# Collaborating on Planning Equity-focused Research to Advance Young Adolescents' Sexual Health Development Support in Rochester, NY



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UR CTSI Equity-Focused
Dissemination and
Implementation Seminar
10/31/2023

## Presentation Outline

- Definition of sexual health terms
- The need to focus on sexual health support and research for young adolescents
- General overview of young adolescent sexual health development study
- Collaboration to plan equity-focused research

## The Researcher's Frame of Reference

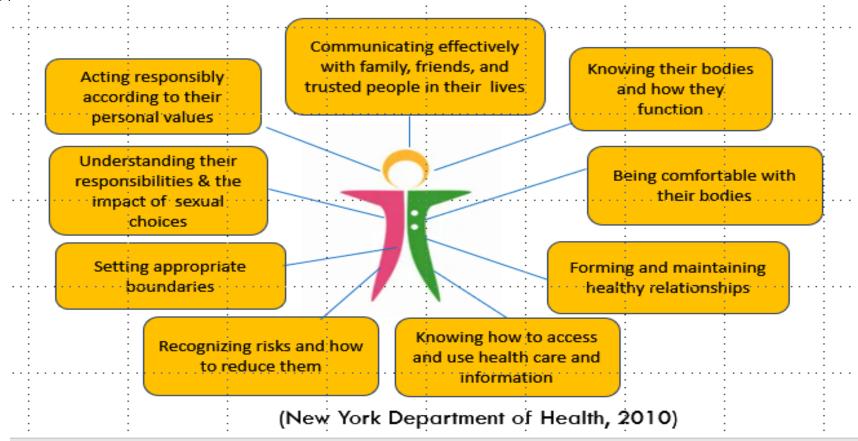
Who I am	Malawian, Catholic, Registered Nurse and Midwife						
	Nurse and Midwife Educator						
	UR Interdisciplinary Sexual Health and HIV Research Fellow						
Scholarly	HIV, Maternal and Child Health						
work	Counseling & Sexuality						
	Young adolescent sexual health development support						
Personal beliefs	Any child's sexual knowledge and behavior is strongly influenced by age, environment and education						
	True prevention happens long before the encounter						

### Sexual Health Definition

A state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. It requires a positive and respectful approach to sexuality and sexual relationships and the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled (World Health Organization 2006).

## Definition of Sexual Health for Young Adolescents

- Ability of the young adolescents to realize and put into action their individual potential around critical developmental tasks related to sexuality
  - This includes:



### **Definitions** cont'd

#### Sexual Health Development for Young Adolescents

A combination of physical, social, emotional, and cognitive sexual
maturation, the formation of a positive sexual identity and a sense of
sexual well-being, and recognition of consequences (Kågesten and van Reeuwijk
2021)

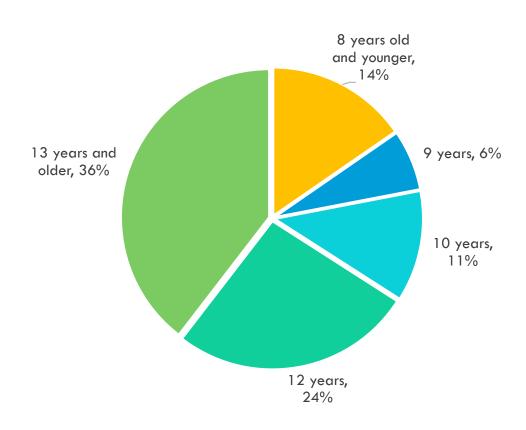
#### Sexual Health Development Support for Young Adolescents

 A human-centered, environmental and system-level strategies, policies, and actions that help prevent early sexual activities among young adolescents, and strengthen their autonomy to delay sexual debut (Centers for Disease Control and Prevention 2004)

