



A team-oriented approach to pregnancy prevention in exceptional populations.

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Contents

Executive Summary	1
Program Rationale	3
Needs Assessment	10
Mission Statement, Goals, and Objectives	15
Theoretical Basis	17
Implementation	21
Program Resources	24
Program Marketing	27
Budget	28
Evaluation	30
Contact Information	31
References	32
Appendix A- Project TEASE	38
Appendix B- Intellectual Disability and Sexuality	44
Appendix C- Disability Statistics in Dillon County	52

"Can unplanned pregnancy in women with IDD be prevented through interdisciplinary team intervention?"

Executive Summary

Pioneer is a team-oriented approach to unplanned pregnancy prevention in exceptional women with intellectual and developmental disabilities (IDD) living in Dillon County, South Carolina. This program is the first of its kind in the southeastern United States, and was inspired and designed as an undergraduate research project, and as a daughter program of Project TEASE (see appendix A for more information on Project TEASE). Pioneer hopes to build a unique interdisciplinary team consisting of researchers, clinicians, personal care aides, community-based organizations, and clientele to refine and evaluate Pioneer within a clinical environment.

Pioneer will provide, assess, and evaluate sexual and reproductive health (SRH) training for clinical staff in the treatment and care of women with IDD, from the ages of 13-25. This program represents opportunities to address a crucial, yet elusive clinical question in the sexual and reproductive care of women within this exceptional population: Can unplanned pregnancy in women with IDD be prevented through interdisciplinary team intervention?

Women with IDD have significantly less access to preconception, prenatal, and sexual healthcare; compounding risk factors for injury, abuse, neglect, and exploitation; medical conditions which, when combined with contraction of a sexually transmitted disease (STI), may produce a higher likelihood of comorbidity; physical and economic barriers to healthcare access; challenges with societal stigma in relation to their sexual health needs and practices; and exclusion from research that could contribute to evidence-based practice for SRH in their population (UNFPA, 2009). In addition, healthcare workers are rarely prepared for the needs of those with disabilities, as they may lack knowledge of sex practices that are unique to this population, and are often not equipped with sufficient resourcing of services, support tools, and educational curriculum tailored to women with IDD (WHO, 2009).

Pioneer will target education for clinical healthcare workers and patients with IDD in a three-phase program to address all of the above-mentioned barriers to care that contribute to the overrepresentation of women with IDD in unplanned pregnancy. This program plan features Phase I, which will concentrate on training for clinical site staff in providing appropriate sexual and reproductive health care for their female patients with IDD. Phase II will encompass the provision, implementation, and surveillance of clinical care to women between the ages of 13-25, following clinical site staff training. Phase III will involve a complete data analysis of the quality and efficiency of the program implementation for use in research, advocacy, and

subsequent use in other populations with disabilities, as well as similar regions affected by unplanned pregnancy.

As data is lacking or, in some cases, non-existent in the SRH care for those with disabilities, Pioneer enables a significant improvement in surveillance and data acquisition, as well as evidence-based clinical practice in the realm of SRH care for this exceptional population. There are global implications for the implementation of a project such as Pioneer, a potential front-runner in exceptional clinical care: The World Health Organization (WHO) estimates that 80% of those with disabilities are living in developing countries, although other sources may grant an estimate as high as 25% of the world's population. Although people with disabilities constitute a considerable portion of the population, they are often hidden away and secluded from social interaction. This invisibility contributes to the lack of inclusion in policies and programs, as well as education and access to sexual and reproductive health care services. After implementation, Pioneer will be able to contribute the expertise of a successful SRH program that is tailored specifically to the needs of women with IDD and a curriculum that is created upon the experience of clinical site staff with the assistance of an interdisciplinary team that has years of proficiency and competence in working with this population.

Risk management will be balanced with the opportunities stated above in a time-efficient, cost effective manner, in accordance with best practices. The risks involved are minimal, but the benefits have the capacity to work within the preventative health structure of the Affordable Care Act and make a tangible improvement on the economic and health well-being of any community.

Morgan S. Varn
Executive Program Director
April 24, 2016

Program Rationale

- WHO estimates that 10% of any given population is living with a disability.

Women with disabilities have a higher incidence of:

- Gender based violence (GBV)
- Medical conditions which, when combined with contraction of an STI, may produce a higher likelihood of comorbidity (the presence of two or more conditions)
- Significantly less access to preconception, prenatal, and sexual healthcare
- Compounding risk factors for injury, abuse, neglect, and exploitation
- Challenges with societal stigma in relation to their sexual health needs and practices
- Physical and economic barriers to health care access
- Less opportunity for reproductive and sexual health information that is tailored to the needs of their disability in school, at home, and in health care settings
- Exclusion from research that could contribute to evidence based practice for SRH in their population (UNFPA, 2009).

People with disabilities, in relation to their sexual and reproductive health needs, face many societal barriers including:

- The social reinforcement of the "medical model" of care and education
- A predominantly heteronormative, orgasmocentric view of sexuality
- Higher likelihood of being reported for sexual abuse against their own peers because their sexual acts are more likely to be public, and more likely to be seen as deviant by onlookers
- Less access to appropriate learning aids about SRH due to strict classroom guidelines in sex education

- Lessened opportunity for experience in relationships than their peers due to societal beliefs and customs about relationships with persons with disabilities, leading to lower levels of self-efficacy and negotiation skills
- Victimization by those who have contracted HIV/AIDS, due to the belief that intercourse with a virgin may remove the virus
- The belief that the sexuality of persons with disabilities is often seen as either non-existent or deviant
- Underrepresentation in social and political participation in the creation of policies and laws that are reflective of the needs of people with disabilities (UNFPA, 2009).

People with disabilities should have equal rights to:

- Freedom from discrimination (ADA National Network, n.d.; United Nations, 1948, art. 2)
- Freedom from inhumane or degrading treatment (United Nations, 1948, art. 3)
- The right to marry and found a family (United Nations, 1948, art. 3)
- The right to a standard of living adequate for health and well-being (United Nations, 1948, art. 27)
- Access to education that prepares them for independent living
- Creating laws, policies, and curriculum that reflects the health needs of their population.

It is difficult to find data exclusive to the population with disabilities regarding SRH, in both primary and secondary sources (UNFPA, 2009). Often, the data published about women with disabilities which would quantify the frequency and nature of their sexual relationships demonstrates an inconsistency in methods, includes small sample sizes, differs in environment (institutionalized or non-institutionalized) or diagnoses, and uses divergent sources of data (Servais, 2006). In some cases, medical and scientific studies are not inclusive due to economic and social disparities, or mental capacity and lack of education often prevalent in populations with disabilities. Furthermore, the "invisibility" of those with disabilities, in part due to the lack of access and inclusion practices in health care, policy making, and social standing, often

negates the need to create proposals and methods that could make their inclusion in studies non-negotiable (UNFPA, 2009).

Proxy variables are necessary due to the lack of data about women with disabilities in SRH. The National Health and Nutrition Examination Survey (NHANES) 2011-2014, is unique in that it combines both health assessment surveys and laboratory results to assess the national health status. The NHANES methodology is such that by surveying a portion of the population, a valid and reliable snapshot of the entire national population is produced. By first filtering the entire population surveyed (n=10,000), including only those who have answered "yes" to the disability questionnaire, which asks about limiting difficulty in hearing, seeing, concentrating, walking, bathing or dressing, and doing errands alone, then further excluding those who were not able to answer the sexual health questionnaire, an accurate, viable dataset can be extracted (n=1,059). The resulting percentage of the self-reported disabled population, 10.59% (approximately 6% female and approximately 5% male), correlates with the WHO estimate of the entire global population.

