

# COMING IN LOUD & CLEAR: How to Grow Meaningful Youth Involvement

---

Maryann Davis, PhD

Kathryn Sabella, MA

Amanda Costa, BS

The Transitions Research and Training Center  
UMass Medical School, Worcester MA

Lye Yin Poon, MBA,

Community Health Assessment Team,  
Institute of Mental Health, Singapore

Ashley Tritt

M.D.,C.M. Candidate (Class of 2019, McGill University)



# Meet Your Presenters!



# Themes of the Day

1. Barriers and facilitators to youth participation
2. Balance of youth and family involvement
3. The role of social media and technology

# Overview of the Day

Part 1&2: Housekeeping & Icebreaker

Part 3: Overview of meaningful youth involvement

Part 4: Breakout Activity #1- Grow your goal!

## Tea Break 10:30-11:00

Part 5: Effective Approaches Part 1: Paid Roles

Part 6: Breakout Activity #2: How to Achieve your Goal

## Lunch: 12:30-1:30

Part 7: Effective Approaches Part 2: Volunteer/Unpaid Roles

Part 8: Effective Approaches Part 3: Involving Youth in Their own Care

Part 9: Breakout Activity #3: Developing Action Steps

## Tea Break: 2:45-3:15

Part 9: Breakout Activity #4: How to Measure Your Success

Part 10: Wrap-Up

# Housekeeping



# Stay Connected Through Social Media!

- Twitter/Fbook conference hashtags:

#IAYMH2015

#youthmh

#SGChat

- Conference Twitter Page:



@IAYMH (<https://twitter.com/IAYMH>)

@TransitionsRTC

# Group Disclaimer

- Just our experience (what we have learned...)
- It's okay to disagree!
- Different organizations do youth engagement differently, there is no “best” way, all have strengths and weaknesses
- Youth are heterogeneous – no “one fits all”
- Continuous learning experience – trial and error
- References for this entire presentation: youth who wished to remain anonymous
- Direct youth quotes
- “Honestly, this is a new field of research. And like a lot of research **it's basically going to tell you themes of what might work but it won't actually give you a guide about how youth engagement works best in a specific project.**”

# Icebreaker Activity!

1. Where are you from?
2. What is your role/title
3. How long have you worked with young adults/youth?





# OVERVIEW OF MEANINGFUL YOUTH INVOLVEMENT

---



# Fostering Youth Voice in Own Care/Services

- Important for self-determination skills
- Decision-making skills & planning skills are critical to adult functioning
- Nothing about us without us – buy-in
- All models to increase youth voice in own care: ↑ respectful and active listening
  - Respectful provision of information for informed decisions
  - Non judgemental

# PEER WORKER ROLES

---



# Peer Support Defined

- People with lived experience providing services and supports directly to their peers
- Group settings or 1-on-1
- Same-age or near-age
- Can mentor on various life skills/domains
- Utilized in a variety of settings: DMH, Hospitals, Drop-in Centers, etc.



# Why Peer Support?

- Research supports positive effects of natural mentoring and near-aged mentoring
- Peers of utmost influence
- Can increase social network
- Serve as a role model
- Instant credibility
- Recovery is a shared experience

# Peer Support Illustrated



**“You don’t have  
to have all the answers,  
you just have  
to be willing to share  
what you know.”**

# Participatory Research and Evaluation

---



# Definition of Participatory Action Research (PAR)

- A collaborative approach to research that equally involves all partners in the research process and recognizes the unique strengths that each brings.<sup>1</sup>
- PAR begins with a research topic that's important to the community with the aim of combining knowledge and action for social change<sup>1</sup>



# PAR in the Mental Health Community

## *Adult Movement*

- Strong PAR history with adults with SMHC
- Adults participating in “service-user” research
- Published case studies showcase benefits of PAR with adults with SMI



## *Innovations with Young Adults*

- Little work reported that infuses meaningful youth voice in mental health research and service design however...