## Why Focus on Young Adolescent Sexual Health Support

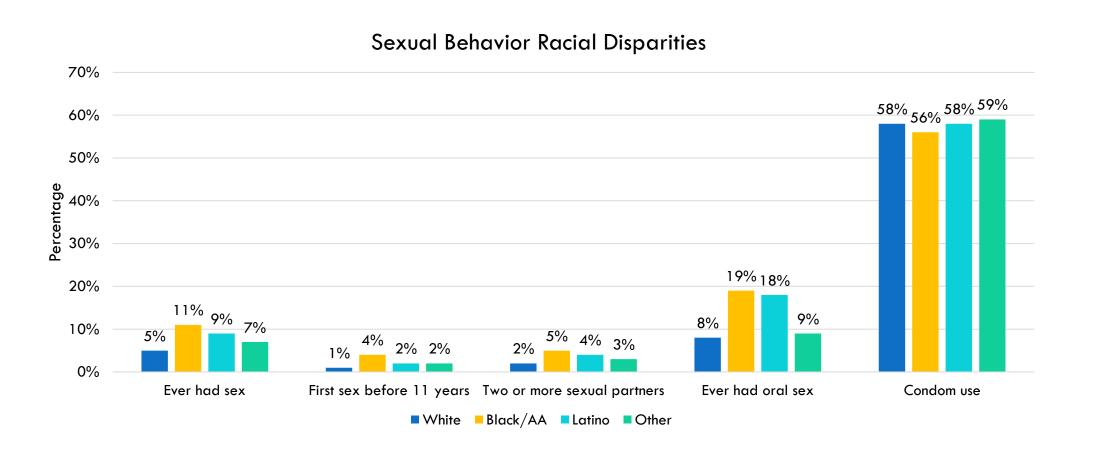
- There is an increase in early sexual debut
- 2019 Middle Sch YRBS analysis (N = 60,272)
  - 8% of 10-14 years old adolescents have had sex
  - 10 % reported having oral sex
  - 30% had sex before 11 years
  - 45% had multiple sexual partners
  - 56% used a condom the last time they had sex

#### Age of First Penetrative Sex



(CDC, 2021; Muheriwa Matemba et al. 2023)

## Black/African American young adolescents have the highest percentages of early sexual debut and low percentage of condom use



## Sexual behavior for young adolescents is underinvestigated

- Sexual behavior among young adolescents is under-investigated
- The 2019 Middle School YRBS data were only available in 10 states

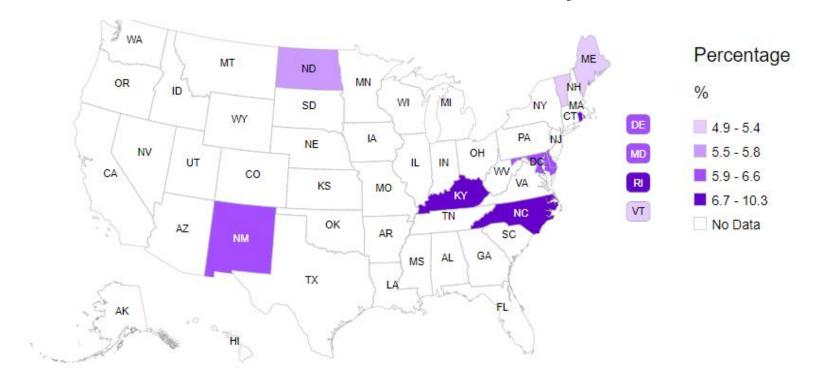
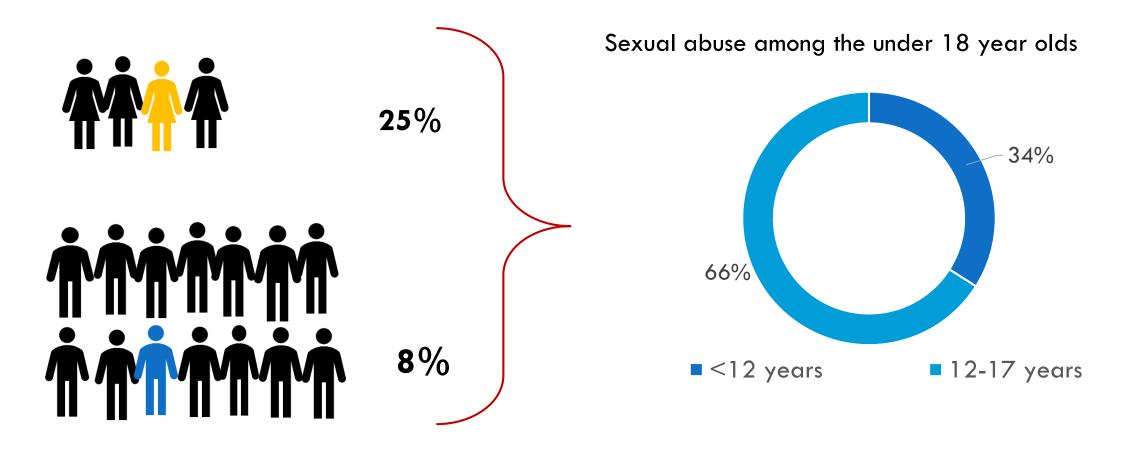