Some of the societal perceptions that contribute to the condition of SRH in women with IDD is that this population is asexual and therefore not at risk for sexually transmitted infections or pregnancy. However, using the compiled NHANES data, of the 1,059 eligible participants, 869 (82%) answered "yes" to the question "Have you ever had vaginal, anal, or oral sex?" Additionally, after comparing the laboratory data, 30% of the males with disabilities, and 35% of the females with disabilities population demonstrated reactive hepatitis B surface antigen (HBsAG) results. Although hepatitis B is not typically considered an STI, it can be sexually transmitted, and it is the only STD that is completely preventable by vaccine. Both female and male persons with disabilities demonstrated positive results for chlamydia equally, (4/869) or 0.46%, and HIV (6/869) or 0.69%. Herpes simplex virus 2, or genital herpes, was present in both female and male segments, 8.4% for female and 2.6% for male.

Utilizing the NHANES data, an accurate idea of the sexual health practices of people with disabilities can be obtained, thereby creating easier access to information that can promote evidence-based practices for intervention.

The largest portion of participants in the NHANES data (answered “yes” to limiting difficulty in concentrating, bathing or dressing, and doing errands alone) could fall into those classified with “mild” or “moderate” intellectual disabilities, defined in the DSM-5 as

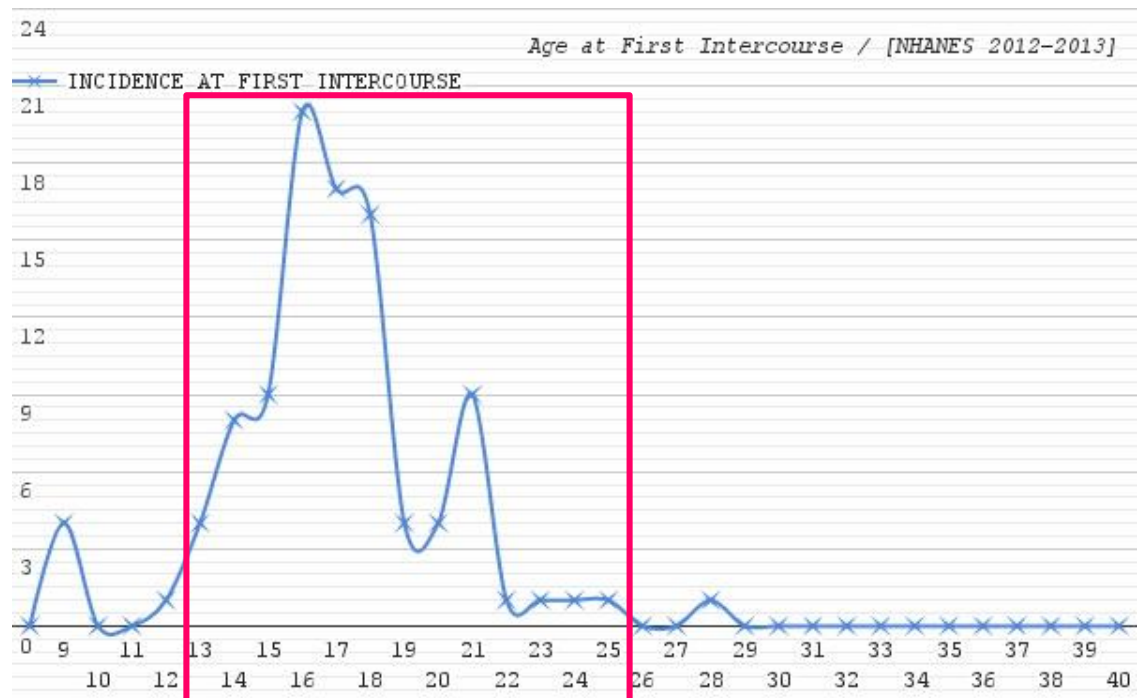
[a] disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains [...] in which the following criteria must be met: deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgement, academic learning and learning from experience, and practical understanding confirmed by both clinical assessment and individualized, standardized intelligence testing (Intellectual Disability [Intellectual Developmental Disorder], 2013).

Severity levels are measured by Intelligence Quotient (IQ) tests, scoring 55-70 for mild intellectual disability, and 40-55 for moderate IDD. In this way, some patients with Autism Spectrum Disorder (ASD) may be included, while some cases of acquired IDD, those who may have developed an ID by trauma or other means after the developmental period, will be excluded (for more information on intellectual and developmental disabilities, see appendix B).

Further, Dillon County, South Carolina has an unusually high proportion of persons with disability, most recent data stating that the percentage of the population with a disability is 20.7 (n=16,930) in the age range of 16-64 (for more information on disability statistics in Dillon County, see appendix C). Of the percentage in the age range of 21-64 (22.3%), 53.3% are female (InfoUse, 2007).

In the NHANES data assessment, a multimodal incidence of first intercourse indicates the most beneficial age group for providing sexual and reproductive care and education is 13-25, which coincides with the ages included in the sexuality education program offered by Able SC. In the interest of possible collaboration, as well as producing enough potential clients (Phase II) and clinical site staff (Phase I) for an appropriate evaluation, this age range was found to be most beneficial.

Age at First Incidence of Intercourse in Population of Disability



Persons with disabilities are often viewed as asexual, and therefore have no perceived risk for STIs or unintended pregnancy (UNFPA, 2009). In addition, health workers are rarely prepared for the needs of those with disabilities, as they may lack knowledge of sex practices that are unique to them, and are not equipped with medical devices, such as adjustable exam tables (WHO, 2009).

In the US, persons with disabilities are just recently advocating for inclusion, as previously, deinstitutionalization and normalization were the primary focus. Despite this graduation to inclusion, persons with disabilities are still excluded from sex education curriculum, health care access, and participation in policy-making (WHO, 2009). Stigmas and beliefs vary from culture

to culture, but the shift from the medical model, the dehumanizing practice of categorizing a person by medical diagnoses rather than personal attributes, is slow-moving. Additionally, beliefs held about being in a relationship with persons with disabilities are often based on societal views of "disability" as being synonymous with "broken," which create additional barriers to experiencing self-efficacy in a relationship.

For women with IDD, the lack of control, self-efficacy, and education can be demoralizing and removes the personal autonomy about decisions in sexuality to which every human has a right (UNFPA, 2009). There have been documented cases of rape and forced marriage, forced abortion or sterilizations, use of restraints, and medical experimentations on persons with disabilities, globally. The psychological damage caused by actions such as these, in combination with systematic marginalization and exclusion, is irreparable.

Barriers to health are spread across several ecological levels, including inter- and intrapersonal, organizational, community, and policy. Some of these are as follows:

- *Intrapersonal (Individual)*: knowledge/information, risk perception, skills (condom use, negotiation), physical health, overtly clinical perception of self, fear of stigma, self-efficacy, perceived social norms, empowerment, fear of embarrassment, gender and cultural beliefs about reproductive health knowledge, past negative experiences (WHO, 2009).
- *Interpersonal*: relationship power and equity, family/peer support and trust, relationship satisfaction, communication level and ability, interpersonal violence or sexual abuse, attitudes, beliefs and knowledge about sexual and reproductive health services from friends, family; misinformation from peers, disapproval from family (WHO, 2009).
- *Organizational (Institutional)*: provision of appropriate services, stigma (health care providers), access to in-house services, sufficient resourcing of services, support tools, education curriculum, regulations in assisted living facilities, disapproval from

health workers, geographical accessibility, inadequate counseling from health providers, lack of privacy (WHO, 2009).

- *Community*: lack of awareness, stigma, peer pressure, social norms (multiple partners, gender roles, condom roles, and community), loss of traditional support, conflicting information from health institutions and media, lack of organizations, lack of peer reviewed research, lack of data (WHO, 2009).
- *Policy*: access to services (transportation), cost of services/covered care, funding for appropriate intervention, education curriculum, public policy (medically accurate sex education), national policies on sexual and reproductive health, HIV/AIDS, lack of free services (WHO, 2009).

Although all of these issues deserve attention, Pioneer believes that focusing by focusing on the organizational and community ecological levels, the **primary level** of prevention could address the needs for availability of information, access to preventative health services, and proper training for health workers.

