates involved have support and education.

Significance

Individuals with developmental disabilities experience many barriers to healthcare, from decreased access or physical barriers to discriminatory attitudes and beliefs of healthcare providers. Though this group of individuals make up a large and diverse population, they experience sexual healthcare disparities, both in accessing care and while receiving care, when compared to the general populace (Rowen, Stein, & Tepper, 2015). This is a population engaging in sexual activity at similar rates to their non-disabled peers (Weinholz, Seidel, Michel, Haeussler-Sczepan, & Riedel-Heller, 2016), showing a need for appropriate healthcare policies, practices, and education to guide their encounters.

More concerningly, emerging data shows that individuals with developmental disabilities are experiencing sexual violence at more than 7 times the rate of individuals without disabilities (Bureau of Justice Statistics, 2017). This number is considered by the United States Justice Department to "almost certainly be an underestimate," as it comes from a survey of individuals in home settings and does not include those living in institutions, where they may be at an even higher risk and be more vulnerable to assault and trauma (Shapiro, 2018). Individuals with developmental disabilities may be more easily manipulated, physically overpowered, or even reliant in some way on the person who assaults them, putting them consistently at higher risk for sexual assualt, rape, and physical trauma (Martin et al, 2006). Moreover, they may have difficulties with speech or verbalizing their needs, have been taught compliance or obedience to

caregivers and authority figures from early childhood, or be considered not credible due to an intellectual disability (Shapiro, 2018).

As healthcare providers providing services and resources to individuals with developmental disabilities increase their capacity to provide sexual healthcare and women's healthcare services, they will be guided by evidence-based protocols and institutional frameworks when encountering individuals in this patient population who have been the victims of sexual violence. In the Omaha metro area, the therapy team at the Munroe-Meyer Institute's transdisciplinary clinical program for sexual healthcare and women's healthcare identifies patients in need of forensic nursing services and refers them on to forensic nursing services, specifically Sexual Assault Nurse Examiners (SANEs) at one of two local healthcare systems: Methodist Health and CHI Health.

SANEs are registered nurses, typically operating out of trauma, emergency, or women's services with specialized forensic training to provide "timely and comprehensive medical examinations, treatments, and support services for victims of sexual assault," as well as more holistic, patient centered care than non-SANE providers (Upshaw Downs & Swienton, 2012, p. 137). SANEs work as part of a Sexual Assault Response Team (SART), that includes advocates, community members, and emergency responders. Victim exams include a focused medical history and physical, forensic evidence collection, and collaboration with medical services for treatment of injuries and prophylactic medications while maintaining a chain of custody of the collected evidence for law enforcement purposes. SANEs also provide crisis intervention and psychological support, resources and information, and education (Upshaw Downs & Swienton,

2012), and may provide legal testimony and be called in court as experts in their field (Humphreys & Campbell, 2011).

SANE nurses in the Omaha metro area practice under the guidance of the Nurse Practice Act of Nebraska, available through the Nebraska Department of Health and Human Services (Nebraska Department of Health and Human Services, 2019). There currently is no language in the Nebraska Nurse Practice Act specific to SANE policies or practices, so each health system is responsible for maintaining a policy to not only guide their employees but render the best health, holistic, and legal outcome for their patients.

Examination of an individual with a developmental disability by a SANE requires the nurse to rely not only on verbal histories, but possibly direct interviews with caregivers if applicable, and forensic record reviews (Humphreys & Campbell, 2011). Time and physical accommodations must be made as needed. Though an individual with a cognitive disability or an individual whose caretaker is their legal guardian may present challenges when obtaining consent to an exam, a patient's medical rights and bodily autonomy requires that they are given the opportunity to assent or decline each part of the examination (Upshaw Downs & Swienton, 2012).