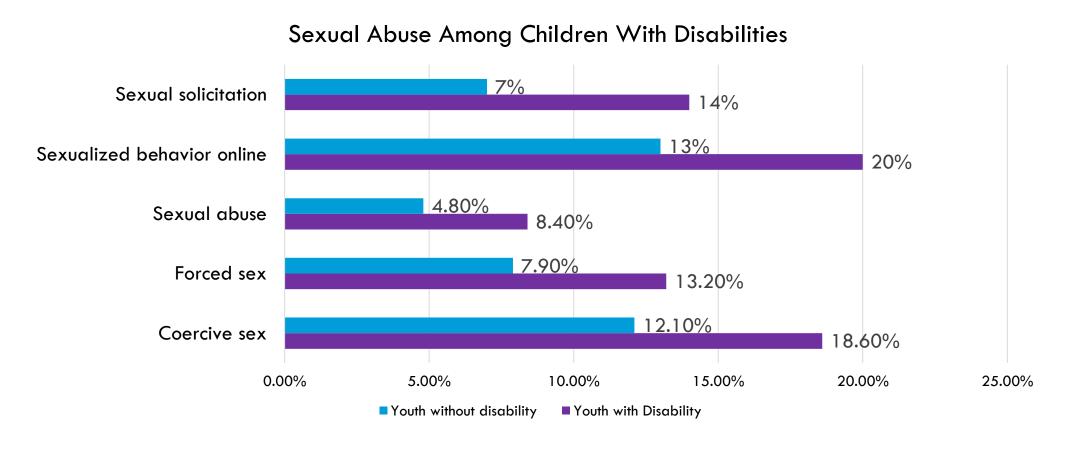
Fig. 1: Map of 2019 Middle School Youth Risk Behavior Survey Participation (CDC, 2020)

### Child sexual abuse is common



• The total lifetime economic burden of child sexual abuse in the United States in 2015 was estimated to be at least **\$9.3 billion** (CDC 2022)

## Children with disabilities are more likely to be victims of sexual abuse



Smith & Harrell, (2013)

## Impact of Early Sexual Debut



Over 4000 pregnancies occur among 10-14 years old adolescents in the US
•2.6% of total abortions are among girls <15 years



- •0.2% of STIs occur in adolescents <13 years old
- •21% of new HIV infections occur among youth ages 13-24 in the US



60% of the medical costs for new STIs is accounted for new STIs among youth 24 years younger

Teen childbearing in the United States costs taxpayers at least \$9.1 billion In New York State, the total cost for teen childbearing is estimated at \$421M

(New York State Department of Health, 2021, 2022; Zucker & Pino, 2021)

## Sexual Initiation and Impact in Rochester



#### Sexual debut

25% of high school youth have had sex

15% initiate sex before the age of 13

48% use condoms



## Early pregnancies and births

2/10,000 girls <15 years old give birth every year

26/1000 of 15–19year-old teens give birth



#### HIV and STIs

42 cases of chlamydia & 22 cases of gonorrhea occurred among youth 14 years and younger in 2020

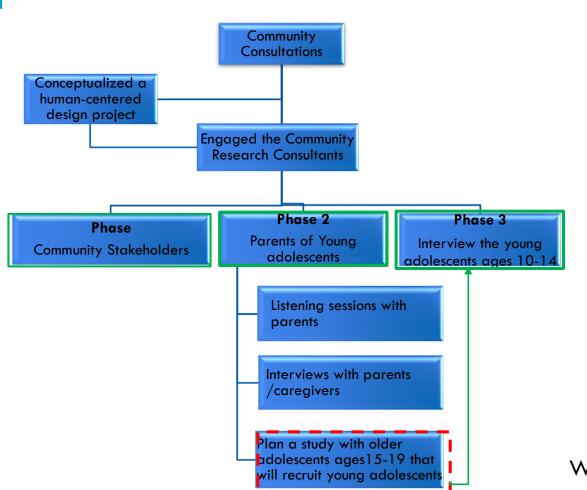
16% of the increase in new STI diagnoses between 2019-2020 was among 15-19 teens

26% of the increase in new HIV diagnoses between 2020-2021 was among youth 25 years and younger

## Why Focus On Young Adolescent Sexual Health Support

- There is inadequate sexual health support for young adolescents
  - Less than 20% of all middle schools teach sexual education as recommended by the CDC
  - Less than 50% of sexually active 15-19-year-old adolescents, receive sex education before their first sexual experience (CDC, 2022)
- Sex education often covers topics that youth of color do not find culturally relevant (Dixon et al 2021)
- Non-Hispanic Black and Hispanic youth are less likely than non-Hispanic Whites to receive instruction on sexual health (Lindberg & Kantor, 2021).
- Early adolescence is a critical time to lay the foundation for positive sexual and reproductive health outcomes.
- Ensuring universal access to sexual and reproductive healthcare services is one of the targets for Sustainable Development Goals to be achieved by the year 2030

## Young Adolescent Sexual Health Development Support Study





#### The Main Question

What are your views of the sexual health support for young adolescents (ages 10-14) and what needs to be done?