Needs Assessment

Narrowing the focus- Behaviors/factors related to behaviors

- Women with IDD have fewer sexual experiences than their non-disabled peers, demonstrate more negative attitudes towards sexuality, and demonstrate lower levels of self-efficacy in their own sexuality (McCabe & Holmes, 2013).
- Significantly limited conceptual processes, social skills, and practical adaptive skills, or skills required to negotiate one's daily tasks (Burgen, 2010).
- Women with IDD often demonstrate insufficient or incorrect sexual knowledge from peers or the media (CHANGE, 2010).
- Desire to "fit in" with peers causes women to mimic unsafe sexual behaviors.
- Previous negative experiences may be misinterpreted as normal behavior.
- Misconception of risks associated with multiple partners and lack of condom use.
- Communication level and ability.
- Fear of embarrassment for asking questions about a "dirty" topic.

Narrowing the Focus- Environmental Risk Factors

- Health promotion materials are often inappropriate (does not contain pictures, simple language), inaccessible (not readily available or offered by health professionals), or irrelevant (not tailored to specific health needs of women with IDD).
- Lack of services that provide SRH education for women with IDD.
- Limited public health surveillance to identify women with IDD who do not receive disability-friendly screenings, including mammography, and cervical cytology (Scheepers et al., 2005).

- Limited provisions for privacy in care settings prevents the ability to build therapeutic relationships with women with IDD, in order to discuss sensitive information.
- Limited training of clinical staff to meet the SRH needs of women with IDD.
- Discourse on SRH is minimized in comparison to other medical or health issues (McCabe & Holmes, 2013).
- Policymakers often underestimate the importance of inclusivity in SRH curriculum and materials included in policies for women with IDD (CHANGE, 2010).
- Transportation for access to contraceptives is lacking for women with IDD (Burgen, 2010).
- Interpersonal violence or sexual abuse.
- Family values and beliefs may conflict with individual's need for sexual health information to be provided by care staff, clinical staff, or family (McCabe & Holmes, 2013).
- Societal gender roles.

Narrowing the Focus- Risk Factors that Cannot Be Changed

- Genetic factors and environmental exposures contributing to predisposition to comorbid conditions (Scheepers et al., 2005).
- Time constraints contribute to nursing staff inability to provide sexual health information in clinical settings (McCabe & Holmes, 2013).
- Relationship power or equity.

Priority Analysis Matrix

	<i>More Important</i>	<i>Less Important</i>
<i>More Changeable</i>	<ul style="list-style-type: none"> • Insufficient or incorrect sexual knowledge. • Inappropriate, inaccessible, or irrelevant public health materials. • Lack of services. • No transportation. • Limited provisions for privacy in care settings. • Limited training of clinical staff. 	<ul style="list-style-type: none"> • Limited public health surveillance. • Time constraints in clinical settings. • Family values and beliefs. • Interpersonal violence or sexual abuse. • Desire to “fit in” with peers causes women to mimic unsafe sexual behaviors. • Previous negative experiences may be misinterpreted as normal behavior. • Misconception of risks associated with multiple partners and lack of condom use.
<i>Less Changeable</i>	<ul style="list-style-type: none"> • No autonomy in medical health choices. • Discourse on SRH is minimalized. • Policymakers underestimate the importance of inclusivity in SRH curriculum and materials included in policies. 	<ul style="list-style-type: none"> • Fewer sexual experiences. • Negative attitudes towards sexuality. • Lower levels of self-efficacy in their own sexuality. • Significantly limited conceptual processes, social skills, and practical adaptive skills. • Genetic factors and environmental exposures. • Societal gender roles. • Communication level and ability. • Relationship power.

Pioneer will focus on the following behaviors/risk factors:

- Inappropriate (does not contain pictures, simple language), inaccessible (not readily available or offered by health professionals), or irrelevant (not tailored to specific health needs of women with IDD) health promotion materials.
- Lack of services that provide sexual and reproductive health (SRH) education for women with IDD.
- Limited public health surveillance to identify women with ID/DD who do not receive disability-friendly screenings, including mammography, and cervical cytology.

- Limited provisions for privacy in care settings prevents the ability to build therapeutic relationships with women with IDD, in order to discuss sensitive information.
- Limited training of clinical staff to meet the SRH needs of women with IDD.
- Minimalized discourse on SRH in comparison to other medical or health issues

All of these factors could be included in workshops/ programs for preconception care for clinical staff, which is usually covered by disability insurance. With the advent of preventative care, rather than clinical treatment, partnered with the Affordable Care Act, funds may be available to create sustainable programs. Rather than trying to change sex education in schools or adult care programs which are often lacking in funds and staffing, clinical care settings hold societal prestige, the ability to monitor screenings and public health surveillance, and are bound by HIPAA laws, which may serve to protect the privacy of the individual.

What factors cause or influence the health behavior?

<i>Factor Type</i>	<i>Factor</i>	<i>Explanation of relationship with behavior</i>
<i>Predisposing</i>	<ol style="list-style-type: none"> 1) Communication level or ability of women with ID/DD and 2) Fear of embarrassment 	If 1, 2) a women with a disability is afraid to ask questions for fear of embarrassment, or is unable to communicate her needs, she may not receive answers to her questions.
<i>Enabling</i>	<ol style="list-style-type: none"> 1) Limited provision for privacy and 2) limited training for clinical staff about the needs of women with ID/DD 3) Inappropriate or lacking materials 	When there is 1) no privacy, staff may not be able build a relationship of trust, so that she would feel comfortable discussing sexuality, and 2) if the staff is not trained in working with women with ID/DD, or in discussing SRH, they may misinform or confuse her.
<i>Reinforcing</i>	<ol style="list-style-type: none"> 1) The traditional medical model of treatment and 2) Perceived more important medical concerns by medical staff 	The 1) medical model of treatment is normative in clinical care, and 2) staff may not consider that she is sexually active or has any interest in sex, and may only be concerned with treating current medical concerns.

Based on this information, the population most in need is that of **women with mild to moderate intellectual and developmental disabilities, between the ages of 13-25**, in the area of **sexual and reproductive health**.

For Phase I of this Pilot Project, Pioneer will focus on training **clinical site staff in working with this population to provide instruction on proper condom use during clinical visits**.

Mission Statement, Goals, and Objectives

Mission Statement

To prevent unplanned pregnancy in women with IDD, by providing access, clinical advocacy, and training about SRH needs to them, their families, and communities through the health care system.

Goals

Increase access to appropriate SRH care counseling for women with IDD and their families in clinical settings by:

1. Providing training for health care practitioners and their constituents about the SRH needs of women with disabilities.
2. Facilitating appropriate training curriculum and workshops for the SRH of women with disabilities.
3. Procuring necessary access including transportation, equipment, and teaching materials to assist clinicians with clinical SRH care for women with disabilities.

Formative Objectives

1. By January 1, 2017, program planners will have hired five trained special needs educators and/or social workers to facilitate and collaborate on training curriculum.
2. By March 1, 2017, program planners will have contacted health care practitioners, nursing staff, and personal care aides from the health center and surrounding clinical offices in Dillon County to obtain six tentative available dates for workshops and training conferences.

Learning Objectives

1. Upon completion of Phase I of the program, 90% of staff members will be able to successfully negotiate a clinical appointment with their patients with IDD, including providing necessary and appropriate materials, time spent with each client, and proper follow-up appointments, if required.
2. Upon completion of Phase I of the program, 90% of participating clinical site staff will be able to effectively counsel female patients with IDD about condoms and provide available options for SRH care.

Behavioral Objectives

1. After one year of participating in Phase II of the program, 70% of participating clients and patients will be able to identify condoms and their appropriate use, including demonstrating skill in the application of, and knowledge of when to use the contraceptive method.

Outcome Objectives

1. By 2020, the incidence of unplanned pregnancy in women with IDD, ages 13-25, in Dillon County, South Carolina will decrease by 30%.



Theoretical Basis

Social Cognitive Theory

Public health interventions involving women with IDD and their caretakers, families, or clinical team would be most effective because of the focus on self-efficacy, due to both the nature of their dependent relationships and the scope of these disabilities (McCarthy, 2010). Behavioral change using the social cognitive theory utilizes the reciprocity of the environment, interpersonal factors, and characteristics of the behavior itself, creating an efficient model that includes the needs of the client with IDD and those who assist with daily living activities (Binkley et al., 2014).