To provide the best care and build the most comprehensive, inclusive policies and practices, healthcare providers address the barriers, gaps in service, and disparities challenging individuals in this patient population as they seek services. Emergency services and nursing staff have been found to have a deficit of knowledge regarding both the disabled community and the appropriate amount of reliance upon their caregivers for information (Sowney & Barr, 2006). A lack of confidence regarding the extent to which an individual with a developmental disability

can navigate a new or challenging situation, an unfamiliarity with assistive devices for mobility or communication, and utilizing caregivers as the sole sources of and receivers of information keeps existing barriers in place, reduces the opportunities for nursing staff to expand their own knowledge and clinical skill sets, and actively works against reducing health disparities (Noronha & Pawlyn, 2019). Nursing staff have also been found to have less confidence when working with patients with learning disabilities than patients with physical disabilities (McConkey & Truesdale, 2000).

This gap in knowledge, confidence, comfort level, and service, as well as the increasing contact between patients with developmental disabilities and nursing staff in emergency and trauma settings highlights the need for policies and programs that increase awareness, education, and training (Noronha & Pawlyn, 2019). To develop a confident, culturally competent, and knowledgeable healthcare workforce, individuals and groups receiving training and education will need support to be lifelong learners, capable of self-reflection and growth.

Communication between healthcare teams is also a component for providing high quality, patient centered care. In a 2009 Cochrane Database Collaboration review, researchers found that the extent to which different healthcare providers were able to work together can impact the quality of the healthcare they are providing to their patients (Zwarenstein, Goldman, & Reeves, 2009). From a public health perspective, understanding the patient's life course and the impact trauma has had, and can continue to have, gives insight into how best to treat, care, and advocate for individuals with developmental disabilities. Collaboration between the Munroe-Meyer physical therapists, direct service line providers of people who experience sexual assault at the Women's Center for Advancement, and Omaha metro area SANE service providers will ensure

that all involved healthcare staff have access to support and education, and enable providers to focus on reducing disparities in sexual health services to patients with developmental disabilities.

Chapter 3

Methods: Data Collection and Outcomes Identification

Data collection

The first step in exploring current resources, potential knowledge deficits, and unmet needs of sexual assault nurse examiners caring for individuals with developmental disabilities was seeking information from Sexual Assault Nurse Examiner/Sexual Assault Response Teams. A tour of facilities was conducted during October 2019 at Methodist Women's Hospital, CHI Health Bergan Mercy Medical Center, the Women's Center for Advancement, and the newly dedicated clinical space for Women's and Sexual Health at the Munroe-Meyer Institute. Following the facility tours, questionnaires were sent to the Sexual Assault Nurse Examiner/Sexual Assault Response Team Coordinators from two Omaha metro area health systems, CHI Health and Methodist Health System, and staff at the Women's Center for Advancement, including victim advocates and the Director of Prevention and Education, researching the educational needs and current resources within forensic nursing services. The completed questionnaires were returned by November 2019.

Interview Questionnaire for SANE/SART Coordinators

1. What organization do you work for, and what is your position and title in this organization?
2. Please describe your forensic nursing program, such as: services provided, average number of patients provided services and/or exams in a given month, types of staff members/community partners involved.

3. Who are the various other medical teams/departments and agencies that work with your program in providing care and services (ex: emergency/trauma services, social work)?
4. How do your staff accommodate individuals with developmental disabilities (ex: physical disabilities, reliance on caregivers, individuals who are not their own medical guardian)?
5. What resources or supplemental education would be the most useful to the forensic nursing staff when providing best, individualized care and exams for patients with developmental disabilities? Additionally, what format would be most useful when receiving these resources and education (ex: video modules, reading material, lists of community resources relevant to individuals with developmental disabilities)?

Data was collected from the aforementioned individuals as they belonged to the established Omaha metro area SANE/SARTs within agencies and organizations with administrative chains of command, budgets, and committed staff. These teams would therefore be able to implement a new training intervention, maintain the program, and document results from a training intervention. The program directors were emailed a five part interview questionnaire for further program details, and returned their responses via email. Transcription software was not required. All three directors provided responses. Ms Eliason from the WCA also chose to share the questionnaire with her staff, and received four responses from victims advocacy staff. The staff responses contained their position and titles but not names. These four

anonymous responses were included in the emailed responses from the Women's Center for Advancement, for a total of seven questionnaire responses.