A Preparatory Project for A Study on Young Adolescents' Perspectives on Sexual Health Development Support in Rochester, NY

**Project Tittle:** Collaborating on planning research on young adolescents' sexual health development support in Rochester, NY

Funding: University of Rochester Clinical and Translation Science Award # UL1 TR002001 from the National Center for Advancing Translational Sciences of the NIH. Equity-Focused Dissemination and Implementation Research Pipeline-to-Pilot Grant

#### **CONCEPTUAL FRAMEWORKS**

#### 1. The ConNECT Framework

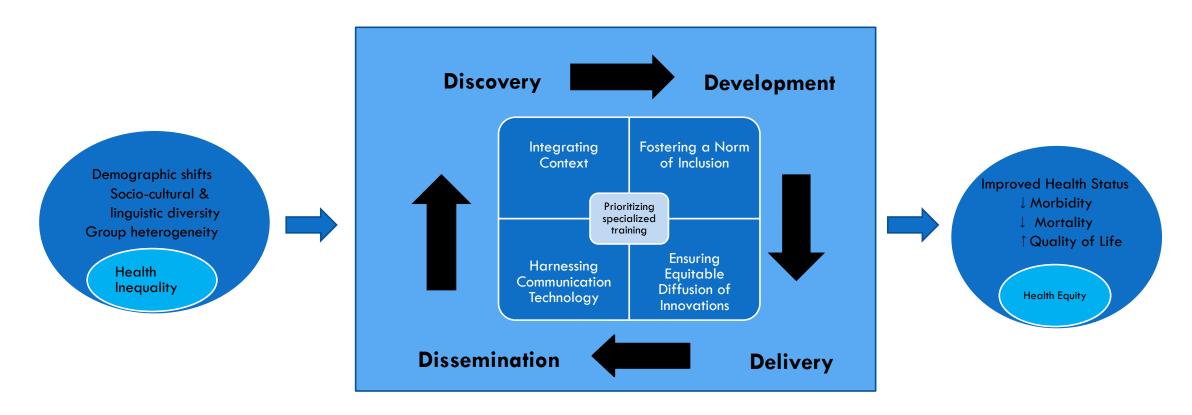
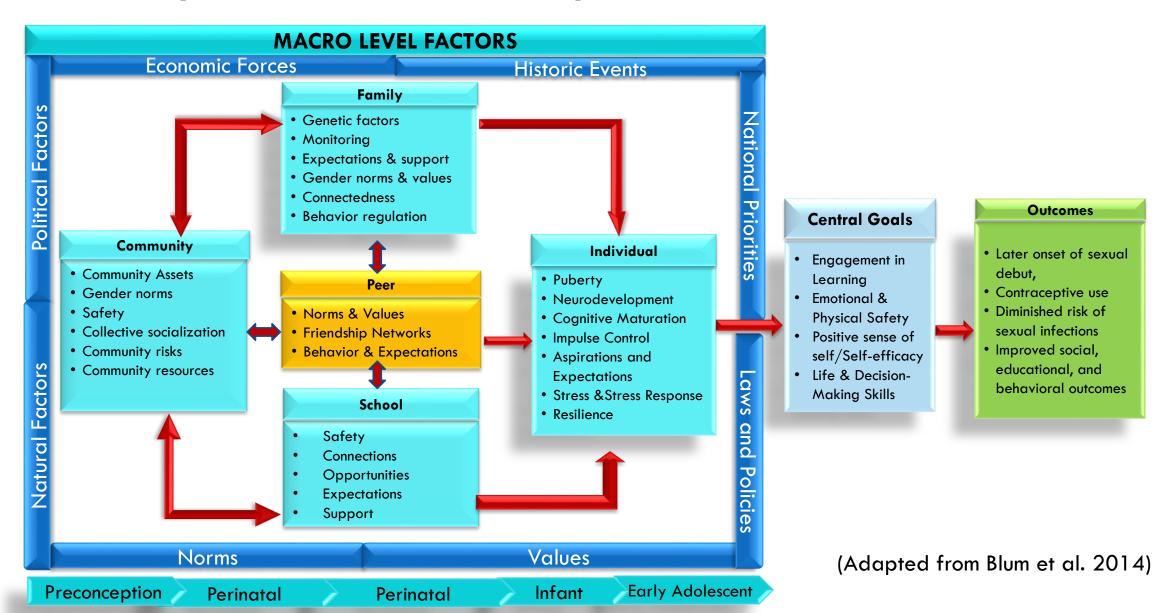


