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2016 Presentation

# Pioneer

first in exceptional women's care

A team-oriented approach to pregnancy prevention in exceptional populations

# Objectives

1. Discuss risk factors for STD/STIs directly associated with women with intellectual and developmental disabilities

2. Introduce Pioneer

3. Discuss ways to “Bridge the Gaps” in SRH for women with IDD

# 1. Risk Factors

# Sexuality & Disability

**Women with Disabilities Have Higher Incidences of:**

- **Gender-based violence**
- **Compounding risk factors for injury, neglect, abuse, and exploitation**
- **Societal stigma related to sexual health needs and practices**

# Sexuality & Disability

**Women with Disabilities Have Higher Incidences of:**

- **Physical and economic barriers to health care access**
- **Medical conditions, which if combined with STI, may produce a higher liklihood of comorbidity**
- **Exclusion from research that could contribute to evidence-based practice for this population**

# Sexuality & Disability

**Women with Disabilities Face Societal Barriers, such as:**

- Social reinforcement of the "medical model"
- Predominantly heteronormative, orgasmocentric view of sexuality
- Higher liklihood of being reported for sexual abuse against their own peers

# Sexuality & Disability

**Women with Disabilities Face Societal Barriers, such as:**

- **The belief that the sexuality of persons with disabilities is either non-existent or deviant**

- **Underrepresentation in social and political participation in the creation of policies and laws that are reflective of their needs**

# 1. Background

# Project TEASE

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.

# 2. Program Rationale

# Sexuality & Disability

## Disability

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

## Education

Women with IDD have less access to SRH information that is tailored to the needs of their disability in school, at home, and in health care settings

## Services

Women with IDD have significantly less access to preconception, prenatal, and sexual healthcare

# Sexuality & Disability

## Training

Limited training of clinical staff to meet the SRH needs of women with IDD

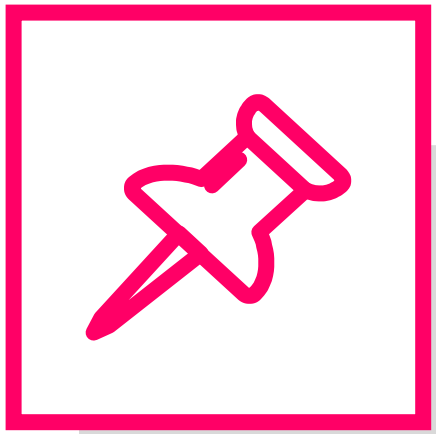
## Materials

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)

## Priorities

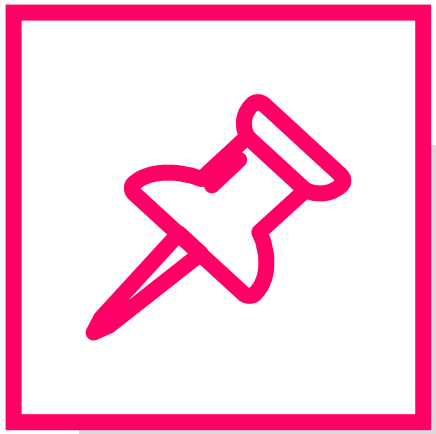
Discourse on SRH is minimized in comparison to other medical or health issues

# 3. Executive Summary



# Executive Summary

Pioneer will target **education for clinical healthcare workers and patients with IDD in a three-phase program** to address all of the barriers to care that contribute to the overrepresentation of women with IDD in **unplanned pregnancy and STI**.



# Executive Summary

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.

# 4. Needs Assessment

# Prioritization Matrix

| | More Important | Less Important |
|---|---|---|
| **More Changeable** | • Insufficient or incorrect sexual knowledge<br>• Inappropriate, inaccessible, or irrelevant public health materials.<br>• Lack of services.<br>• No transportation.<br>• Limited provisions for privacy in care settings.<br>• Limited training of clinical staff. | • Family values and beliefs.<br>• Interpersonal violence or sexual abuse.<br>• Desire to "fit in" with peers causes women to mimic unsafe sexual behaviors.<br>• Misconception of risks associated with multiple partners and lack of condom use. |
| **Less Changeable** | • No autonomy in medical health choices.<br>• Discourse on SRH is minimized.<br>• Policymakers underestimate the importance of inclusivity in SRH curriculum and materials included in policies. | • Fewer sexual experiences<br>• Significantly limited conceptual processes, social skills, and practical adaptive skills.<br>• Genetic factors and environmental exposures.<br>• Societal gender roles.<br>• Communication level and ability. |