Discussions of resources and needs for individuals with developmental disabilities within the Omaha metro area were collaborative and ongoing, and were held with Anne Woodruff Jameson, PT, DPT at the Munroe-Meyer Institute throughout the course of the research. As Ms Woodruff's program continues to build capacity, awareness, and provider knowledge, Omaha metro area SANEs may see an increase in referrals for forensic nursing services for individuals with developmental disabilities. The services provided and resources needed will vary with each individual and their situation.

Purpose of data collection	**Questionnaire responses**
● The first two parts of the questionnaire collected data regarding the makeup and functions of the Omaha metro area SANE/SART teams: services provided, average number of patients provided services and/or exams in a given month, types of staff members/community partners involved ● The responses indicated staff have a variety of professional backgrounds and experiences	● "Our FNEs respond to patients after sexual assault, domestic violence, strangulation, elder abuse, and human trafficking. Our patients come through the ED but we also get consults throughout the hospital – most often from elder abuse and suspected trafficking. We see on average 1 patient/day. We try to maintain a staff of at least 25 nurses since most have a primary/full time job in addition to their FNE position: obstetrics, med/surg, ED, PACU." Jen Tran, Methodist Health ● "We provide services to patients that present with or are suspected of being victims of sexual assault, intimate partner violence, and human trafficking. We see on average 45 patients per month. We have 15 Forensic Nurse Examiners representing nearly every department that respond 24/7 to all of our Omaha/Council Bluffs locations (inpatient, emergency departments, and outpatient clinics)." Jodi Hayes, CHI Health ● Staff from the WCA responded with their titles: "Director of Prevention and Education" Sara Eliason, WCA ● "I work for the Women's Center for Advancement and I am an advocate" ● "Bilingual Advocate for Women's Center for Advancement"

	● "Women's Center for Advancement as a Shift Advocate" ● "Women's Center for Advancement. Advocate." Anonymous staff responses, WCA
● The third part of the questionnaire sought information about interdisciplinary and interagency communication and coordination. These partnerships and collaborations show the current networking and support systems needed by SANE/SARTs	● "Our other community partners include: Women's Center for Advancement (WCA), Heartland Family Services (HFS), Project Harmony. We sit on several community committees in Douglas and Sarpy Counties that include law enforcement, prosecutors, advocates, 911 dispatch, Mayor's office, etc. We work with the Methodist Emergency Department, Methodist Community Health Clinic (follow-up), Social Work, Pastoral Care, WCA, HFS." Jen Tran, Methodist Health ● "We collaborate with community advocates and law enforcement when appropriate and/or required by law. We also collaborate with Trauma Services, Community Benefit, Medical Providers, Risk Management, Ethics, Social Work/Care Managers, The CHI Health Foundation, and all inpatient and outpatient units. I am sure there are some that I forgot but each group listed above does have some sort of touch on how we do things." Jodi Hayes, CHI Health ● "Our program focuses on safety planning for our clients, helping with protection orders, and helping our clients find resources throughout the community. We also help with referrals to our counseling, case managers and legal department." Sara Eliason, WCA ● "We have services like case management, safety planning, legal services like divorce/custody/immigration, assisting with protection orders, utility assistance and crisis counseling. We have partnerships with hospitals, and other non-profit organizations." ● "Advocacy, Case Management, counseling, legal services, support groups/classes, human trafficking services. Partnerships with hospitals and other nonprofit organizations" ● "We currently work with all Douglas county hospitals: Methodist Main, Women's Methodist, Immanuel, UNMC, Creighton, CHI, and OIC agency, Emergency Rooms, Omaha Police Department, OIC, Catholic Charities, Sisters of Notre Dame, YES, CPS, Micah House and other shelters.