Fig1: Adapted from Alcaraz et al (2017). The ConNECT Framework: A model for advancing behavioral medicine science and practice to foster health equity. *Journal of Behavioral Medicine*, 40(1):23-38. doi: 10.1007/s10865-016-9780-4.

## A Conceptual Framework of Early Adolescence



## Project Aims

**Aim 1:** Ascertain community-identified needs for young adolescents' sexual health development support research

**Aim 2:** Determine the accessibility of young adolescents and identify methods of recruiting them

**Aim 3:** Develop a study that will recruit young adolescents to assess the feasibility and acceptability of engaging young adolescents in sexual health research

## Original Plan: Activities and Timeline

Activities Year		2022		2023						
Month	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun		
Analyze existing data and disseminate the findings										
Formulate a study team and the youth advisory board										
Conduct community mapping										
Conduct listening sessions with the youth ages 15-19 years										
Community Engagement Studio										
Develop young adolescent study & prepare a study protocol										
Submit a Letter of Intent to Robert Wood Johnson Foundation										
Prepare grant report & disseminate project results										

## **Actual Implementation: Activities and Timeline**

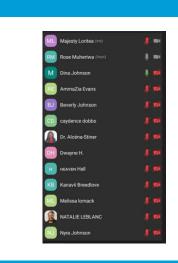
Activities Year		2023										
Month	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	
Analyze existing data and disseminating the findings												
Modifying protocol and determining how to pay the youth												
Formulate a study team and the youth advisory board												
Conduct community mapping												
Conduct listening sessions with the youth ages 15-19 years												
Develop young adolescent study & prepare a study protocol												
Submitting report to CTSI												
Planning and conducting a Community Engagement Studio												
Prepare grant proposal & disseminate project results												
Submit grant proposal for pilot study												

## The Youth Advisory Board

 Engaged 14 youth 15-19 years old to form a youth advisory board (YAB)

 The YAB was oriented to the basics of research and community mapping.







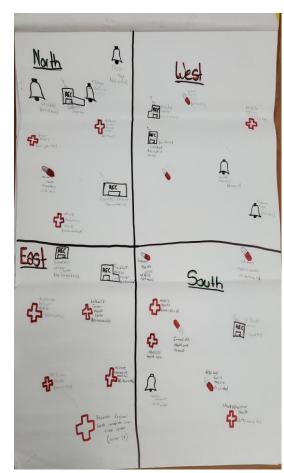
## **Community Mapping Exercise Findings**

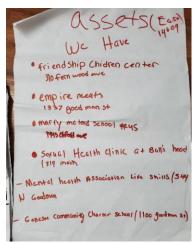
#### Assets:

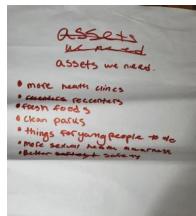
- Community centers
- Sexual health clinics e.g. Jordan health that provides birth control resources
- Mental health association that teach life skills
- Center for adolescents and young adults health
- Recreation centers

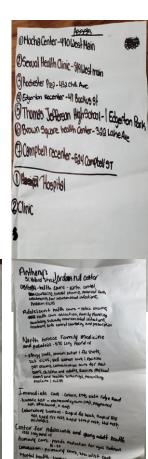
#### Needs

- More health clinics
- Recreation centers for young adolescents
- More sexual health awareness for young adolescents
- Safety









## **Youth Listening Sessions**

#### **Question** asked

- 1. What support do young adolescents in the community receive that might help them navigate changes that occur during puberty, develop and maintain healthy relationships?
  - What worked well in your experience? and what support did you wish you or other young adolescents had?
- 2. What support do young adolescents in your community receive that might help them make decisions about developing healthy relationships and their sexual behaviors?
- 3. What do the 10-14-year-olds in our area need for their sexual health?
- 4. If you had an opportunity to create a program or intervention to help young take care of their bodies, have healthy relationships, and prevent HIV or other STIs, or delay sexual initiation, what would that program look like?

