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## **Addressing Sexual Violence Against People with I/DD: Blueprint for an Empowered Future**

The Arc of New Jersey has worked tirelessly over the years to empower people with intellectual and developmental disabilities (I/DD) in their homes, workplaces and communities. As important conversations are happening in the boardroom and around the kitchen table, we *must* be part of the conversation and ultimately, the solution.

People with I/DD are seven times more likely to be the victim of a sexual assault than a person without disabilities.<sup>1</sup> While it can be hard to face a painful issue like sexual violence in our community, we have an obligation as family members, self-advocates and professionals, to ensure a positive life for people with I/DD, and that means taking on this difficult issue. In this time of the #MeToo Movement, years of Department of Justice reports that identify high numbers of victims, and media reports that capture people's stories, the unique challenges facing people with I/DD must not be overlooked. The Arc of NJ has been at the forefront of these issues for many years and we feel that the time is right, and we want to make the most of this opportunity to make positive, lasting change.

On June 14, 2018, The Arc of New Jersey hosted a Leadership Summit, bringing together stakeholders in New Jersey who are committed to ending sexual violence and/or work in the field of I/DD, and who could provide real solutions to preventing future sexual violence and redressing the abuse of the past. Summit participants represented the following disciplines:

- People with I/DD
- Family members
- Direct Support Professionals
- Service providers/administrators
- Law enforcement
- Prosecutors
- Victim-Witness Advocates
- Sexual Assault and Domestic Violence professionals
- Social services professionals – disability/mental health
- Health care providers
- Disability advocates
- Sex educators
- Government officials

Following a keynote address by Leigh Ann Davis, Criminal Justice Initiatives Director from The Arc of the US, and James Meadours, self-advocate and social activist, participants were divided into seven working groups and proceeded to discuss a number of issues. Each group developed a series of goals and objectives which were reported back to the entire group. The summit findings form the basis of this White Paper that The Arc of New Jersey will use as a blueprint for enacting change.

## **What is Sexual Violence?**

Sexual violence includes sexual assault and sexual abuse. Implicit in the act of sexual assault is the crime of assault. Sexual assault is a crime of violence, anger, power and control where sex is used as a weapon against the victim. It includes any unwanted sexual contact or attention achieved by force, threats, bribes, manipulation, pressure, tricks, or violence. It may be physical or non-physical and includes rape, attempted rape, incest and child molestation, and sexual harassment. It can also include fondling, exhibitionism, oral sex, exposure to sexual materials (pornography), and the use of inappropriate sexual remarks or language.

Sexual abuse is similar to sexual assault, but is a pattern of sexually violent behavior that can range from inappropriate touching to rape. The difference between the two is that sexual assault constitutes a single episode whereas sexual abuse is ongoing.

Sexual violence occurs in the home (sexual abuse of children, sexual assault by partners or relatives), outside the home (in community programs), on the job, on transportation systems (while riding the bus or a taxi) and virtually anywhere.<sup>1</sup>

Sexual violence is a serious and widespread problem.

- About 1 in 3 women and nearly 1 in 6 men in the United States have experienced some form of contact sexual violence during their lifetime.<sup>2</sup>
- People with I/DD are sexually assaulted at seven times the rate of people without disabilities.<sup>3</sup>

Sexual violence occurs when someone is forced or manipulated into unwanted sexual activity without their consent. Consent means permission for something to happen or agreement to do something. A person may choose not to consent to sexual activity or be unable to consent due to fear, age, illness, disability, and/or influence of alcohol or drugs.

Anyone can experience sexual violence, including children, teens, adults, and seniors. Those who sexually abuse can be acquaintances, family, trusted individuals, or strangers; of these, the first three are most common. The majority of perpetrators are someone known to the victim. Approximately 7 out of 10 sexual assaults are committed by someone known to the victim, such as in the case of intimate partner sexual violence or acquaintance rape.<sup>4</sup>

## **Sexual Violence and Prevention**

The good news is that prevention is possible, and it's happening.

With the country focused on this very important issue, we have an unprecedented opportunity to improve understanding and change behaviors. The time to rally our communities and the broader public is now. Individuals, communities, and the private sector are already successfully combating the risk of sexual violence through conversations, programs, policies, and research-based tools that promote safety, respect, and equality. By promoting safe behaviors, thoughtful policies, and healthy relationships, we can create safe and equitable communities where every person is treated with respect.