	● "We have a working relationship with the area SANE programs and a partnership with Community Alliance. We also have Omaha Integrative Care provide services to our clients on-site." Anonymous staff responses, WCA
● The fourth section of the questionnaire asked how the respondents currently made accommodations when necessary for individuals with developmental disabilities seeking care at their agency or organization.	● "We depend a lot on what the patient tells us/their caregivers. We have physical therapists in house that we could consult if the patient came in during day hours. There is a slide board in our rooms that we can use to assist transfers." Jen Tran, Methodist Health ● "We always try to provide every patient we see with patient centered trauma informed care. Those with developmental disabilities do sometimes have additional barriers to care but we try to work with caregivers, POAs, etc. to provide education, information, and care the same as we do for those without disabilities." Jodi Hayes, CHI Health ● "We do training on developmental disabilities and refer clients to Community Alliance, our OIC team, or other community agencies. If they need medical emergency, we contact our supervisor on shift to contact 911. We also provide clients with resources that they could benefit from according to their disability." Sara Eliason, WCA ● "We can provide many services to these populations. We have accessible entry into our building and an elevator to move between floors, if needed. Caregivers are welcome here and can be present if the client wishes them to be." ● "We partner or refer to agencies that work with individuals with developmental disabilities and work with them to the best of our ability. (Ex: Call shelters and other organizations with them present, help them find resources, fill out applications etc). Also we work with guardian to help support client (Ex: Have guardian sign ROI so that we can speak with them on clients behalf.)" ● "Bring in interpreter when needed (For clients who are blind, hard of hearing etc)" ● "Interpret when needed (Such as on a PO when the client can't read or write, can interpret for them on affidavit or verbally discuss resources/services offered)"

	Anonymous staff responses, WCA
● The fifth and final portion of the questionnaire prompted SANE/SART members to mention resources or supplemental education they could use to provide the best, individualized care and exams for patients with developmental disabilities. They were also asked what format would be most useful when receiving these resources and education.	● "I think picture options would be great. Something that they can take with them since they are in trauma and receive so much information when they are with us. We've found that it's helpful to send the information with them so they can review it when they are ready. Community resources are sooo important and especially all the services that the local advocacy agencies offer. Follow-up is also hard and so we usually send them with follow-up recommendations for them – but also to take to their provider so that they know what the expectations are, too." Jen Tran, Methodist Health ● "Community Resources available would be extremely helpful. Also education pertaining to specific needs of this population, for example: the need for age appropriate language, barriers to care, rights of the individual who has a POA etc. I think people have a tendency to treat these adults similarly to pediatric populations due to lack of knowledge or awareness." Jodi Hayes, CHI Health ● "I think we need more resources on exams for patients and how to care for each disability or what to look for when we see a disability. I would like a list of community resources and reading material to help understand more of what to look for." Sara Eliason, WCA ● "Specific training on all types of disabilities and how we could better serve them." ● "I would like additional information on working with clients who have disabilities and/or guardianship." ● "Video modules and lists of community resources can be helpful." ● "Trainings on guardianship, community services relevant to individuals with developmental disabilities, reading materials, documents in brail if client is blind." Anonymous staff responses, WCA

Recommendations based on emerging themes

Interviews conducted with the SANE/SART team members and directors revealed three distinct themes: access to needed resources used to provide individualized care and treatment,

ongoing education, and communication with fellow health professionals. Addressing these areas of concern will increase also increase forensic nursing staff's awareness of, exposure to, and understanding of this facet of their patient populations. In turn, SANE/SART teams will be able to better provide the needed individualized and evidence-based treatment for individuals with developmental disabilities from the moment of referral to forensic exams, and through follow up care (Noronha & Pawlyn, 2019). Interaction, networking, and communication with a variety of interdisciplinary teams can also be promoted to ensure both the healthcare staff and community advocates involved are best utilizing the resources currently at their disposal, and have strong support within their health systems (Zwarenstein, Goldman, & Reeves, 2009).

The questionnaire data also shows a need for the Omaha metro area SANE/SART teams and associated referring and consulting interdisciplinary teams to have patient education materials that are both specific to the care and treatment being provided and appropriate to each patient they encounter. While current electronic medical charting systems in place at CHI Health and Methodist Health have inpatient and discharge educational materials available in multiple languages and easy-to-read versions, there is a deficit of materials designed for patients who cannot read, cannot see, are deaf or hard of hearing, or who use non-verbal assistive communication devices and other adaptive equipment.