The social cognitive theory (SCT) focuses on the impact the social environment on behavior change. For this purpose, four main components were identified to modify the behavior, by modifying the physical and clinical environment, providing framework for a solid interpersonal interaction, and working with challenges for the client regarding the physical act of the behavior, in and of itself. All of the components are designed to increase self-efficacy in the clinical worker and the client. Many of the components in the model for this project were adapted from an oral health strategy and pilot study by Binkley et al. (2014).

The social cognitive theory (SCT) focuses on the impact the social environment on behavior change.

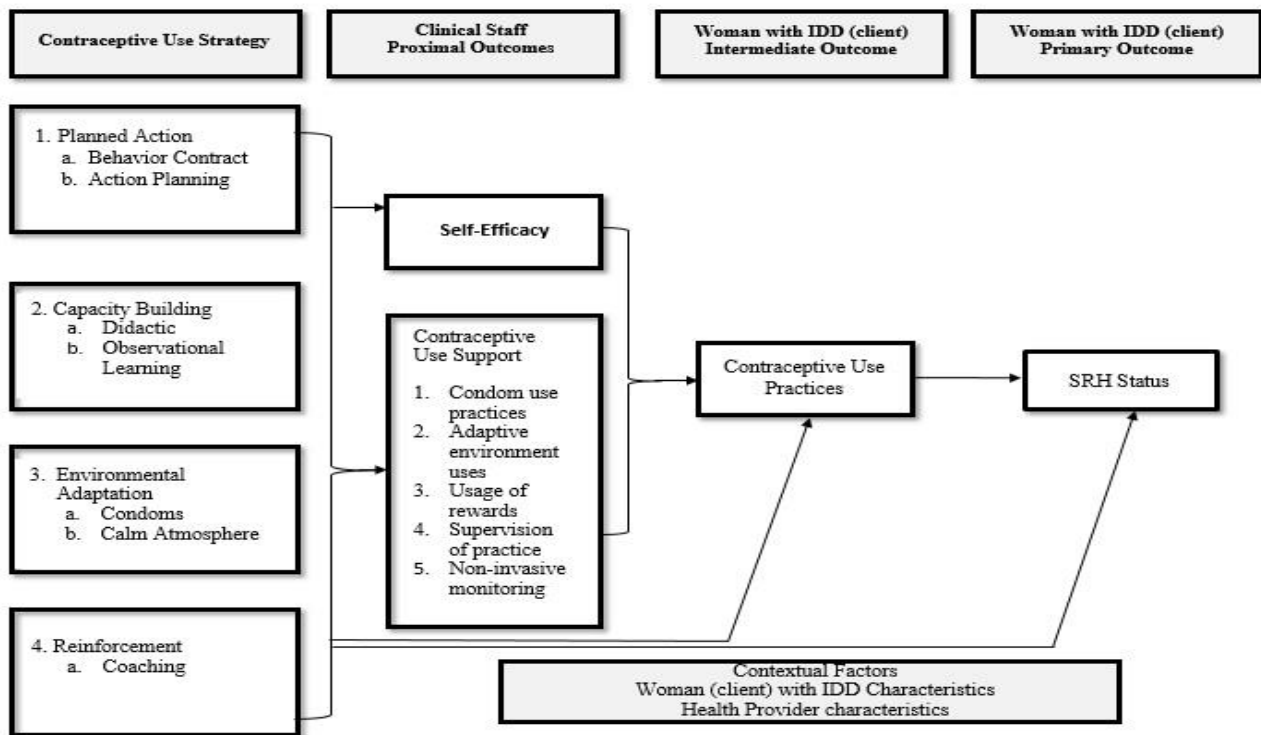
The model contains four components:

1. **Planned Action (modifying the clinical environment)**
 - a. Behavior Contract: requires the clinical worker to enter into an agreement to:
 - i. Receive training on working with women with IDD
 - ii. Work with the client to educate her on the proper use of the condom
 - iii. Provide appropriate instruction and literature, as needed
 - b. Action Planning: requires clinicians, social workers, clients, and caretakers (family members, personal care aides, and assistants) to work together to create a plan most appropriate for the client to learn proper use of contraception
2. **Capacity Building (providing framework for a positive interpersonal interaction)**
 - a. Didactic:
 - i. Training for the clinical worker in working with women with IDD in the form of workshops, as meets the scheduling needs of the clinician
 - b. Observational Learning:
 - i. Hands-on training with experienced social workers, personal care aides, and assistants in care and communication with women with IDD
3. **Environmental Adaptation (modifying the physical environment)**
 - a. Condoms:
 - i. Procuring supplies including condoms and models, to educate the client on use and facilitate practice
 - b. Calm Atmosphere:
 - i. Creating an atmosphere that is quiet, unobtrusive, and comfortable for the client
4. **Reinforcement (working with challenges for the client regarding the physical act of the behavior)**
 - a. Coaching: Clinical staff, social workers, and caretakers coach clients on:
 - i. Appropriate behavior in the clinical setting
 - ii. Preparation for the clinical appointment
 - iii. Use of a condom on a model
 - iv. Appropriate situations in which to use a condom

Clinical staff proximal outcomes after moving through the four components should increase self-efficacy, and provide continuing support through the program by discussing condom use, creating an area away from the clinical site for the client to practice condom use (with a model), usage of rewards for proper use, supervision to ensure appropriate use, and non-invasive monitoring of safe sex practices by discussing personal use with partners.

The expectation for intermediate outcome in women with IDD in the program is proper use of a condom and increased self-efficacy in sexual and reproductive health, measurable by observation of use on a model and non-invasive monitoring of private use. The primary outcome of improved SRH and self-efficacy in making appropriate contraceptive decisions are measurable in decrease of unplanned pregnancy in women with IDD who have participated in the program.

Contraceptive Use Strategy



Intervention Strategies

<i>Objective Type</i>	<i>Theory and construct</i>	<i>Intervention Strategy</i>	<i>Possible Activities</i>
1. Environmental/ Behavioral	SCT- Reciprocal Determinism	Health Education	<ul style="list-style-type: none"> • Condom use practices • Adaptive environment uses • Usage of rewards • Supervision of practice • Non-invasive monitoring
2. Learning/ Environmental	SCT- Behavioral Capability	Health Education	<ul style="list-style-type: none"> • Didactic training • Procurement of condoms and models
3. Learning	SCT- Observational Learning	Health Education	<ul style="list-style-type: none"> • Observational learning
4. Learning/ Environmental	SCT- Reinforcements	Health Education	<ul style="list-style-type: none"> • Coaching • Calm atmosphere
5. Learning	SCT- Expectations	Health Education	<ul style="list-style-type: none"> • Proper use of condom (on model) • Measurement of SRH
6. Behavioral	SCT- Self-efficacy	Behavior Modification, Environmental Change	<ul style="list-style-type: none"> • Behavior contract • Action planning

Implementation

Possible Members of a Planning/Steering Committee

Note: The following is an exhaustive list of possible members of a planning/steering committee. Although all of them may not be interested or able to provide services or resources, optimal members would include at least two or three from each category.