# Prioritization Matrix

| | More Important | Less Important |
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| More Changeable | | • Family values and beliefs.<br>• Misconception of risks associated with multiple partners and lack of condom use. |
| Less Changeable | • Policymakers underestimate the importance of inclusivity in SRH curriculum and materials included in policies. | • Fewer sexual experiences<br>• Communication level and ability. |

# 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

# Risk Factors

- Limited public health surveillance to identify women with IDD who do not receive disability-friendly screenings, including mammography, and cervical cytology

- A limited provision for privacy in care settings prevents the ability to build therapeutic relationships with women with IDD, in order to discuss sensitive information

# Risk Factors

- 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

# NHANES (National Health and Nutrition Examination Survey)

- **Proxy variables were necessary due to the lack of data about the sexuality of women with disabilities.**

- **NHANES data combines both health assessment surveys and laboratory results to assess the "National health status."**

# NHANES (National Health and Nutrition Examination Survey)

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**n=10,000**

(total population surveyed)

**n=1,059**

(answered “yes” to the disability survey)

**10.59%**

percentage of the self-reported disabled population

**n=869**

answered “yes” to the sex survey

# NHANES (National Health and Nutrition Examination Survey)

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**30% male and 35% female**

**Positive for HBsAG**

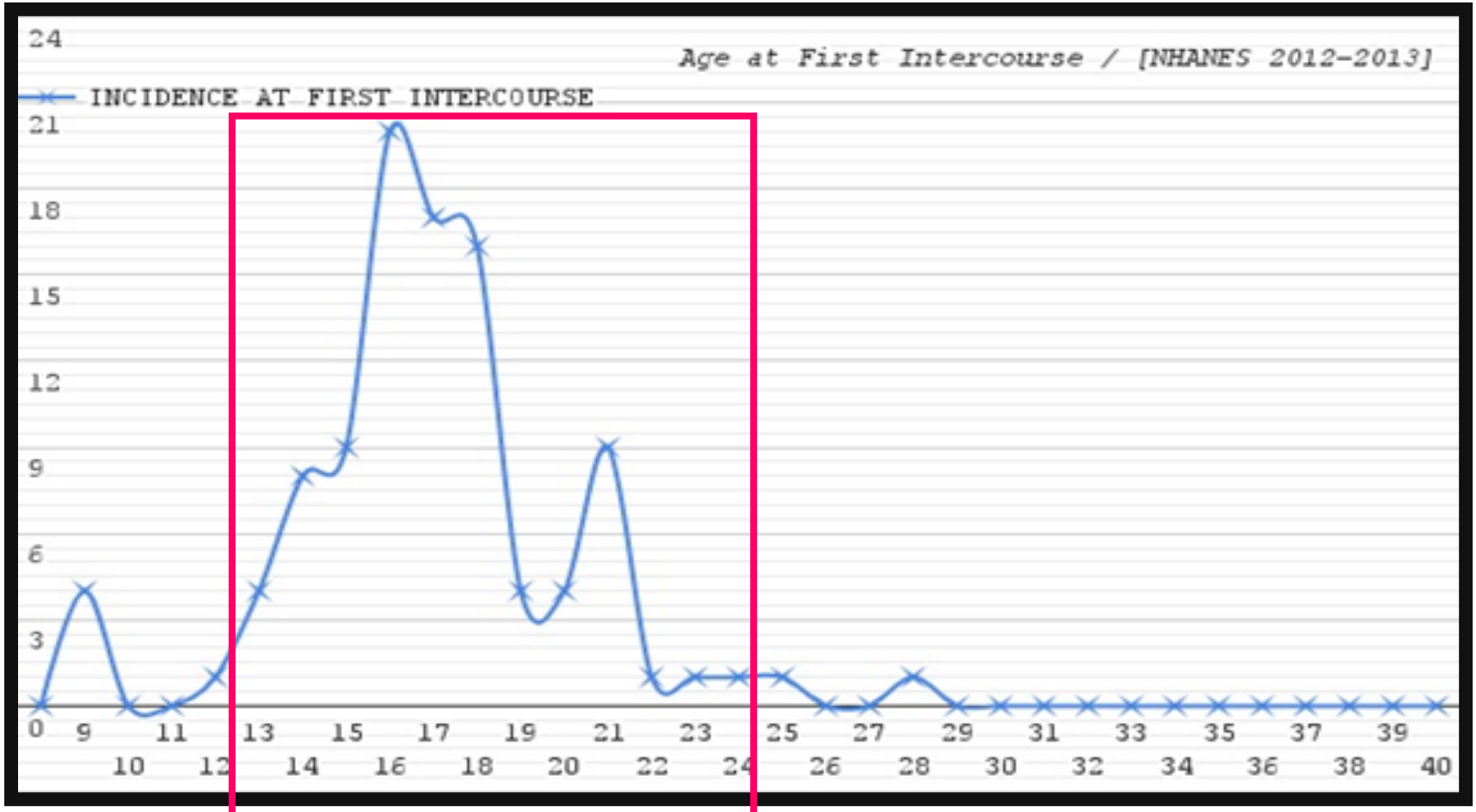
**0.69% equally male and female**

**Positive for HIV**

**2.6% male and 8.4% females**

**Positive for Herpes Simplex Virus 2 (genital herpes)**

# NHANES (National Health and Nutrition Examination Survey)



# Dillon County, SC

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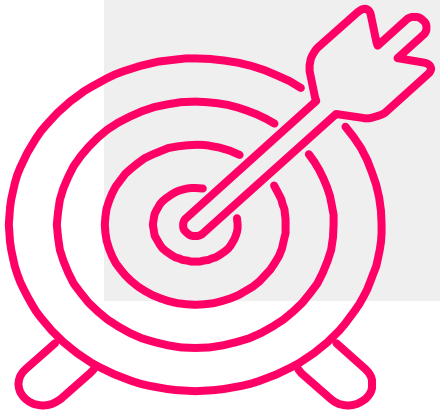
- ✓ **Has an unusually high proportion of persons with disability**
- ✓ **The percentage of the population with a disability is 20.7% (n=16,930) in the age range of 16-64**
- ✓ **Of the percentage in the age range of 21-64 (22.3%), 53.3% are female**

# Target

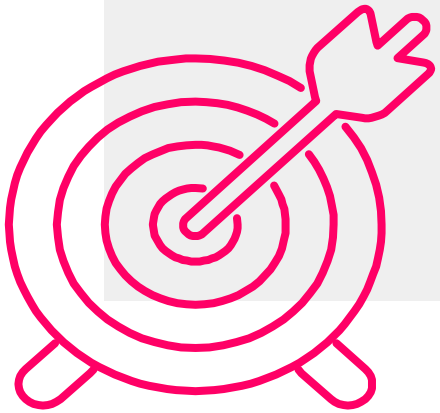
## POPULATION

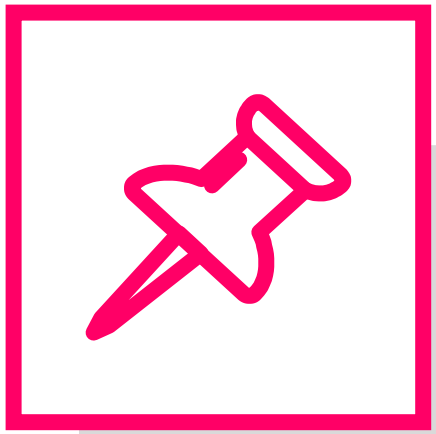
**Women with mild to moderate intellectual and developmental disabilities,** between the **ages of 13-25,** in the area of **sexual and reproductive health.**



# Target POPULATION

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

To prevent unplanned pregnancy [and STI transmission] in women with IDD, by providing access, clinical advocacy, and training about sexual and reproductive health (SRH) needs to them, their families, and communities through the health care system.

# 5. Program Goals

# Program Goals

***Increase access to appropriate SRH care counseling for women with ID/DD and their families in clinical settings by:***

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

# 6. Program Objectives

# 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.

# Program Objectives

## Behavior Objectives

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.