Community resources

The following is a listing of current Omaha metro area resources for individuals with developmental disabilities and their care providers. This list is comprehensive, but not exhaustive, and meant to be added to as new resources become known.

Category	Resource	Service
Clinical spaces	Physical and occupational therapy services at the Munroe-Meyer Institute Women's and Sexual Health Clinical Program, patient's current medical and clinical home	Reproductive system and sexual health exams tailored and adapted to meet the needs of individuals with developmental disabilities Well care and established provider interactions
Inpatient services and interdisciplinary teams	emergency and trauma services, physical and occupational therapy, risk management, ethics, care management, social work, pastoral care, security, gynecology, women's services, inpatient/ outpatient hospital units	Assessments and evaluations through consultations, identification of additional needs
Physical equipment and adaptive devices	Hospital and clinic assistive and adaptive medical equipment for activities of daily living: lifts, safety/restraint/fall avoidance devices	Use of lifts, transfer equipment, gait belts, additional staff Use of patient's own medical equipment, adaptive and assistive devices for movement, communication, safety, quality of life Use of non-standard equipment sizes, creative patient positioning to increase comfort and reduce anxiety
Post-care and follow up services	Women's Center for Advancement, Omaha Integrative Care Services, Nebraska Department of Health and Human Services Division on Developmental Disabilities, Nebraska Resource and Referral System, Community Alliance, law enforcement precincts, legal services, counseling services, area shelters and charities	Navigation of available services, resources following traumatic event Victim and trauma-related support groups Individual therapy and counseling sessions Safety planning, crisis counseling, case management Legal matters such as pressing criminal charges, restraining orders, civil actions, change of power of attorney, guardianship, or address
Nebraska state disability and	Nebraska Advocacy Services, Disability Rights Nebraska, Answers	Connections, networking, and support for individuals with developmental

advocacy services	4 Families, Arc of Nebraska, Nebraska Family Support Network, PTI Nebraska	disabilities, their families, and caregivers

SANE Training Program

The training intervention is designed for SANEs providing forensic nursing services, who will most likely be working in an inpatient hospital setting such as CHI Health or Methodist Health emergency departments. The suggested timeline of this program is two years, with eight 60 minute training sessions held quarterly. Each training module will have the option for in-person attendance (preferred) or completion through video conferencing.

The SANE training program will be implemented as an objectives based curriculum, with participant's successful completion of the program realized by the ability to complete the five goals listed below. The specific objectives for this program were developed to address the questionnaire respondent requests while adhering to the 2005 US Surgeon General's Call to Action for healthcare professionals working to improve the health and wellbeing of individuals living with disabilities: treatment of the individual with respect, supporting healthcare workers by providing the knowledge and resources they need to provide the best care, and closing the existing service gap to promote the individual's independence, health, productivity, and dignity (Department of Health and Human Services, 2005).

While the information and population being defined and discussed may be less familiar to program participants, utilization of the nursing process (assessment, outcome identification, planning, and implementation) will not change as they provide care for individuals with

developmental disabilities (Betz & Nehring, 2010). The program objectives are also in line with the International Association of Forensic Nurses' Vision of Ethical Practice, which states that:

> Forensic nurses acknowledge the importance of membership in a global society. This includes providing forensic nursing care in a manner that respects the uniqueness of the patient or client. Forensic nurses collaborate with nurses, healthcare providers, and other professionals throughout the world to promote ethically informed and culturally competent practices (International Association of Forensic Nurses, 2008, para 2).

The objectives, as each participant completes the SANE training program, are:

1. To be able to define developmental disability
2. To understand the unique challenges and barriers to care that individuals with developmental disabilities face as they seek forensic nursing care following sexual trauma
3. To become culturally competent as they learn to identify their patients with developmental disabilities and what changes, accommodations, equipment, or resources they may need for their best care and outcomes
4. To become familiar with the current community services and resources for individuals with developmental disabilities, and identify deficits in services or resources at their home agency or organization
5. To initiate dialogues with and build a baseline support network of at least 5 individuals from multidisciplinary Omaha metro resources, including disability advocates, physicians, legal agencies, law enforcement, and sexual violence survivor service providers

As the first full cycle of this program is completed, an online education library will be built as well for nurses who want the full program content or to complete sessions they may have been unable to attend. This online library can also serve as a supplemental resource to all Omaha metro area SANE/SART members, in addition to requested resources compiled from questionnaire responses. Supplemental resources, including those requested by the participating agencies and organizations are shown below.