This White Paper creates an outline for state and local efforts to prevent sexual violence against people with intellectual and developmental disabilities (I/DD), with a specific focus on primary prevention. Primary prevention refers to preventing sexual violence before it occurs.<sup>5</sup> The plan recognizes that a comprehensive approach also includes secondary and tertiary prevention. Secondary prevention emphasizes an immediate response after sexual violence occurs, such as hotline services and advocacy to improve medical, legal, and mental health services for victims. Tertiary prevention emphasizes long-term survivor services to support the

process of recovery, such as counseling services and support groups for survivors, and sex offender treatment and monitoring.<sup>6</sup>

Collectively, these efforts aim at creating a world free of sexual violence.

### **Primary Prevention Efforts**

In order to engage in successful primary prevention, we must take two approaches to address the root causes of sexual violence and to shift the culture of perpetration: changing social norms (i.e. common behaviors) and building skills.<sup>7</sup> By mobilizing communities to challenge these norms and develop skills to address risk factors for sexual violence, we will shift culture and create lasting change for a safer and healthier community.

The Arc of New Jersey proposes a number of strategies and activities to focus on primary prevention of sexual violence against people with I/DD. They are categorized under the broader focus areas of awareness, policy, education and support.

### **General Concepts**

Throughout the presentations and discussions at the Summit, attendees identified a number of overarching concepts that are critical to the success of any of the proposed activities. These include:

- The focus for all initiatives needs to be proactive as opposed to reactive.
- The focus should be on empowerment, rather than a focus exclusively on the aspect of sexual violence.
- Recognize that this is an issue which many people don't want to discuss at all, and this is particularly true when it concerns people with I/DD.
- The discussions and remedies should not blame any particular group but instead encourage everyone to do a better job at prevention, awareness, education and support.
- Recommendations need to focus on positive messages – what we should be doing as opposed to what we're not doing.
- Through a variety of educational efforts, change the public perception that this issue is someone else's responsibility.
- The overarching focus should be on changing cultural norms around sexuality, encouraging and promoting healthy sexuality in all its forms.
- Focus on empowering people with I/DD to be leaders in this movement.

### **Awareness**

Building on the powerful voices that have emerged following the #MeToo and Time's Up movements, The Arc can push the conversation forward and encourage individuals to speak up and use their voice to promote safety, respect and empowerment toward ending sexual violence against people with I/DD. While a campaign alone isn't enough to solve the serious, widespread issue of sexual violence, it is a potent reminder that we can change the culture through the things we say and do every day.

The goal of a campaign is to raise public awareness about sexual violence, educate communities on how to prevent it, and bolster prevention efforts throughout the year. In addition to publishing toolkits for individuals and organizations to plan and implement a campaign in their local communities, resources can be developed on specific topics such as sexual harassment, bystander intervention, sexual violence prevention, the importance of consent and respect, and supporting survivors.

Components of the campaign could include:

- Design a model similar to the R-word campaign to promote safety, respect, and equality to stop sexual violence before and as it happening. Ensure that people with I/DD are included in, and are given the support to lead, every aspect of any campaign.
- How individuals can embrace their voices to show their support for survivors, stand up to victim blaming, identify and end humor that directly or indirectly encourages criminal sexual behavior such as, “rape jokes”, correct harmful misconceptions, promote an understanding of consent, and practice healthy communications with people with I/DD.
- How to utilize the attention the campaign generates as an opportunity to energize and expand prevention efforts throughout the year.
- Incorporate social media including developing a hashtag, theme, slogan and symbol.
- Create resources, tools, graphics, planning guides, and make them available to the public. Establish a hotline for the public to call for more information. Develop PSAs that can be broadcast as well as shown before movies/TV/cable.
- Create media kits that include statistics, a guide to responsible reporting, story ideas and opportunities for interviews. The goal is to make the media a partner in the prevention and awareness effort.
- Create materials to address societal perceptions about people with I/DD, including the perception of “otherness”. Examine factors that isolate people with I/DD, and develop materials that create a culture of respect for people with I/DD that work to eliminate isolation and barriers between communities
- Identify and examine specific issues which lead to heightened risk factors for people with I/DD, such as the lack of safe transportation alternatives or “trained compliance” with staff or authority figures, and develop ways to shed light on these issues, increasing safety and preventing abuse in these situations.
- Utilize non-traditional avenues of information dissemination in order to reach populations who may not access materials and resources through typical awareness campaign models. One example would be to include information in the school lunch form packages which are sent to families of school age children, making them aware of the issue and giving them tools to discuss the issue in an age appropriate manner with their children. Another example would be to create programs which can be shared with and supported by faith-based communities.
- Utilize existing parent-to-parent forums or e-mail groups to promote this initiative and share resources.
- Utilize existing self-advocacy forums and e-mail groups to promote the initiatives, share resources and educate the community.
- Participate in existing law enforcement/community programs such as “Annual National Night Out” Programs and create new opportunities to engage with local law enforcement in positive ways.