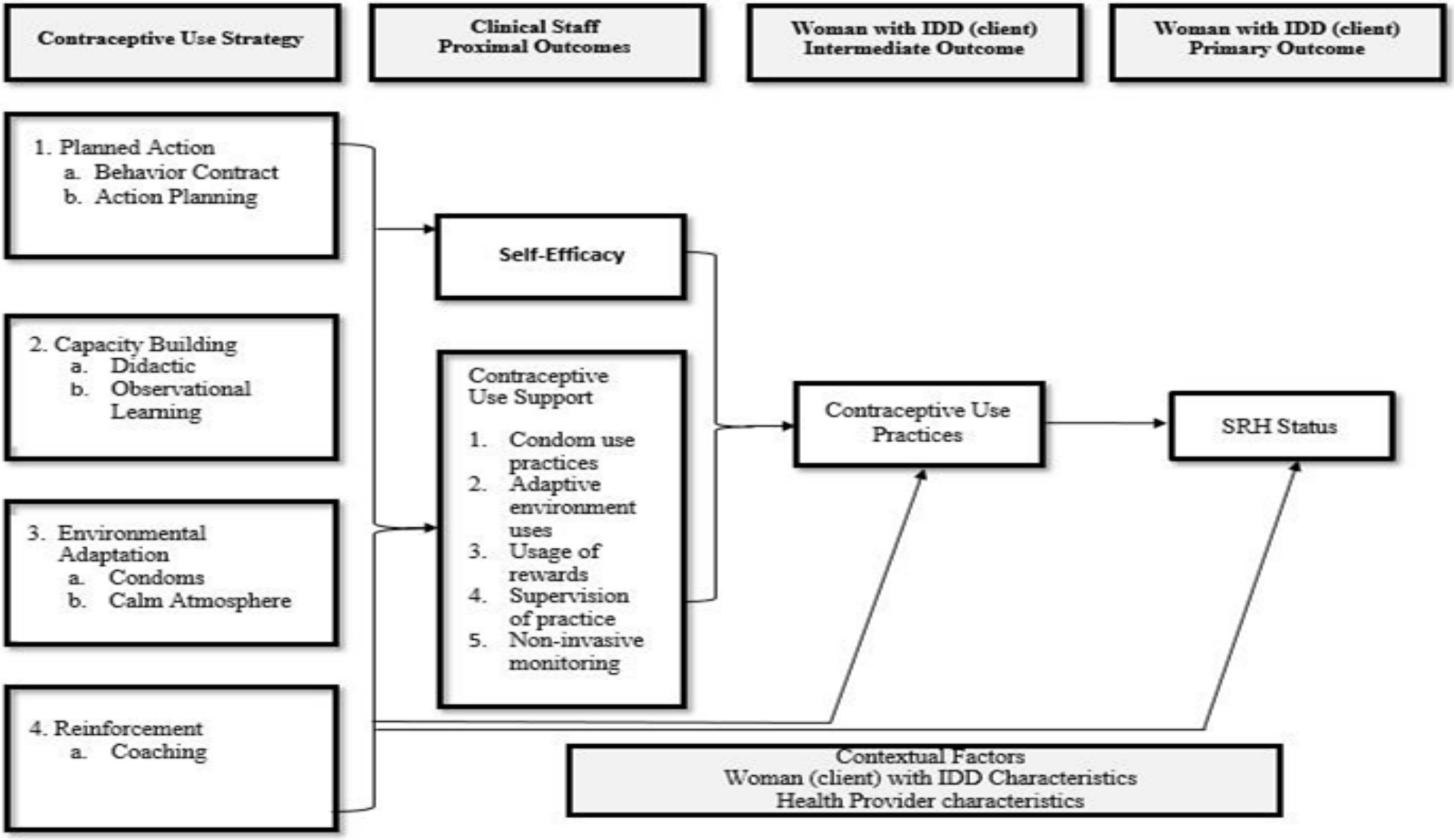
## Outcome Objectives

By 2020, the incidence of unplanned pregnancy [and STI/STD transmission] in women, ages 18-25, with ID/DD in Dillon County, South Carolina will decrease by 30%.

# 7. Theoretical Foundation

# Social Cognitive Theory

*Focus on self-efficacy.*



# 8. Intervention Overview

## modifying the clinical environment

*Educate the staff, provide appropriate instruction*

## providing framework for positive interpersonal interaction

*Capacity Building through didactic and observational learning*

## modifying the physical environment

*Create a calm atmosphere, introduce condoms and models*

## working with challeges with the client regarding the physical act of the behavior

*Coaching staff to assist clients on appropriate behavior in clinical setting, appropriate use of condom*

# 9. 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.

- CE 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 precedent 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 cerebal palsey rather than Down syndrome, but after education or meeting someone with DS, the need becomes more understandable and acceptable.