1. Family members of women ages 13-25 with diagnosed IDD in Dillon County
2. Family advocacy groups including:
 - Able SC
 - PRO-Parents
 - ARC of South Carolina
 - Marion-Dillon Parent Guardian Association
 - Friends of Persons with disabilities
 - Parents Reaching Out to Parents
3. Potential clients (women ages 13-25, with diagnosed ID/DD in Dillon County)
4. Representatives from:
 - Marion-Dillon County Board of Disabilities and Special Needs (MDCBDSN)
 - South Carolina Department of Disabilities and Special Needs (SCDDSN)
 - Consortium for Citizens with Disabilities
 - Partners in Policymaking
 - Special Needs Advocacy
 - The South Carolina Statewide Independent Living Council
 - SC Developmental Disabilities Council
 - Protection & Advocacy for People with Disabilities
 - SC Human Affairs Commission

5. Self-advocacy groups:
 - Impact SC Self Advocacy Council
 - People Power
 - P.I.E. Group Able South Carolina
6. Representatives from County Election Commission Boards:
 - Dillon County
 - Marion County
7. Representatives from Assistive Technology Recycling Loan Programs:
 - MedNeed of SC
 - EnableTech
 - disAbility Resource Loan Closet
 - SC Equipment Distribution Program
 - SC VR Assistive Technology Loan Program
 - Touch the Future
8. Representatives from Health Benefits and Services:
 - The Benefit Bank
 - Department of Health and Environmental Control
 - Medicaid/Medicare
 - State Health Insurance Program- Region 7- Vantage Point
9. Representatives for Education of Exceptional Populations:
 - Office of Exceptional Children
 - SC Department VR- Transition Program
 - Dillon County School District 3 and 4
10. Representatives from Independent Living Organizations:
 - APRIL (Association of Programs for Rural Independent Living)
 - National Council on Independent Living
 - SC Statewide Independent Living Council
11. Representatives from Disability and Special Needs Boards:

- Marion/Dillon County
12. Representatives from other Disability Agencies and Organizations:
- Disability.gov
 - National Down Syndrome Society
 - South Carolina Access
 - SC Partnership of Disability Organizations
 - American Association on Intellectual Disabilities
 - American Association of People with Disabilities
 - Berkeley Citizens, Inc.
 - Healing Farm
13. Representatives from Transportation Services:
- Project Action Accessible Travelers' Database
 - Nonemergency Medical Transportation
 - Aging, Disability, & Transportation Resource Center
 - Best Friend Express
 - Dial-A-Ride Transit Service (DART)
 - PDRTA- Paratransit Marion
14. Administrative, medical, and associated staff from medical care facilities within thirty minutes of Dillon County:
- Dillon Public Health Department
 - Care South Carolina- Lakeview Center
 - Dillon County Free Medical Clinic- Dillon
 - McLeod Health Hospital
 - Maxton Medical Center- Maxton
 - Lumberton Health Center- Lumberton
 - Julian T Pierce Health Center- Pembroke
 - Healthcare Inc. Florence- Florence
 - Scotland Community Health Clinic- Laurinburg

Program Resources

<i>Personnel</i>	<i>Space</i>	<i>Equipment</i>	<i>Supplies</i>
Salaries or wages (excluding general operating/administration costs)	Classroom space- rent or mortgage payments	Telecommunications: phones, internet, cell phones (installation, equipment, monthly charges)	Supplies (consumables)- letterhead, envelopes, paper, toner
Child care allowances	Utilities: gas, electricity, water	Equipment lease fees, maintenance contracts, photocopier	Computers, software
Employment ads	Furnishings	Textbooks	Office equipment
Drug screening	Maintenance and cleaning supplies		Marketing and advertising (ad design and production; brochures and flyers; printing; recruitment campaign)
Background checks	Maintenance, repairs, and inspections		Postage, shipping, delivery
Volunteer employees			
Travel, mileage, parking			
Professional development, staff training, technical assistance			
Chef, food vendors, caterers			
Executive and management staff- Project coordinator, curriculum developer, assistant director			
Consultants			

Further Explanation of Resources

Some part of the curriculum for Phase I is existing, while others will have to be developed using “best experiences.” Pioneer hopes to fund the project through grants and donations, but building partnerships throughout the community, encouraging buy-in, and generating a feeling of ownership is integral to the end sustainability of the project. The Project Coordinator will manage the program and ensuing activities. Few limitations are placed on the applicable participants, but they must be:

- Clinical staff in the Dillon County, SC area
- Some discussion is warranted as to the gender of the participants. Some studies have shown that female patients with IDD prefer female physicians, nurses, and nurse practitioners, although other staff (receptionists, nurse techs, and laboratory staff) may be male or female (McCarthy, 2010).

Next Steps

- Create/convene planning committee
- Hire and orient Project Coordinator
- Set up criteria and procedures of Phase I of the program
- Recruit and enroll qualified educators and curriculum developers
- Recruit and enroll clinical staff participants
- Secure classroom space
- Develop curriculum with clinical staff educators
- Pursue opportunities to collaborate with Able SC to “fine-tune” curriculum
- Meet with medical providers to develop and maintain positive relationships for the purpose of marketing the project
- Keep records updated and report progress toward the objectives
- Develop a plan to offer catering for 90-minute training sessions
- Have curriculum and activity sheets bound and printed
- Set up classroom for training
- Conduct bi-monthly training sessions to equal eight 90-minute sessions

Implementation Timeline for Phase I												
Tasks	Jan '17	Feb '17	Mar '17	Apr '17	May '17	Jun '17	Jul '17	Aug '17	Sep '17	Oct '17	Nov '17	Dec '17
Hire Project Coordinator	█											
Set up criteria and procedure		█	█									
Recruit/enroll educators			█	█								
Find classroom for training			█									
Develop curriculum					█	█	█					
Collaborate with AbleSC		█		█		█		█		█		█
Meet with clinical staff	█		█		█		█		█	█	█	█
Update records and reports			█			█			█			█
Develop catering plan							█	█				
Print and bind curriculum							█	█				
Prepare classroom							█	█				
Conduct training sessions									█	█	█	█
Conduct Evaluation	█	█	█	█	█	█	█	█	█	█	█	█
Disseminate Evaluation Report											█	█

Program Marketing

- Promotion for this project should focus on a “personal touch.” Program promotion flyers should be e-mailed to clinicians, and a follow-up meeting should follow soon after delivery. Clinical staff should be invited to dinner to further discuss details.
- Continuing Education (CE) credits should be offered as well as catering for class sections.
- It may be prudent to introduce the project using more medically-based diagnoses of intellectual or developmental disabilities, rather than creating a precedence that could be received as “deviant” or “inappropriate” until personal contact can be made. For example, it is easier for the layperson to discuss sexual difficulties concerned with diabetes rather than cerebral palsy, but after education or meeting someone with cerebral palsy, the need becomes more understandable and acceptable.

Budget

	<i>Grant Funds Requested</i>	<i>Other Cash Committed</i>	<i>In- Kind Support</i>	<i>Other Cash Anticipated</i>	<i>Total Budget</i>
A. Personnel					
Salaries					
1. Project Coordinator (6%)	3,600.00				3,600.00
2. Curriculum Developers (15%)	9,000.00				9,000.00
3. Assistant Director EFT (3%)	1,800.00				1,800.00
					14,400.00
Payroll/Taxes/Benefits					
1. Project Coordinator (5%)	3,000.00				3,000.00
2. Curriculum Developers (5%)	3,000.00				3,000.00
3. Assistant Director (5%)	3,000.00				3,000.00
					9,000.00
B. Other Expenses					
1. Child-care allowances (5%)	3,000.00				3,000.00
2. Hiring Costs (3%)	1,800.00				1,800.00
3. Travel, Mileage, Parking (3%)	1,800.00				1,800.00
4. Food Vendors (6%)	3,600.00				3,600.00
5. Consultants (5%)	3,000.00				3,000.00
					13,200.00
C. Space/ Venue					
1. Classroom Rent or Mortgage (10%)	6,000.00				6,000.00
1. Utilities: gas, water, electricity (4%)	2,400.00				2,400.00

	<i>Grant Funds Requested</i>	<i>Other Cash Committed</i>	<i>In-Kind Support</i>	<i>Other Cash Anticipated</i>	<i>Total Budget</i>
2. Furnishings (1%)	600.00				600.00
3. Maintenance/ Cleaning Supplies (1%)	600.00				600.00
4. Maintenance, repairs, inspections (2%)	1,200.00				1,200.00
					10,800.00
D. Equipment					
1. Telecommunications: phones, internet, cell phones (installation, equipment, monthly charges) (4%)	2,400.00				2,400.00
1. Equipment lease fees: maintenance, contracts, photocopier (2%)	1,200.00				1,200.00
2. Textbooks (7%)	4,200.00				4,200.00
					7,800.00
E. Supplies					
1. Consumables (letterhead, envelopes, paper, toner) (1%)	600.00				600.00
2. Computers, software (2%)	1,200.00				1,200.00
3. Office equipment (2%)	1,200.00				1,200.00
4. Marketing and advertising (ad design and production; brochures and flyers, recruitment campaign) (2%)	1,200.00				1,200.00
5. Postage, shipping, delivery (1%)	600.00				600.00
					4,800.00
Total					60,000.00