In addition:

- County Task Forces on Healthy Sexuality should be created to include a variety of stakeholders in the discussion of awareness, prevention and outreach. Participants could include: health care professionals, community organizations, therapists, PTAs, schools, faith-based organizations, service providers, sex educators, etc.
- Develop a Speakers’ Bureau which would be available to present workshops on sexual violence against people with I/DD to various stakeholder groups. Develop sexual abuse prevention and support cross-training with relevant individuals and agencies, such as NJCASA, youth sports organizations, colleges, victim-witness organizations, SANE nurses, etc.
- Utilize resources within all applicable Departments in State Government (including, but not limited to: DHS, DCF, DOH, DOE, etc.) to disseminate information and act as contact points for referrals and

resources. For example, Special Child Health Services (SCHS) case management could be an excellent entry point of contact for information, resources, referral, and reporting.

- Develop a needs assessment to look at risk factors. Widely disseminate the needs assessment tool across stakeholders. Analyze data from the assessments and develop training based on outcomes. Involve community organizations, therapists, PTA, and any other community group which may interact with people with I/DD in the identification of risk factors and the resources available to prevent abuse and/or support victims of abuse. Include health care providers in the identification of risk factors and possible abuse. Ensure health care providers have the necessary information to facilitate reporting and referrals to resources.

## Policy

For 70 years, The Arc of New Jersey has been advocating for children and adults with I/DD and their families. Our advocacy includes any issues of importance to people with I/DD, their families, support staff and caregivers, and provider organizations. Our staff and constituents testify before state legislative committees, contact legislators, and track bills that affect people with I/DD, families, and communities.

Additionally, The Arc attends meetings of state and national agencies to make the voices of people with I/DD heard in discussions about issues and activities that affect their daily lives. People with I/DD, their families and caregivers play a vital role in guiding our public policy work and we actively seek their input, ideas, and involvement through every step in the process.

Our advocacy has - and must - include all aspects of sexual offenses against people with I/DD on the state and national level, and focuses on victim services, sex offenses, the criminal justice system, technology, prevention and many other issues. The Arc monitors, tracks and advocates on policy, regulation and law addressing a broad spectrum of categories such as sex offenses; victim rights and investigations; protection orders; confidentiality, privacy, and privilege; mandatory reporting and investigation; and rape shield.

In addition, The Arc seeks to take action on specific policy issues affecting people with I/DD which would have an impact on decreasing risk factors for sexual offense victimization. These include:

- Currently, students in special education in New Jersey are automatically opted out of health/sex education classes. The Arc proposes an amendment to special education regulations so that students in special education are automatically included in health/sex education classes with the provision to opt out as appropriate. In the event that an opt out option is exercised, the student's Individual Education Plan needs to address other ways that healthy sexuality will be addressed with the student.
- Review current policy and regulation regarding the New Jersey Teen Prevention Education Program (Teen PEP) and, if appropriate, amend to require that schools offer the program to students with I/DD in special education. While not appropriate for every student, Teen PEP should be offered to students with I/DD who can actively participate.
- Create a pilot project within a select county/counties to have a court designated to handle cases involving crime victims with disabilities. An option could be the creation of a statewide Disability Response Team (DRT) made up of a multidisciplinary group including court staff, prosecutors, victim-witness service providers, sexual assault program providers etc., which could be deployed to the county to assist in individual cases, provide referral information to appropriate agencies in each county and conduct training.
- Work to codify common language and training regarding sexual assault, prevention, response and the legal process throughout the human service, legal and educational systems. The purpose would be to create standard language so that individuals with I/DD and their families would be better able to

recognize when they are at risk, when a crime has been attempted/committed, how to report a crime and would help to prepare them to testify.