## Listening Session Participants' Characteristics (N=16)

Sociodemographic Characteristics	n	%
Age		
15-17 years old	11	68.75
18-19 years old	5	31.25
Gender		
Male	6	37.50
Females	10	62.50
Race		
Black/ African American	12	75.00
Caucasian	1	6.25
Mixed race	3	18.75
Ethnicity		
Hispanic/Latino	4	25.00
Non-Hispanic	12	75.00
School grade		
High school (grades 8-12)	11	68.75
Completed high school	2	12.50
Enrolled in College	3	18.75

## Major Themes from the Listening Sessions

#### Perspectives on sexual health support during early adolescence

 Some young adolescents have open and supportive families, and are well supported, while majority are not.

I don't think there's really support for younger ages. Because I think that people always say, "They're not mature enough. They wouldn't really understand sexual health conversations or wouldn't really matter to them because they're young. For example, I wasn't really taught more on the physical and hygienic healthcare. They didn't show me a lot of that. I had to learn a lot of it on my own. And I think I would've been a lot more appreciative if they would've taught me certain things like that, how to take care of myself (A 15-year-old female).

I agree with that. I feel a lot of people, they like to have the conversation when you turn 18. They're like, Yeah, when you turn 18. That's when we can have this conversation (A 16-year-old female youth).

I don't think it's adequate at all. My nine-year-old brother is not even having health education.. I asked him, "Do you take health class?" He said no. So, I'm not aware of any type of support in terms of raising awareness about sexuality to 10 to 14 year olds. I don't think there's any at all (A 19 year old Male Youth).

## Perspectives on sexual health support during early adolescence cont'd

 Some youth felt the sexual health conversations mainly focus on physical changes.

Looking back and reflecting on what happened in middle school, I feel like my emotional state was more charged...So I felt very unprepared I feel like maybe a little more talk about how those hormones affect your psychological side of things could help. Right? Because there is so much emphasis placed on your physical aspects. Oh yeah, you're going to grow taller, You're going to grow that hair. And so there's so much emphasis because it's so obvious, but I think maybe having a little bit more talks about that heightened emotional sense or what those kind of things will do just to your brain as well. (An 18-year-old Male Youth)

## Perceived young adolescents' sexual health support needs

• Early and progressive access sexual health information and health education classes including free education, materials and counseling

The young adolescents would love to know earlier about their body changes, physical and emotional. Having a health class in one year is not enough (A 15-year-old female adolescent).

Parents that are open about sexual health talk and education

A resource I would've appreciated was just simply a parent talking to me about it. Something as simple as that, honestly that would've made a big difference... That, or brothers or anybody, just to make me aware of the situation. That would've been really nice (A 19-year-old male adolescent).

- More support from schools and school health nurses
- Access to community resources such as community centers and clinics

Youth need community centers where they could go if they do not feel comfortable talking to their parents. You need somebody to help you with that, but many do not have the access to the clinics or some programs that are available in their communities (A 17-year-old Male youth).

## Perceived age to initiate sexual health conversations

- Parents should start when children are toddlers
- Schools should start in first grade

Anyways. I agree because I feel like it's never too early, especially since it's like me personally if I was talked to a little more in depth about it at a different age, a lot of things wouldn't happen. I feel like there's a lot of things going on out there and you never know. If someone's touching you, it's like you don't know that that's something that no one should touch because you don't know what it is. People learn nothing about it (A 15 year old female youth).

So I feel like we should be taught at different ages because you never know what's going to happen in life. You never know when you're going to become active, anything like that. You should always be protected with that knowledge. And I feel like you should start, first grade. You can learn about periods or what your month is, things like that. (A 16-year-old Male youth)

## Perceived barriers to accessing sexual health support

- Lack of transportation
- Financial constraints
- Not knowing the services that clinics offer
- Fear of being judged

...In middle school, they didn't really tell us the pros and cons of it. They just said how it worked. Like what I said, I didn't know about how you could catch disease, and disease itself, until high school. So, I feel like if they taught you at an early age about the diseases and stuff, it would've been easier to know about it (A 17-year-old female youth)

Some teachers not knowing how to deliver sexual health content

I'd say in school, for me, they educated about the different diseases. But it was never from a standpoint of trying to reach to the person, it was just like, "This is the syllabus, you learn this, study this, write it on the exam." But it was never to connect [that content] to you. And I think a lot of it was they were just trying to tell you, "Just don't do this...And I think when they tried to tell you not to engage in sexual relations, people went out there, and tried it for themselves. They knew about the diseases, but if you closed them off, educating them in certain ways, I think that's how youth ended up in those situations, with STDs because they didn't know (A 16-year-old female youth)