**Young adults are more engaged and committed to services & supports that they have an active voice in** (Kirby et al, 2003; Oliver et al, 2006)

# PAR in Youth Mental Health

Active involvement of young adult research staff with serious mental health conditions (SMHC) in **all phases of research and evaluation efforts** from defining the problem to disseminating results



# Hart's Ladder

## Key Questions

Which level of Hart's Ladder is our project on?

Which level of Hart's Ladder should our project be on?

What do we need to do to move to the right level on the ladder for our project?

### NON-PARTICIPATION

It is important to remember that tokenism, decoration and manipulation are not examples of youth participation. You do have the choice to move away from these methods towards more meaningful participation.

### QUALITY OF PARTICIPATION

### EXAMPLES

Young people and adults share decision-making

Young people have the ideas, set up the project and invite adults to join them in making decisions throughout the project. They are equal partners.

Young people decide they need a one-stop shop in their community. They partner with adults in different youth organisations and together lobby the government for resources.

Young people lead and initiate action

Young people have the initial idea and decide how the project is to be carried out. Adults are available and trust in the leadership of young people.

A group of students get permission from their principal to run an environmental day. The students make the decisions, and the school provides support.

Adult-initiated, shared decisions with young people

Adults have the initial idea, and young people are involved in making decisions, planning and implementing the project.

A community co-ordinator asks young people for event ideas for Youth Week. The young people suggest having a skating event. The co-ordinator and young people work together to make decisions and apply for funding.

Young people are consulted and informed

Adults design and facilitate the project, and young people's opinions are given weight in decision-making. Young people receive feedback about their opinions.

A local council runs several consultations to get young people's input about a recreation park. Young people tell the council about features in the park they want changed. The council provides feedback to the young people about how their views affected decision-making.

Young people assigned but informed

Adults decide on the project and young people volunteer for it. Young people understand the project and adults respect their views.

A conference creates positions for two young people on a panel of speakers. Young people decide how to select their representatives and work with adults to understand their role.

Tokenism

Young people are given a limited voice and little choice about what they can say and how they can communicate.

A young person is asked by adults to be on a panel and represent 'youth'. The young person is not given the opportunity to consult with peers or understand the role.

Decoration

Young people take part in an event in a very limited capacity and have no role in decision-making.