- Review and amend court rules to determine changes that ensure compliance with the Americans with Disabilities Act (ADA) in the court room setting and support people with I/DD in testifying in court proceedings. This could include alternate means of communication, the assistance of a support person, adapting locations, and/or modifying physical settings. Work with existing ADA coordinators within courtrooms to support these activities.
- Review current laws and regulations regarding the qualifications and screening of caregivers (paid and unpaid) as well as procedures for reporting incidents of abuse, abuse investigations and policies pertaining to abuse registries. Work with the relevant procedural entities to amend as needed.
- Review regulations to ensure that abusers are held accountable for abuse of people with I/DD and also for keeping people with I/DD safe from abuse. Increase the penalties for abuse of an individual with I/DD.
- Examine areas that lead to increased risk factors for people with I/DD and consider regulations to minimize risk factors. This could include such actions such as requiring surveillance cameras in vans and in programs for people with I/DD, and/or increasing staffing ratios or adding aides in programs serving individuals with I/DD (including transportation).
- Review the Prison Rape Elimination Act of 2003 and determine if elements of PREA are appropriate to replicate for people with I/DD.

## Education

Healthy sexuality and sexual abuse prevention education are important in raising awareness, eliminating stigma, changing societal views, and empowering individuals to advocate for themselves and others. Education curricula need to be multi-dimensional, addressing issues and concerns from different perspectives including age, race, disability, ethnicity, socio-economic status, religion, sexual orientation and culture. It also needs to focus on different populations such as individuals with I/DD, families, caregivers, support staff, community organizations, health care professionals, law enforcement, etc.

One methodology is to develop toolkits for a variety of stakeholders including: parents, individuals with I/DD, schools, DSPs, providers, etc. which assist each group in recognizing the issues and where to go for more information. In addition to creating toolkits and other curricula, it is important that all training is not only developed but becomes an ongoing, mandatory training over time.

Other more specific educational curricula should be developed which contain the common core concepts, including but not limited to:

- Promoting self-worth
- Fostering empowerment
- Identifying and reducing risk factors
- Explaining that sexual abuse is linked to bullying
- Identifying what makes up healthy sexual relationships
- Explaining sex literacy
- Understanding boundaries
- Defining sexual harassment
- Providing prevention training
- Defining consent, how it is given and acknowledged, and the risks involved with consent
- Promoting self-advocacy

- Understanding the concept of implicit bias
- Explaining that yes means yes and everything else means no

These trainings would be developed for:

- Training for students and adults with I/DD which would include:
  - A section in the IEP/ISP dedicated to sex education and awareness
  - Education on healthy expressions of sexuality
  - Age appropriate education for school age children starting at pre-K
  - Promoting self-advocacy from an early age
  - Utilizing flexible approaches, language and focus for different ages and levels of disability
  - Adoption of a lifespan curriculum
  - Focusing on empowerment, including the concepts of staying safe, saying no, and speaking up
  - Teaching the difference between abuse and romantic involvement
  - Ensuring that people with I/DD who are non-verbal receive particular attention and are given the necessary tools to communicate and participate in trainings
  - Utilizing age appropriate and disability appropriate materials, books, videos, etc.
  - Incorporating peer to peer training
  - Ensuring social media literacy
  - Exploring and implementing inclusive communities and opportunity for socialization that is safe and appropriate
  
- Trainings for parents and family members of people with I/DD that would include:
  - Overcoming family members' denial and reluctance to discuss the issue of sex and sexual abuse
  - Education regarding the dangers and risk factors
  - Education on how to talk to their family member with I/DD about sex and sexual abuse
  - Incorporating faith-based communities to assist in changing cultural norms and helping families and people with I/DD address healthy sexuality
  
- Trainings for DSPs/Staff that would include:
  - How to recognize risk factors and signs of abuse
  - How to recognize "grooming behavior" on the part of abusers
  - Understanding healthy sexuality
  - How to identify and overcome personal biases regarding sexuality
  - Awareness that DSPs may also be survivors of sexual violence and how that impacts their willingness or ability to support people with I/DD who are also survivors.
  