## Perceived content appropriate for young adolescents

- Sexual health, intimacy, body changes, and different STDs
- Developing relationships
- Safety/ domestic violence
- Consent
- Sex, but were uncertain on how to tell the youth

#### Questions to ask Young Adolescents in Research:

- What they know about sex, STIs,
- Whether they ever contracted an STI and
- What they did, their practices

## Suggestions on the intervention to support young adolescent sexual health development

- Have a story book that young people can read that would have situations and consequences of actions
- Having TV educational programs for young adolescents
- Have young adolescent sexual health programs delivered by School Counselors
- Include outreach programs
- Use older siblings to provide that support
- Engage people who are three, four years older than young adolescents, about 16, 17 years, and not their peers
- Include question and answer sessions
- Introduce the intervention as early as 5 years

## Designing Research For Young Adolescents

Naming Research Project

Youth Legends Striving for Social Awareness (YLSSA)





## Designing Research For Young Adolescents cont'd



#### Design

Mixed methods

- Survey
- •Individual in-depth interviews



#### Recruitment

- School setting
- Recreation centers
- Develop flyers
- Schools to advertise
- Presentation in classrooms
- •Small group sessions
- •Experts, YAB, to assist with recruitment
- •Use of robal calls
- •Letters going out to parents



#### **Data collection**

For surveys, use multiple choice questions and true or false

Use technology, I pad

Use colorful cartoon characters

Dr Rose Muheriwa and other trained youth to collect data



## Designing Research For Young Adolescents Cont'd

#### **Research Questions**

- The YAB developed the questions to be included in the interview guide
- Revised the Global Early Adolescent Study: Health Measure (Blum, 2017)







## Community Engagement Studio

- The investigators gave feedback on the results of the formative studies
- Participants offered further guidance on how to engage the young adolescents in sexual health research and interventions
- Gave tips on how to engage schools to support sexual health research for young adolescents
- Offered further guidance on how to meaningfully disseminate the findings
- Provided further opportunities for connecting with community

#### Are you the caregiver for a child 10-14 years of age and interested in education programs for sexual health?

Share your experience and give input to design better health programs

Community Engagement Studios give people in the community the opportunity to provide feedback on health studies and programs. A researcher gives a brief and simple 10-minute presentation describing the study/project and poses specific questions for feedback. A facilitator guides the group discussion for the remaining time.

DATE/TIME: Wednesday, August 9, 6:00 - 7:30 p.m. Online

TOPIC: Community perspectives on sexual health support for adolescents 10-

UR Investigator: Dr. Rose Muheriwa



#### Investigator requests community input regarding:

- What are your reactions to previous research about sexual health support for youth ages 10-14
  and suggestions for how best to use this information?
- What are the highest priorities for sexual health needs for young adolescents in the Rochester area?
- What are some possible challenges to conducting research with youth and how can we overcon these challenges?

#### Neede

 8-10 people who are parents, guardians and/or caregivers of youth. The Studio will be held virtually, so preferably (but not required) you will have access to a computer, including webcam

#### Note:

· People who participate will receive compensation of \$50

If you are available and are interested in providing feedback on this project, please contact us by Monday, August 7, 2023.

Laura Sugarwala via email (laura\_sugarwala@urmc.rochester.edu) or by phone (585) 602-0808.



Community Engagement Studios are offered in partnership with the Center for Community Health & Prevention at URMC.



Experiences that Support Young Adolescents' Healthy Sexual Development in Western NY.

Sadandaula Rose Muheriwa
University of Rochester School of Nursing

COMMUNITY ENGAGEMENT STUDIO

08/09/202

## Challenges

- Determining how to pay youth under the CTSI grant
- Some parents could not leave the youth to be on their own during Zoom meetings.
- Some youth missed meetings
- One community consultant also stopped attending meetings and was replaced.