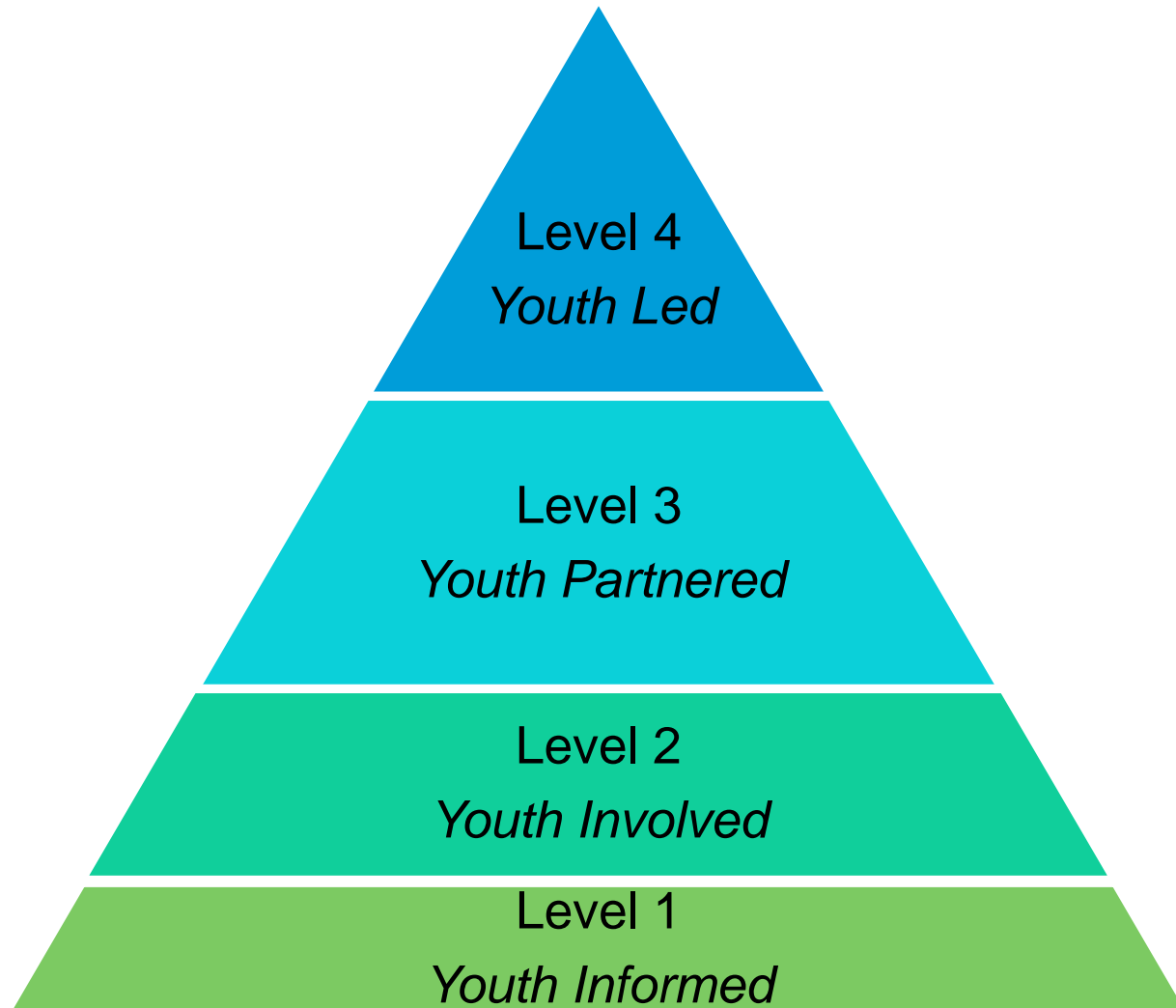
A group of young people are given a script by adults about 'youth problems' to present to adults attending a youth conference.

Manipulation

Adults have complete and unchallenged authority and abuse their power. They use young people's ideas and voices for their own gain.

A publication uses young people's cartoons; however, the publication is written by adults.

# PAR Levels of Involvement



# References

Kirby P, Lanyon C, Cronin K, Sinclair R. *Handbook - Building a culture of participation: involving children and young people in policy, service planning, delivery and evaluation*. Nottingham: Department for Education and Skills;2003.

Oliver K, Collin P, Burns J, Nicholas J. Building resilience in young people through meaningful participation. *Adv Mental Health*. 2006;5(1):34-40

# **PARTNERING WITH YOUTH TO PRODUCE SYSTEMS CHANGE**

---

# What is Systems Change?

"**Systems change**" is a shift in the way that a community makes decisions about policies, programs, and the allocation of its resources — and, ultimately, in the way it delivers services to its citizens.

Source:

[http://www.ccitoolsforfeds.org/systems\\_change.asp](http://www.ccitoolsforfeds.org/systems_change.asp)