Evaluation

- Surveys should be given to all eligible participants before participating, requesting information that is hoped for, and after, to determine the intrinsic value to the clinical staff.
- Prior to the training sessions, participants should be given a comprehensive pre-test, and following training sessions, a comprehensive post-test.
- A test should be given after each of the modules, with a minimum score of 80% required. If the score is not achieved over the majority of participants, module instruction should be reevaluated.
- Focus groups should be conducted with staff and clients from Able SC to determine the appropriate outcome of the training sessions.
- Surveys inquiring about the quality of the program (what went well, what could be modified or changed for next time) should be given monthly. In this way, both qualitative and quantitative assessments can be conducted, although the final assessment cannot be measured until after the final phase of the project.

Contact Information



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Appendix A- Project TEASE

T(RANSSPARENT) E(VOLVED) A(UTHENTIC) S(ELF) E(XPRESSIVE)

It's all about sex.

Originally created as an assignment for a contemporary issues in sex course at Arnold School of Public Health, Project TEASE is a website designed to empower and enable women with disabilities to create a transparent, evolved, authentic, self-expressive sexual identity. Like other sexuality and disability sites, Project TEASE provides medically accurate information that's tailored to the needs of disabled women, answers questions, and dispels the myths surrounding disability and sexuality.

Project TEASE is also designed for disabled women to communicate with each other, sharing stories and experiences, while creating a forum to add local events, news, and issues surrounding disability and sexuality for women in the South.

Goals

1. **Educate:** Women with disabilities have significantly diminished knowledge in areas of sexuality, such as sexually transmitted infections, pregnancy, and contraception. This can be attributed, in part, to the lack of appropriately tailored sex education for girls and women with disabilities, but also to increased rates of victimization, isolation due to lack of mobility, and lessened access to sexual services. Current sex education curriculum uses a predominately heteronormative, orgasmocentric view of sexuality, which does not fit an atypical body in an extraordinary population. Further, women with disabilities have often had procedures that create a clinical feel to their bodies, lessening self-esteem and the potential to enjoy their own sexuality. The World Health Organization (WHO) recently advocated the creation of a disability component to be

added to sexual health policies in programs to decrease the likelihood for poor health, comorbid conditions, premature death, and the spread of communicable diseases.

2. **Advocate:** Current legislation does not require medically accurate information to be included in sex education curriculum in South Carolina. There has been little research conducted about disability and sexuality, making it difficult to create sexual health programs that are evidence based for this population. Women with disabilities should be given the opportunity to work with policy makers to address issues specific to their own sexual health as well as researchers to broaden the intellectual platform on which programs tailored to their needs can be produced. They should be given a voice to reorganize the bounds of independent living, and should be educated about their own bodies in order to make healthy decisions concerning relationships with others and their own, unique sexuality.
3. **Collaborate:** Project TEASE aims to connect women with disabilities to organizations on the local, state, and federal level, as well as create a forum in which ideas about their sexuality can be discussed, discretely or publicly. They should be given the opportunity to educate the public about disability and sexuality in order to combat the stigma surrounding disability, participate in social involvement, and to finally eliminate the "medical model" of care for women in this population.

Specifications

The website includes an overview of many topics, each containing pictures and diagrams, detailed descriptions, videos, and links for further information. The pages allow the reader to comment, ask questions, or begin a forum topic anonymously, if they so choose. Each of these pages contain information for a broad range of disabilities, and therefore is not the most comprehensive guide on every sexual issue for every type of disability, but can be easily edited to add or delete information, if necessary.

★ **Anatomy and Physiology**

- Highly detailed descriptions of female and male sex organs, as well as basic physiology of sexuality. These topics will be broadened for those with spinal cord injuries and other disabilities that include differences in tactile or neural processing.

★ **Personal Hygiene**

- A “how-to” guide to the vagina. Basic information on cleanliness, symptoms and signs of general vaginal infections, and information about lubrications.

★ **Dating and Relationships**

- Discussions about safety and trust, and building relationships with others, both disabled and non-disabled. Project TEASE would love to find a blogger for this page.

★ **Losing Your Virginity**

- Videos, descriptions, and models discussing both the choice to remain abstinent and to have sex. Information on the “first time” and what to expect. A brief overview of contraception methods and links to sites that provide condoms and more detailed information about protection. This may be very detailed for potential blind and loss of sight visitors.

★ **STI/STD**

- Pictures, descriptions, and information about signs and symptoms of STIs and methods of protection against them. Further links to sites that provide condoms and more detailed information about protection. A section including information about Hepatitis B, as the rate for this disease is high in women with disabilities.

★ **Restrictive Sex (including techniques, tips, and tools)**

- Discussions about positions for those who need assistance, and ways to lessen discomfort for those with chronic pain. Various tips from many different sites, as well as links to sites with toys that can be adjusted for different body types. Links and information about assistive devices. A broad discussion about alternative orgasm and non-orgasmic pleasure.

★ **Vanilla Or Kink?**

- Topics including paraphilias and alternative sex, with heavy emphasis on SSC (safe, sane, and consensual) practice. Differential considerations for those with neural disorders. Those with chronic pain issues find that they can control the pain using this technique. Links to sites made by disabled women for those interested in kink and alternative sex.

★ **Abuse and Neglect**

- Criteria for healthy, happy relationships. A discussion concerning the “novelty factor” (this is a term loosely used to describe sex by a non-disabled person with a disabled person purely for the vicissitude of the act). Links for assistance in cases concerning neglect or abuse.

★ **Gradient of Sexualities**

- Due to current time constraints, Project TEASE is not all inclusive of the LGBTQIAMSMM population, but basic definitions and descriptions of the “gradient of sexualities” will be discussed. Links for women with disabilities who fall into these categories will be added.

Terminology for acts of sexuality, anatomy, and physiology should include both medical and informal (but frequently used) language. Additional links include pages for family members, medical health professionals, and personal care aides. Areas for posting questions or sharing stories are included, as well as links to literature, books, other sites, and support tips.

Accessibility

Currently, Project TEASE is collaborating with special services and technology gurus to make the page accessible to users with assistive technology. The page is being tested in a number of ways, including NVDA, WAVE (Web Accessibility Evaluation Tool), iPad technology, and ChromeVox. Also, text is simple with contrasting color, images are labeled, and the number of links per page are limited and include simple titles. The website platform used is Weebly, primarily because html/css code is relatively easy to adjust by the builder. Youtube videos are reviewed for closed captioning and auto captioning accuracy.

After the “go-live” date, it will take time for Google’s “spiders” to catch the site. However, Project TEASE is committed to blogging regularly, searching for local and web events, and promoting the site, even if it must be accomplished manually. Accessibility is still a “work-in-progress.”

Evaluation Plan

1. Basic Page Layout and Graphic Design Completion (September, 2016)

At this time, the basic pages should be finished with working links. The text will not be available at this time, as it is still a work in progress. The chatboards will not be accessible, and the videos will not yet be linked. The site is password protected at this time to block users from creating visiting data that will be used later for evaluation.

2. Tentative Go-Live Date (December 1, 2016)

The website and all graphics, pictures, and videos will be accessible to the public. The chatboards should be live, and viewing data will be tracked at this time. The website will be reviewed. After presentation, password protection will be reinstated until the official go-live date.

3. Official Go-Live Date (June 20, 2017)

The week prior, the web address will be sent to a group of academics, sexual health professionals, and clinicians with an attached survey. They will review the site for accuracy, completeness, and basic form and function. Their surveys will be used for the final editing before the official go-live date.