### **Lessons Learned**

- Zoom meetings are not appropriate for meetings with youth particularly when discussing sexual health issues
- Public libraries are good places for recruiting youth
- Recruiting youth is more effective when you meet them in person, flyers, are good but not effective
- Community research consultants/partners play a key role in community engaged research
- Community engagement studio is one of the most effective ways to get community voices and guidance on research

## **Potential Contribution To EQ-DI**

- The findings of this project will be used to support grant proposals for larger EQ-DI multi-site studies and community-informed interventions
  - Grants in preparation: R03 to pilot young adolescents' study
    - : R34 to plan and pilot a study to explore sexual health support for children and adolescents with intellectual and developmental disabilities
    - : William T Grant to explore sexual health education policy and implementation in middle schools
  - Long-term plan: NIH R01 grants for EQ-DI Intervention studies

## Potential Contribution to EQ-DI cont'd

- We continue our partnerships with youth and communities to develop interventions for supporting young adolescents' sexual health development
- Currently we are analyzing phase 2 data with our Youth Advisory Board
- We continue engaging parents in a shared decision-making process on meeting sexual health support needs of young adolescents
- We plan to work in close collaboration with school districts to examine sexual health education to inform policies for implementing sexual health education in schools

## **Acknowledgments**



Dr Natalie M. LeBlanc
(Primary Mentor)
Assistant Professor,
Harriet J. Kitzman Endowed Fellow in
Health Disparities



Dr James M. McMahon
Associate Professor
Endowed Chair for Innovation in Health Care
Co-Director, Dissemination and Implementation Science
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## Our Community Research Consultants



**Tremain Harris**Operations Associate
Youth Voice One Vision |
The Mayor's Youth Academy,
Rochester City DRHS



Asimi Coleman
Resource Coordinator
Rochester's Sexual and
Reproductive Justice Task
Force



**Dina Johnson**Founder and CEO of the Monroe County Family Coalition, Inc.



**Loritea Ellis**Community Outreach
Specialist, Rochester, NY

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- University of Rochester School of Nursing for Post doc opportunity
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- University of Rochester School of Nursing Interdisciplinary Sexual Health and HIV Research Group (INSHHR) for support and feedback
- Youth in Rochester for participating in listening sessions
- Community Consultants, community partners and Youth Advisory Board

#### References

- Alcaraz KI, Sly J, Ashing K, Fleisher L, Gil-Rivas V, Ford S, Yi JC, Lu Q, Meade CD, Menon U, Gwede CK. The ConNECT Framework: A model for advancing behavioral medicine science and practice to foster health equity. J Behav Med. 2017 Feb;40(1):23-38. doi: 10.1007/s10865- 016-9780-4.
- Blum, R. W., et al. (2014). "A conceptual framework for early adolescence: A platform for research." International Journal of Adolescent Medicine and Health, 26(3): 321-331.
- Center for Disease Control and Prevention, (2021). 2019 Middle school youth risk behavior survey state and combined data set use's guide. Atlanta, GA, Centers for Disease Control and Prevention.
- Center for Disease Control and Prevention (2022). Preventing child sexual abuse Retrieved from National Center for Injury Prevention and Control, Division of Violence Prevention: https://www.cdc.gove/violenceprevention/childabuse/fastfact.html
- Coole, M. (2000). Human-centered design. In R. Jacobson & R.S. Wurman (Eds.). *Information design*, PP 59-81. Cabridge, Massachusetts, The MIT Press

### References Cont'd

- Kågesten, A. and M. van Reeuwijk (2021). "Healthy sexuality development in adolescence: proposing a competency-based framework to inform programs and research." Sexual Reproductive Health Matters 29(1): 1996116.
- Lindberg L.D. and Kantor, L.M. (2021). Adolescent receipt of sex education in a nationally representative sample 2011-2019. Journal of Adolescent Health, 70 (2022) 290-297. doi:https://doi.org/10.1016/j.jadohealth.2021.08.027
- Monroe County Department of Public Health, (n.d.). 2021-22 Rochester city school district youth risk behavior survey report. Retrieve from <a href="https://www.monroecounty.gov/files/health/health-action/RCSD%20YRBS%202021-22.pdf">https://www.monroecounty.gov/files/health/health-action/RCSD%20YRBS%202021-22.pdf</a>

### References Cont'd

- Muheriwa Matemba, S. R., Anson, E., McGregor, H., Zhang, C. & LeBlanc, N.M. Early sexual debut among young adolescent boys and girls (10-14 years): Prevalence of early debut among young adolescents in the United States. *Journal of Adolescent Health (In press)*.
- New York State Department of Health: Guiding principles for sexual health education for young people: A guide for community-based organizations. Retrieved from https://www.health.ny.gov/publications/0206/
- Smith, N & Harrell, S., (2013). Sexual abuse of children with disabilities. Center on Victimization and Safety. Retrieved from <a href="Sexual Abuse of Children with">Sexual Abuse of Children with</a>
  <a href="Disabilities: A National Snapshot (americanbar.org">Disabilities: A National Snapshot (americanbar.org)</a>

Thank You!!!

Questions, Comments?

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