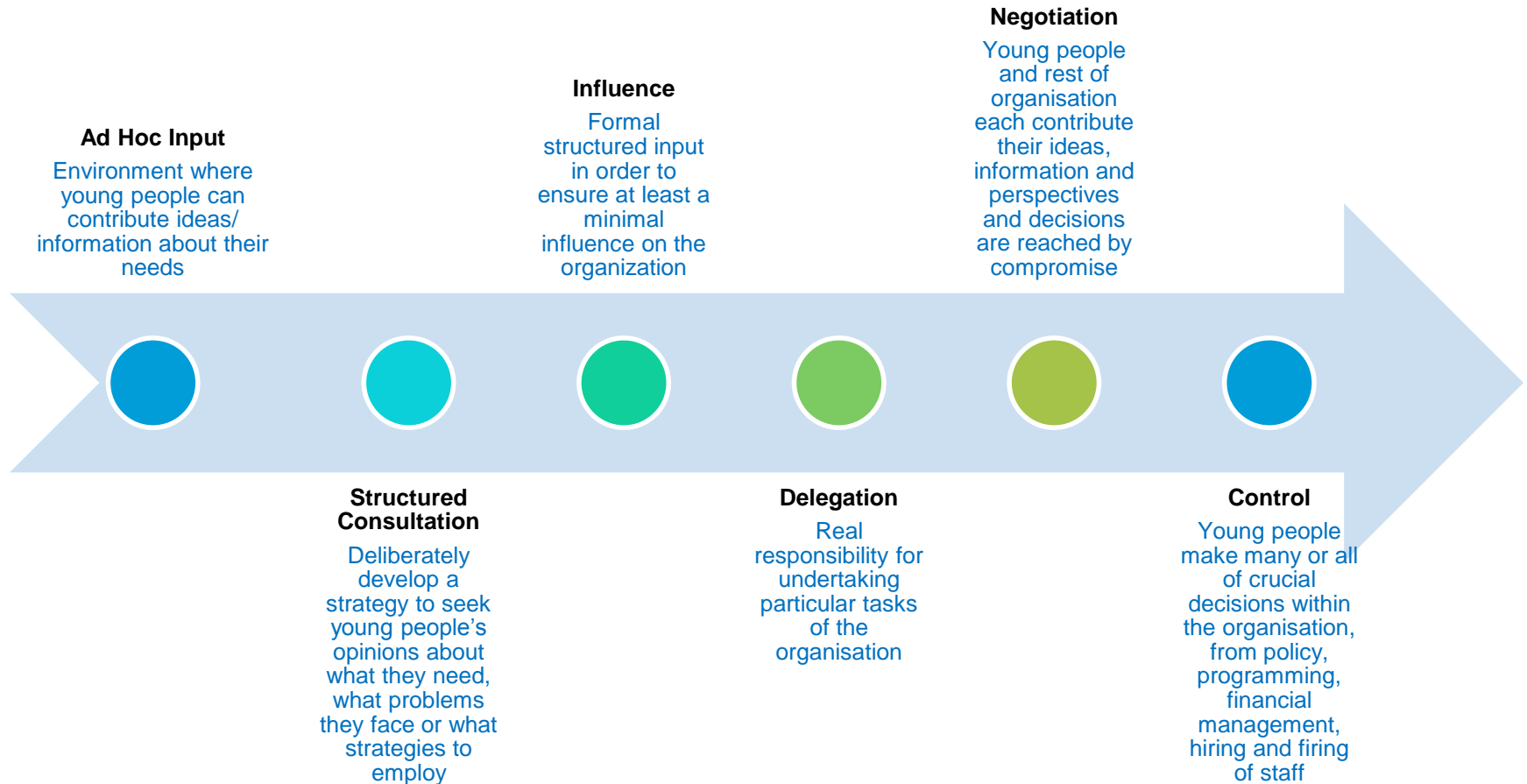
# Systems change

- **Change systems** to change the way a service is delivered to its target audience!
- No to status quo
- Change underlying structures and supporting mechanisms

*“In Headstrong we have young people participating at all levels including board level. We get expenses paid and accommodation if we need it. Things like that enable everyone to participate”*