Print items available for patients to take home (to be added to and kept with current discharge materials in SANE examination room)	● Printed lists of community services and organizations that work with individuals with developmental disabilities, including contact information ● Printed lists of advocacy organizations for sexual trauma and sexual violence, including contact information ● Printed or printable picture and braille options to for all discharge education and printed word lists ● Contact information for inpatient interpreter services
Resources to be kept on-site for SANE/SART members' ongoing use	● Video modules on disability ● Access on online SANE training program education modules ● Reading materials on disabilities ● Printed lists of community services and organizations that work with individuals with developmental disabilities, including contact information, updated as needed for new services and organizations in the Omaha metro area ● Printed lists of advocacy organizations for sexual trauma and sexual violence, including contact information, updated as needed for new organizations in Omaha metro area ● Contact information for community interpreter services
Future training suggestions	● Understanding and identifying types of disability ● How to best serve individuals with developmental disabilities ● Using age appropriate language ● Barriers to care ● Legal issues: the rights of an individual with an in-place Power of Attorney, understanding guardianship ● How to conduct exams when an individual has a disability

Program Modules

The SANE training program will be comprised of eight modules that utilize traditional classroom teaching, guest speakers and guest panels, and brainstorming sessions for a multifaceted approach modeled after the longitudinal "spiral of learning" (Shakespeare & Klein, 2015). These modules will help the participants complete the objectives by utilizing a range of teaching strategies to reinforce learning points, as opposed to curriculum comprised of strictly didactic lectures (Symons, McGuigan, & Akl, 2009). Over the program's two year timespan, the participants will receive:

1. Two didactic modules, one that presents content on defining developmental disability and understanding providing care to individuals with developmental disabilities, and one that explains the healthcare service gap and barriers to care for individuals with developmental disabilities. Suggested content includes the Center for Disease Contraol and Prevention's factsheets on Developmental Disabilities (Centers for Disease Control and Prevention, 2019), The International Association of Forensic Nurses' Vision of Ethical Practice (International Association of Forensic Nurses, 2008), and the Pennsylvania Coalition Against Rape's Techical Assistance Bulletin (Pennsylvania Coalition Against Rape, 2011).
2. Three modules featuring guest speakers from Omaha metro area agencies and organizations that provide services and resources to individuals with developmental disabilities. Suggestions include speakers from the Munroe Meyer Institute, Arc of Nebraska, PTINebraska, and Nebraska Family Support Network
3. One module featuring a guest speaker from Omaha metro area legal services to discuss disability rights, power of attorney, and guardianship.

4. One module featuring a panel of individuals with developmental disabilities who are survivors of sexual violence, and their caregivers if needed, to share their experiences. This panel could also be formed and introduced by the SANE participants for their organization's medical rounds.
5. One module as a wrap up and closure session providing an opportunity to reflect, discuss, brainstorm, build contact lists, initiate dialogue, exchange ideas, information, and experiences, grow support networks, and complete post-evaluations

Expected outcomes

The expected outcomes of this research is the development of a rigorous, evidence based, useful training program for Sexual Assault Nurse Examiners to improve health outcomes for individuals with developmental disabilities in their care. This training intervention will increase awareness amongst Omaha metro area forensic nursing staff of individuals with developmental disabilities, work to close the gap in healthcare and services this population experiences, and build capacity to assess population needs, assets and capacities that affecting this community's health. Implementing the training program will promote understanding of the importance of ongoing education and utilization of current resources for optimal patient care, and build a system of interdisciplinary communication, support, and confidence building for SANEs caring for patients with developmental disabilities. Understanding that education and increased interactions with individuals with developmental disabilities are proven pathways to building awareness, knowledge, and positive attitudes in the healthcare community (Shakespeare & Klein, 2013), SANE/SART teams will develop and maintain cultural intelligence, becoming leaders and self-reflective educators themselves.