The site will be available at this time for public use. It should be accessible to those with assistive technology. Data about site visitors, repeat site visitors, and members will be monitored. Project TEASE intends to find bloggers to assist in discussions and basic site maintenance. At this time, it would be most useful to collaborate with other online

resources and focus groups before promoting the site to ensure accessibility and usability, as well as general appeal.

Current Limitations and Future Endeavors

1. Project TEASE is not designed for young girls with intellectual disabilities (ID). A daughter site should be created with their specific needs in mind.
2. Although the site may be used either by women without disabilities or men, a brother site for men with disabilities should be created.
3. There is a growing population of LGBTQIAMS within the disabled community. This creates the opportunity for yet another site with information tailored to their needs. A website such as this would require a much larger team and more time to complete.
4. Some cultural and religious views were neglected in the creation of Project TEASE. Further research may assist in creating additional information on this site in a more culturally diverse manner.
5. People without disabilities should have a hand in working towards the completion of the site. Through the basic classwork promotion of the site, many non-disabled people have learned much about the subject of "sexuality and disabilities." Many have stated that their work, either in the area of sexuality or public health will now be more inclusive to those with disabilities.

Appendix B- Intellectual Disability and Sexuality

A Short History of “Special Education”

The first special education classes were supplementary to general education, and were focused on delinquency prevention for “at risk” children of lower socioeconomic status, African American children, and the children of non-English speaking Catholic and Jewish immigrants newly arrived to the United States. Manual training techniques were utilized to teach the students of these overcrowded special education programs trade work, including carpentry, metal shopping, and sewing, and were generally held in less desirable spaces of the school building, such as external trailers or basements. In addition, the curriculum was meant to normalize the students by providing morality, social skills, skills for interpersonal relationships, and traditional values (A Short History of Special Education Law, 1998).

Until two landmark cases in the 1970’s, *Pennsylvania Assn. for Retarded Children v. Commonwealth* 334 F. Supp. 1257 (E.D. Pa 1971) and *Mills v. Board of Education of District of Columbia*, 348 F. Supp. 866 (D. DC 1972), intellectually disabled children were excluded from common schools, despite compulsory attendance laws. In fact, it was illegal for parents to attempt to enroll their ID children in school after the child had been excluded, in the state of North Carolina. African American students were overrepresented in these programs and were two-thirds more likely to be assigned to these programs by their general education teachers. In *Brown v. Board of Education*, 347 U.S. 483 (1954), the Supreme Court ruled that African American children had the right to the same educational opportunities afforded other children not of color, and that segregation “[had] no place in the field of public education (Brown v. Board of Education , 1954).” This case served as the catalyst for *P.A.R.C.* and *Mills*, brought forth by parents of disabled children, which argued against the segregation and exclusion of disabled children from public schools. The Supreme Court found that it would be “doubtful that

any child may reasonably be expected to succeed in life if he is denied the opportunity of an education (Brown v. Board of Education , 1954).” Public Law 94-142 was enacted into law on November 19, 1975, giving disabled children the “right to education, and to establish a process by which State and local educational agencies may be held accountable for providing educational services for all handicapped children (Education for All Handicapped Children Act, Public Law 94-142, 1975).” This law was reauthorized in 1990 as the Individuals with Disabilities Education Act [IDEA] (A Short History of Special Education Law, 1998).

IDEA contains extensive regulatory and statutory provisions by which Congress intends to ensure that all children with disabilities are afforded the opportunity for a “free and appropriate education [FAPE] (Education for All Handicapped Children Act, Public Law 94-142, 1975).” The provisions included provide for an *Individualized Education Program* (IEP) which is a plan created by a team of educators, guardians, therapists, and school authorities “designed to meet their unique needs and prepare them for further education, employment, and independent living (Education for All Handicapped Children Act, Public Law 94-142, 1975).” The IEP is then periodically reviewed, tracked, and updated as a means to extrapolate both a quantitative and qualitative measure of the appropriateness and value to the student, in order to efficiently track the student’s progress. This process standardizes an otherwise individual learning plan in order to assess and evaluate, identify needs and current levels of performance, develop goals for the student, and provide the necessary support for all ranges of disabilities in a “special needs” program (A Guide to Disability Rights Laws, 2009).

The Advent of Sex Education in Public Schools

Initially, sex education was a public health preventative measure that began in the late 1800s due to rising incidence of cholera and syphilis, as a means to regulate sexuality using risk-reduction and health care prevention. Between 1892 and 1913, sex education was promoted through all facets of student life by organizations such as The National Education Association, the Congress of Parents and Teachers (PTA), the YWCA through the creation of the Commission on Sex Education, and the 4th International Congress on School Hygiene, by identifying the necessity, creating curriculum, and alleviating public funds in support of

sexuality education for both students and their parents. In the following years, creation of birth control methods, the founding of the Sexuality Information and Education Council of the United States (SIECUS), and cases such as *Griswold v. Connecticut*, 381 U.S. 479 (1965) and *Roe v. Wade* U.S. 113 (1973) propelled issues of public sexuality and education to the forefront of public health, despite opposition from the John Birch Society, Christian Crusade, Parents Opposed to Sex and Sensitivity Education, Sanity on Sex, and Mothers Organized for Moral Stability (Advocates for Youth, 2008).

Sex education continues to be a controversial subject which seems to sway the public in favor or opposition, depending on presented evidence and politics. An example is the \$250 million allocated by Congress for abstinence-only education as part of the welfare reform act in 1996, which was later opposed by Dr. David Satcher, the US Surgeon General, in his 2001 publication of a "Call to Action to Promote Sexual Health and Responsible Sexual Behavior," which argued for more sexuality education. Most recently, Congress provided \$75 million annually for adolescent education that would be both medically accurate and evidenced based in age-appropriate programs, in response to rising teenage pregnancy rates and the HIV/AIDS epidemic (Advocates for Youth, 2008).

Throughout these events, the question of the extent and even the existence of sexuality in people with ID remains nearly unstudied in most of the world, and most notably in the United States. Currently, many special education classes neglect sex education for those with ID, and there is very little, if any, congressional oversight in relation specifically to this issue (Peterson, 2013).

Arguments in Favor of Sex Education for People with Intellectual Disabilities

In the case for sex education, several platforms should be explored including technological and educational advances, the legal obligation to the school district to provide free and appropriate education, and the ethical implications of providing students with the most accurate and evidence-supported information in order to allow the student to make an informed decision about their sexuality. Finally, the psychological, sociological, and biological issues surrounding

human sexuality should be discussed in order to ascertain the level of physiological and cultural importance of understanding one's own sexuality as an integrated member of society.

Moving Away from the Medical Model of Special Education

Although the educational system in the US has undergone many changes in the last century, one of the most significant in relation to special education is the movement from the "medical model" to a more proactive educational model for those with IDs. By comparison, this new style of assessment and teaching which is supported by empirical evidence to be most beneficial to students, affords new opportunities for teaching sex education in special education classes (Peterson, 2013). In addition, the life expectancy for people with Down syndrome was 25 years old in 1983. Due to medical advances and the societal move away from institutionalization and exclusion, the life expectancy has increased to 60 years old (Codina, 2010).

The medical model is described as "a dehumanizing attitude which primarily defines a person by pathological labels associated with disease or sickness (Peterson, 2013)." The detriment of this model is particularly evident when assessing the needs of these students through standardized testing which excludes cultural background and speech pathology. By measuring the extent of special needs services in this way, the abnormal neurodevelopment of the student is understood to singularly represent the deficit in cognitive functioning, rather than a more plausible explanation, in some cases, the simple acknowledgement of a speech impediment. This method of assessment then serves two purposes: the spread of pervasive stereotypes which limits the mode of academia the child may use to learn, as well as the generation of faulty data concerning the population of those with IDs.