# Continuum of Youth Involvement



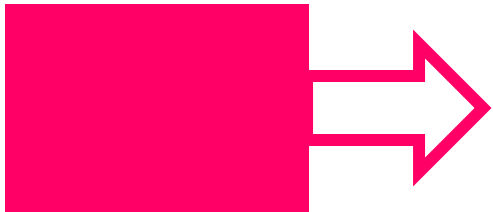
# Breaking Out Into Groups



Youth's Own Treatment



Peer-Workers



Participatory Research/Evaluation



Systems Change

# **BREAKOUT ACTIVITY #1**

---

**Developing a goal to grow meaningful youth involvement**

# Breakout Activity #1

1. Break out into the group that matches your colored notecard from the Icebreaker!
2. Work together with your group to identify where your organization currently stands regarding their level of meaningful youth involvement (see goal sheet)
3. Take notes about where you are now AND where you want to see your organization in five years

# MAKE YOUR OWN HEADLINE: 5 Minutes Of Fame Activity

---



# THE IAYMH GLOBE

[www.IAYMH2015.com](http://www.IAYMH2015.com)

THE WORLD'S FAVORITE NEWSPAPER

- Since 2015-

## INSERT YOUR HEADLINE HERE



**Develop your news headline: This is your 5 minutes of fame!**

1. Take a few minutes and think about where you want to see your organization 5 years from now in terms of growing meaningful youth involvement
2. If a major newspaper in your area decided to interview your organization about it's breakthrough in youth engagement *in 5 years*, what would you hope the headline would say?!

- Make sure your headline addresses where you want to be after 5 years of growth.... Things to consider: what do you wish youth involvement looked like in your organization/state/country? How do you get it there?

*Example Headline:*

"Massachusetts First State to Mandate Youth Voice in all Mental Health Research"

*Example Headline:*

"ABC Organization Hosts 5 Year Anniversary Party for First Ever Youth-Run Homeless Shelter"

# YOUR TITLE HERE

no.203.078

YOUR CATCH PHRASE HERE

- Since 1802

## INSERT YOUR HEADLINE HERE



### Lorem ipsum

In libris graecis appetere mea. At vim odio lorem omnes, pri id iuaret partiendo. Vivendo menandri et sed. Lorem volumus blandit cu has.Sit cu alia porro fuisset.

Ea pro natum invidunt repudiandae, his et facilisis vituperatoribus. Mei eu ubique altera senserit, consul eripuit accusata has ne. Ignota verterem te nam, eu cibo causae menandri vim. Sit rebum erant dolorem et, sed odio error ad.Vel molestie corrumpit deterruisset ad, mollis ceteros ad sea.

In libris graecis appetere mea. At vim odio lorem omnes, pri id iuaret partiendo. Vivendo menandri et sed. Lorem volumus blandit cu has.Sit cu alia porro fuisset.

Ea pro natum invidunt repudiandae, his et facilisis vituperatoribus. Mei eu ubique altera senserit, consul eripuit accusata has ne. Ignota verterem te nam, eu cibo causae menandri vim. Sit rebum erant dolorem et, sed odio error ad.Vel molestie corrumpit deterruisset ad, mollis ceteros ad sea.

*THE*

# SUN SHINE

*CELEBRITY NEWS AND GOSSIP*

*WORLD EXCLUSIVES*

## INSERT YOUR HEADLINE HERE



### Lorem ipsum

In libris graecis appetere mea. At vim odio lorem omnes, pri id iuaret partiendo. Vivendo menandri et sed. Lorem volumus blandit cu has. Sit cu alia porro fuisset.

Ea pro natum invidunt repudiandae, his et facilisis vituperatoribus. Mei eu ubique altera senserit, consul eripuit accusata has ne.

In libris graecis appetere mea. At vim odio lorem omnes, pri id iuaret partiendo. Vivendo menandri et sed. Lorem volumus blandit cu has. Sit cu alia porro fuisset.

Ea pro natum invidunt repudiandae, his et facilisis vituperatoribus. Mei eu ubique altera senserit, consul eripuit accusata has ne. Ignota verterem te nam, eu cibo causae menandri vim.