# 10. Budget Overview

Personnel- $14,400

Payroll, Taxes, Benefits- $9,000

# $60,000

***Total Grant Request***

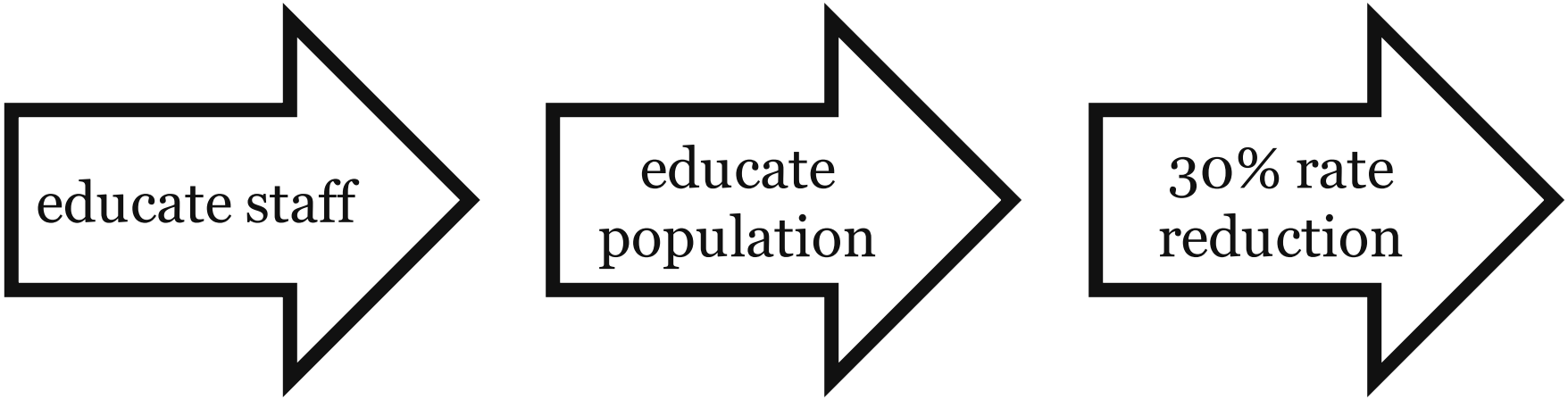
Space, Venue- $10,800

Equipment- $7,800

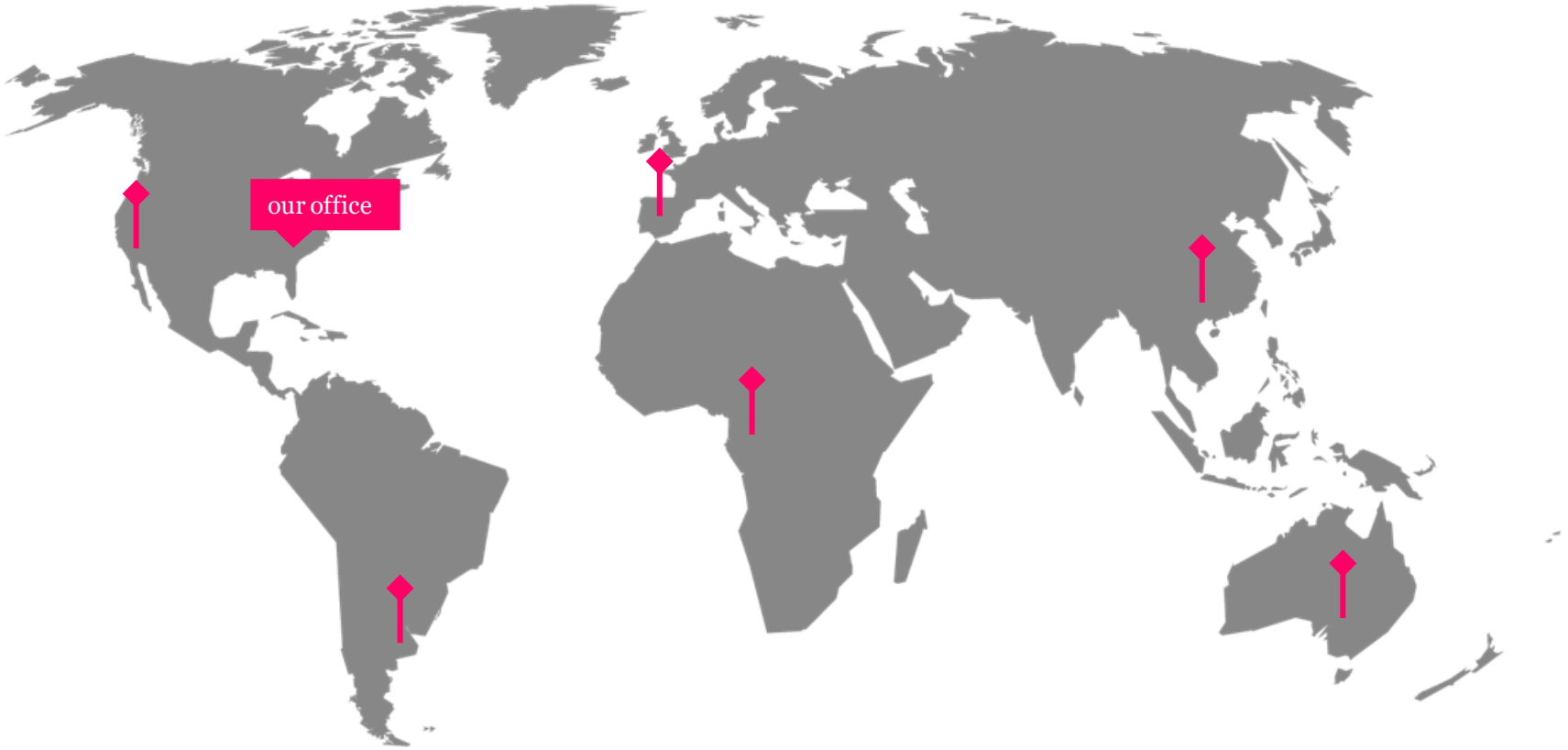
Supplies- $4,800

Other expenses- $13,200

# Our process is easy



# The program is adaptable



# 11. Bridging the Gaps

www.disabilitystatistics.org (2012 Disability Status Report)

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**13.9%**

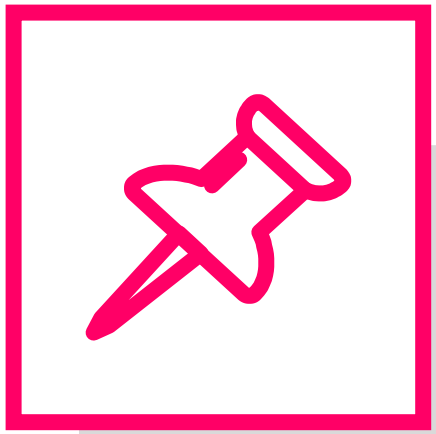
**(prevalence of disability all ages)**

**15.2% (1/6)**

**(Cognitive, Self-Care, or Independent Living)**

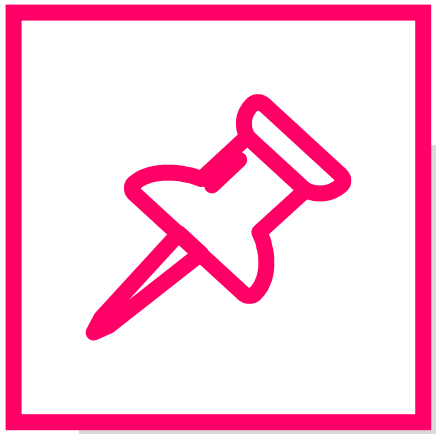
**???**

**(prevalence of STI/STD transmission in disabled population)**



# Surveillance

Although SC law mandates disease reporting, and case rates can be seperated by age, race, gender, and exposure type, **there are no current surveillence studies for this population in the Southeast**.



# Financial Resources

Without quantitative data (specific to SC) to facilitate evidence-based practice, **federal funding and state grants are difficult to obtain**.

# SC Resources

- ***able South Carolina*** **offers classes in sexuality for Independent Living**
- **www.sexualityanddisability.org is a great online resource**
- **Some (out of print) sex ed for IDD books are available on Amazon**

# What can YOU do?

- Start the conversation
- Modify, create, or volunteer with new projects, like Pioneer.
- Include new modules in existing programs for those with IDD
- Advocate for surveillence in populations with disabilities

# thanks!

## Any questions?

You can find me at

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# References

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Special thanks to all the people who made and released these awesome resources for free:


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