If, in fact, the result of the deficit is found to impede "normal" functioning, the student is then offered services that are meant to teach life skills, such as general hygiene, balancing a checkbook, and skills for use in future (post-graduation) jobs. Social skills are of importance in obtaining a career, as well as functioning in any society, and the trend toward "social role valorization" has increased these opportunities for individuals with IDs (Smyth & Bell, 2006). However, this population is often omitted from sex education in class due to the very deficits that place them in this classification. If the movement from the medical model reorganizes the

bounds of independent living, and the life expectancy of these individuals grow exponentially longer, the curriculum should also be updated to include more than just basic interpersonal skills; it should include skills for independent living of a now, much longer life.

A Legal Obligation

Parents often have difficulty coming to terms with their child's sexuality. The case is no different with the parents of individuals with IDs. In the past, surgical sterilization was used to prevent such an event from occurring, yet those with IDs possess fully functioning bodies, which mature in a similar rate to their non-disabled peers (Series, 2014). According to The New York State Office of Mental Retardation and Developmental Disabilities Commissioner's Memorandum, a parent or guardian cannot limit a person's sexual activity (Lyden, 2007). An integral part of becoming a healthy, sexual being is learning about one's own sexuality. The discomfort most parents experience in discussing sex with their child, combined with the decreased likelihood that sexuality will be discussed in the home during the teenage phase of one's life, as well as the possibility of the transference of medically inaccurate information, are some of the foremost reasons that sex education is taught in school (Advocates for Youth, 2008).

The earliest interpretations of equitable treatment in education concerns common curriculum and district location despite socioeconomic and cultural background. The foundation of the *Brown* decision was equality in education, but following lower courts decided on the equity of education, focusing on the output resulting from the input of the school system, namely, funds, facilities, teachers, and curriculum, as well as the obvious disparities between black and white students. For pupils in special education classes, this was reflected in zero-rejection policies, but has now grown to encompass opportunity, full participation, economic self-sufficiency, and independent living goals, as expressed in IDEA (Individuals with Disabilities Education Act, 1990). The difference between the two is often thought of in planes, equality representing the horizontal axis, and equity representing the vertical, although neither of the two are necessarily appropriately measured on an individual level (McLaughlin, 2010).

Some of these goals can be achieved through the IEP, where the student's self-determination is measured through their own involvement in influencing their future, and the state and federal

policy makers are held accountable by the “least restrictive environment (LRE)” clause, which ensures that individuals with IDs’ interests are considered in corresponding policies. This concept occasionally includes integration, which could either be interpreted as the needs of the student or the availability of district resources, concepts that are often juxtaposed based upon the district and the interpretation of the law (Carson, 2015). However, without the opportunity to learn in the LRE, there would be limited social-situational learning opportunities for students in special education. In fact, one might consider it to be inequitable to deny a student access to the same learning opportunities as a non-disabled student by excluding them from the occasion to learn basic anatomy and physiology, the possible consequences of sexual relations, appropriate behavior and context of sexuality, the transaction of sexual choice, and the nurturance of the ability to recognize a dangerous or abusive situation, which would provide skills to reject an unwanted or unsafe scenario (Murphy & O’Callaghan, 2004).

Due to the lessened ability of individuals with IDs to participate in social involvement, their decreased capacities in the areas of cognitive abilities and emotional regulation, and reduced aptitude in both expressive and receptive communication, it would then follow that special education should work as a supplementary means to assist one in developing this knowledge further, through either lengthened and ongoing sex education courses, or by adjustment of the curriculum to fit the intellectual needs of the individual, as defined by their IEP (Martinello, 2014).

Risk Avoidance, Harm Reduction, and Early Intervention

Studies have shown that individuals with IDs possess significantly diminished knowledge in areas of sexuality, such as sexually transmitted infections, pregnancy, contraception, and the law, both as a protective faculty as well as a disciplinary factor for inappropriate behavior (Finlay, Rohleder, Taylor, & Culfear, 2015; Curtice, Mayo, & Crocombe, 2012). This lack of knowledge can be, in part, attributed to the insufficiency of appropriately tailored sex education for persons in special education classes and at home. Individuals with IDs are typically seen as asexual due to the predominantly heteronormative view of sexuality, especially pervasive in the United States (Esmail, Darry, Walter, & Knupp, 2010). This deficit is further

compounded by the risk for sexual abuse, which is significantly higher in this population than in the general population, and carries with it a perceived need to protect individuals from any sexual contact or ideation at all (Lockhart K., Guerin, Shanahan, & Coyle, 2009; Futcher, 2011).

In fact, some estimations purport that 40-50% of abuse perpetrated against those with IDs is by their own disabled peers, although it is important to adjust this statistic by admitting that these acts are three times more likely to be reported as the same act committed by a non-disabled person. This is because they are more likely to occur in public and to be perceived as abusive by an onlooker (Martinello, Reviewing Risk Factors of Individuals with Intellectual Disabilities as Perpetrators of Sexually Abusive, 2015). The very notion that these deeds may transpire in an improper setting illustrates both the lack of understanding of socio-sexual mores, the legality of such an act, and the abstract notion of consent in those with IDs. Perpetrators of sexual crimes who have IDs are also likely to target children, as they have similar psychosexual development and are often at the same developmental level.

Furthermore, there is an increased risk for sexually transmitted infections due to victimization and lack of knowledge about the spread of disease. With the recent push for normalization in this population comes an increased incidence of homosexual acts. Hepatitis B is extremely high in this population, despite the fact that it is the only sexually transmitted disease [as opposed to infection] that can be prevented by vaccination (Servais, 2006). Adolescents with IDs are 15% more likely to become pregnant than their non-disabled peers, and the ensuing storm of complications following pregnancy are overwhelming to the family, school faculty, and justice system (Linton & Rueda, 2014). The choice to abort against the wishes of the mother are typically decided in court, as the ability of the parent to care for a child when she may already have difficulty in caring for herself, is called into question, and the burden of raising the child may fall upon the shoulders of an unwilling or unable guardian (Pollack, 2005). The health of the unborn child may also be at risk, as adolescents in this population experience unique gynecological issues and may take medication (Linton & Rueda, 2014).

For these reasons, the World Health Organization (WHO) recently advocated the creation of a disability component to be added to sexual health policies and programs (Servais, 2006). Because health promotion and prevention strategies are seldom inclusive to those with

disabilities, the likelihood for poor health, comorbid conditions, premature death, or the spread of communicable disease is increased for those with IDs (World Health Organization, Department of Reproductive Health and Research, United Nations Population Fund (UNFPA), 2009). The call for a more comprehensive, early sex education program is well warranted if the WHO definition of health as “a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity (Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, 19 June - 22 July 1946),” is the primary goal of the public health field.

Appendix C- Disability Statistics in Dillon County

Dillon County, South Carolina

Subject	With a Disability	% With a Disability	Without a Disability	% Without a Disability	Total Population	% of Total Population	Sample Size
Population	Total	% of Population	Total	% of Population	Total	% Ages 5+	Sample Size
Ages 5+	25,720	22.2%	89,970	77.8%	115,690	N/A%	3,363
Ages 21-64	16,090	22.3%	56,080	77.7%	72,170	62.4%	2,109
Ages 16-64	16,930	20.7%	64,740	79.3%	81,670	70.6%	2,321
Demographics -- Ages 21-64	Total	% of Ages 21-64 w/ Disability	Total	% of Ages 21-64 w/o Disability	Total	% of Ages 21-64	Sample Size
Male	7,500	46.6%	26,380	47.0%	33,880	47.0%	981
Female	8,580	53.3%	29,700	53.0%	38,280	53.0%	1,128
White	7,610	47.3%	31,100	55.5%	38,710	53.6%	1,305
Non-White	8,470	52.6%	24,980	44.5%	33,450	46.4%	804
Hispanic	N/A	N/A%	N/A	N/A%	N/A	N/A%	22
Non-Hispanic	16,060	99.8%	55,430	98.8%	71,490	99.1%	2,087

Disability POPULATION Statistics for Darlington, Dillon and Marlboro Counties, South Carolina: From Pooled 2005-2007 ACS PUMS Data. Copyright 2007 by InfoUse. Reprinted with permission.