Increased interdisciplinary and interagency communication will also provide support and learning opportunities as staff exchange ideas, experiences, and innovations. Navigating the complex world of disabilities challenges caregivers and healthcare staff alike to adapt resources to their needs, think creatively, and have a collaborative mindset to achieve the safest care and best outcomes for each individual. Additionally, patients will report better interactions and experiences as they feel staff are listening to them and acknowledging their concerns, and show a desire to adapt to and meet their needs (Smith, 2009).

Chapter 4

Discussion and Recommendations for Sustained Success

Strengths and limitations

Strengths of this research include direct conversation with Omaha metro area SANE/SART directors, as well as access to service line providers and disability resources at the Munroe-Meyer Institute. The Munroe-Meyer Institute's development of a transdisciplinary clinical program demonstrates a commitment to addressing women's and sexual health for individuals with developmental disabilities. The resolve of all involved organizations and agencies to provide trauma informed, culturally competent patient care while also supporting and nurturing growth and development in their staff will provide the best opportunities for curriculum building, communication, awareness, and ongoing education.

Limitations of this research are a small number of interviews and a limited amount of prior research in forensic nursing interactions with individuals with developmental disabilities. Both these limitations show an opportunity for future projects and research. Because of these limitations, any agency or organization that further builds a curriculum should maintain thorough documentation of their process for future research use and investigations.

Plans for the training program's sustainability

Using the presented data and research to build a curriculum that is useful, engaging, and sustainable for an agency or organization will require innovation and relationships with the involved stakeholders. As previously discussed, building a training program for SANEs should be an inclusive and multidisciplinary process, with input from nursing and allied health staff, advocates, and individuals with developmental disabilities and their caregivers.

The training program and curriculum should utilize multifaceted teaching strategies that incorporate self reflection and information processing (Duggan, Bradshaw, Carroll, Rattigan, & Altman, 2009) for best outcomes.

In growing and developing a sustainable training program, agencies and organizations should be sensitive to the complex and stressful nature of forensic nursing, and use educational modules and sessions as opportunities for learning, decompression, networking, and support. The common goal of providing the best possible patient care should be clearly stated and accessible in training materials. Additionally, curriculum modules should accommodate a variety of learning styles and allow for flexible scheduling and modes of attendance. As each agency and organization designs, customizes, and implements their training programs, they will be able to document completion of education modules. This will add needed data to internal and external quality improvement implementation and system informatics at each location, helping to defend and justify the education and development budgetary expenses.

Recommendations for Future Use, Development, and Research

This planning and research for future training programs was developed for the University of Nebraska Medical Center's College of Public Health MPH capstone course in collaboration with Anne Woodruff Jameson, from the Munroe-Meyer Institute Department of Physical Therapy. The needs assessment was developed with the help and cooperation of the SANE/SART teams at CHI Health, Methodist Health, and The Women's Center for Advancement in Omaha, Nebraska. The data presented may be used to add to their knowledge

base of their patient populations, as well as develop educational topics and programming, in keeping with each agency's and organization's strategic plans and visions.

Areas for future research are myriad. As healthcare providers diligently work to be more inclusive and patient centered, there is an ongoing need for research regarding underserved, vulnerable, and underrepresented populations. Researchers can focus their investigations specifically to how an area affects individuals with developmental disabilities: providing trauma informed care, improving resources and accessibility, and understanding the impact of sexual and domestic violence. Similarly, the lens can be focused outwards to community and systems levels: understanding the barriers in developing accessible and appropriate resources, discussions amongst service providers, including law enforcement and legal services about advocating for individuals with developmental disabilities and trauma informed communities, and health disparities or barriers to care within health systems for individuals with developmental disabilities seeking trauma services.