- Trainings for law enforcement that would include:
  - A mandate for a series of trainings about people with I/DD, risk factors for sexual violence against people with I/DD and prevention strategies
  - Opportunities for law enforcement to "meet and greet" people with I/DD outside crisis settings, i.e.: a supported employment program for people with I/DD to work in law enforcement agencies or "junior police academies" that accommodate children and teenagers with I/DD
  - Offer continuing legal education classes for state, county, and municipal prosecutors on dealing with victims and witnesses with I/DD, including overcoming witness issues regarding credibility and reliability, and providing for any necessary accommodations in court house facilities

For all of the educational curricula, individuals with I/DD and their families should be involved in the development of training as well as delivery of the training itself. Additionally, a wide variety of existing training curricula such as Family Life And Sexual Health (FLASH), [ESCAPE-Now](#), TEA Consent videos, etc., should be reviewed and utilized as appropriate.

## Support

The concept of support is critical on many levels in primary, secondary and tertiary prevention of sexual violence against people with I/DD. Support can be interventions which are established for people with I/DD, families, caregivers or organizations.

Models of support for families could include developing and implementing resiliency programs, with the focus on awareness and elimination of risk factors, as well as strengthening a family's coping mechanisms. Employee Assistance Programs (EAPs) could be engaged to identify caregivers of individuals with I/DD, offer support and refer caregivers to community resources.

For the greater community, it is imperative that trust, transparency, and collaboration exist between State agencies, and with and among community organizations. This will work to create a more responsive and proactive system of prevention as well as a comprehensive support system for individuals with I/DD. It is also critical to develop a culture of safety through all service systems. Specific activities could include creating a repository of health and sexuality resources that is accessible to the general public as well as State agencies and community providers.

Other support activities could include:

- Create a widely-publicized hotline that makes it easy for individuals to report sexual abuse as well as concerns about increased risks to an individual with I/DD.
- Develop a model of “safe” places and persons to talk to so that people with I/DD, caregivers and other concerned parties have an easily identified and accessible resource for information and support.
- Develop and implement a long term longitudinal study to examine risk factors, interventions and outcomes. Include pre and post intervention assessments. Conduct 1, 3 and 5 year studies.

## Other Considerations

Participants at the Summit also made the following recommendations:

- As campaign activities are researched, identified and considered, conduct a survey about what is happening in other states to gain perspective and ideas.
- Reconvene the Partners in Justice multidisciplinary group, chaired by The Arc of New Jersey, to help implement the goals of the White Paper.
- There is a critical need to improve access to health care for people with I/DD. In addition, physicians, nurse practitioners, and nurses need to be trained to overcome low expectations of people with I/DD and the perceived lack of credibility.
- Address the Direct Support Professional (DSP) staffing crisis. Summit participants felt that DSPs play a unique and critical role in the lives of people with I/DD and sexual abuse prevention efforts. Factors to consider in addressing the DSP crisis include:
  - The need to professionalize the field
  - The importance of mentoring for DSPs
  - The need to negate the “Bystander effect” where individuals don’t feel comfortable intervening



- The need to address issues which arise when individuals with I/DD view staff as family, thereby creating blurred lines of appropriate behavior
- The need to address perceptions that caregivers are “wonderful people” and are not capable of abuse
- The need to address the issues of individual privacy vs. caregiving
- The need to emphasize responsibility and the concept that prevention and safety is every caregiver’s responsibility

## **Conclusion**

The Leadership Summit on Sexual Violence Against People with I/DD resulted in many excellent action steps to address sexual violence, most through primary prevention efforts. However, in order for the blueprint to be successful, these action steps must be prioritized, and concrete, outcome-based plans must be developed. Plans must include goals and objectives, timelines, and the challenges to completion. Also, each of the action steps will require additional resources including staffing, funding and collaboration with other entities. These resources must be identified and secured so that plans have the necessary support to be successfully implemented.

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