With forensic nurses as one component of the overall healthcare system, understanding each community's needs and available resources will lay the foundation for new comprehensive, patient centered training programs. As providers increase communication amongst healthcare teams and ensure both patients and providers have support and education, they will bring about positive change to eliminate the service gap for individuals with developmental disabilities.

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Biography

Emily Blanchard is a registered nurse and graduate student at the University of Nebraska Medical Center's College of Public health in Omaha Nebraska. She has worked in Maternal Child nursing for 15 years in acute medical settings and academic health care centers, is trained as a Sexual Assault Nurse Examiner and disability advocate, and is completing a Masters in Public Health with a focus on Maternal Child Health.

Establishing program competencies, and goals

This training program will utilize the Maternal Child Health Leadership Competencies, developed by the Health Resources and Services Administration's Maternal and Child Health Bureau (available in full at https://mchb.hrsa.gov). This comprehensive list was designed to describe the skills, values, knowledge, and characteristics needed to cultivate and support successful maternal child health leaders. The intention of the Health Resources and Services Administration is for the competencies to be used, "as a framework for training objectives for MCH training programs, for the measurement and evaluation of training for MCH leadership, and to cultivate, sustain, grow, and measure leadership within the current MCH workforce" (https://mchb.hrsa.gov). These competencies and their associated expected outcomes in the SANE training program are as follows:

1. MCH Knowledge Base/Context	Respect and understanding of the individual with developmental disabilities as a member of a vulnerable population impacted by trauma
2. Self Reflection	Incorporation and normalization of individualized, evidence based sexual and reproductive healthcare services for all individuals with developmental disabilities
3. Ethics	Holistic, trauma informed healthcare adapted for individuals with developmental disabilities
4. Critical Thinking	The SANE/SART team's knowledge of trauma informed care and their own role in providing the desired amount of assistance to the individual, their families, and caregivers as they grieve and process their trauma
5. Communication	Increased communication and exchange of information between SANE/SART teams and their multidisciplinary partners in the Omaha Metro area
6. Negotiation and Conflict Resolution	Keeping the focus on patient centered, patient guided care to promote increased trust and sense of security and safety for patients with developmental disabilities during interactions with SANE/SART teams and associated providers and teams

7. Cultural Competency	Omaha Metro area SANEs supported and educated in disability rights, terminology, and resources, and enabled and assisted to be strong disability advocates and partners
8. Family-Professional Partnerships	Connections, networking, and support for individuals with developmental disabilities, their families, and caregivers
9. Developing Others Through Teaching, Coaching, and Mentoring	Reliable and confident communication and exchange of information between learners and teacher/coaches/mentors to learn to best serve the individual with developmental disabilities and their unique needs
10. Interdisciplinary and Interprofessional Team Building	Providers and patients work as a team for the safest and best healthcare outcomes
11. Working With Communities and Systems	SANE/SART member enabled and assisted to be strong disability advocates and partners in the Omaha metro area
12. Policy	Established, effective policies and advocacy strategies using appropriate language and terminology

Incorporating the leadership development process of these competencies into development of the SANE training program allows for new knowledge, skills, and experiences. Starting with a focused lens on self, to impacts on others, and finally to understanding and interaction with their wider community, these competencies plan the intentional, deliberate growth of the trainee. This additionally provides an objective, evidence based framework each participating health organization or agency can use to further build and develop their individual programs to maximize sustainability.

Plans for assessments and evaluations

This training program will utilize the accompanying competency assessment for the Maternal Child Health Leadership Competencies, available at https://www.mchnavigator.org. These assessments are free of cost, online, and available to the public. Individuals or groups

wanting to complete the assessments register and create an account, then complete a multi-step evaluation: full assessment, individual assessment, receipt of an individualized learning plan, and a (if desired and applicable), a group customized report. The assessment tallies evaluations of knowledge and foundational and advanced skill sets for each of the twelve competencies on a scale with answers of none, low, medium, and high. Completion of the assessment can be tailored to the best use by the participant, such as utilizing in a pre and post training setting, longitudinally throughout ongoing curriculums, or to identify and address the biggest or most urgent knowledge gaps.