Date today 00/00/00

**NEWS**

# ARTICLE HEADLINE



In libris graecis appetere mea. At vim odio lorem omnes, pri id iuaret partiendo. Vivendo menandri et sed. Lorem volumus blandit cu has.Sit cu alia porro fuisset.

## WOW NEWS

In libris graecis appetere mea. At vim odio lorem omnes, pri id iuaret partiendo. Vivendo menandri et sed. Lorem volumus blandit cu has.Sit cu alia porro fuisset.

Ea pro natum invidunt repudiandae, his et facilisis vituperatoribus. Mei eu ubique altera senserit, consul eripuit accusata has ne.

In libris graecis appetere mea. At vim odio lorem omnes, pri id iuaret partiendo. Vivendo menandri et sed. Lorem volumus blandit cu has.Sit cu alia porro fuisset.

Ea pro natum invidunt repudiandae, his et facilisis vituperatoribus. Mei eu ubique altera senserit, consul eripuit accusata has ne. Ignota verterem te nam, eu cibo causae menandri vim.

## ARTICLE HEADLINE

In libris graecis appetere mea. At vim odio lorem omnes, pri id iuaret partiendo. Vivendo menandri et sed. Lorem volumus blandit cu has.Sit cu alia porro fuisset.

Ea pro natum invidunt repudiandae, his et facilisis vituperatoribus. Mei eu ubique altera senserit, consul eripuit accusata has ne. Ignota verterem te nam, eu cibo causae menandri vim.

# Tea Time 10:30-11:00



Be back by 11am to  
start back up!

# EFFECTIVE APPROACHES

---

Part 1: Paid Youth Worker Positions

# Paid Work vs. Unpaid Advisory Roles

Paid work = employing young adults consistently

- Remuneration sends a message of appreciation for time, effort, dedication, and expertise
  - Adults are paid for work on projects → equality
  - If you don't pay, you exclude youth who may not be able to afford to volunteer
  - Shows youth their work is valuable → they will feel more confident → they will be more likely to feel engaged → they do great work!
- Allows for ongoing learning opportunities
- Shift in organizational power
- Creates a career ladder vs. stagnant position



# Employer Challenges

- Commitment from all levels of organization
  - Fear of “minimizing rigor”
  - Lack of clarity in role development
- Youth lack of professional experience
  - Professional skills, credentials
- Staff lack of experience supporting youth
  - Lack of education about supporting youth with MHC
  - Shift in “youth culture”

# Hiring Considerations

- Identify level of readiness for employment
  - Organization vs young adult readiness
  - Mental Health Management (i.e. WRAP Plan)
  - Self-Awareness
- Provide detailed role description to **EVERYONE**
  - Responsibilities in role for youth
  - What do youth need to know walking in the door/can learn on the job/provide training as needed
  - Training for staff and supporters on supporting youth

# Hiring Considerations cont..

- Developing disclosure comfort agreement/needs pre-hire
  - Boundaries for disclosure levels
  - Disclosure on the web vs. in person
- Organizations need to embody youth as part of the solution and harness their input, as opposed to seeing them as having problems/issues that need resolution
- Be familiar with youth engagement best practices before involving youth

# Reasonable Accommodations

- Can be mandated by law
- SHOULD be implemented regardless!
- Definition: A modification or adjustment to the work environment or in the way things are customarily done that enables a qualified person with a disability:
  - to perform the essential functions of that position.
  - to enjoy the same privileges and benefits of employment as are enjoyed by employees without disabilities



# Accommodations cont..

- Bring in experts on accommodation process (i.e. ADA, Ask Jan)
- Provide written resources & guidance
- Quarterly review of request/Flexibility

**Accommodations Worksheet:**

1. Name: \_\_\_\_\_
2. Date of Request: \_\_\_\_\_
3. Name of Advocate (if you want one): \_\_\_\_\_
4. What specific Job Tasks that have been problematic/ overall issues you may be having in the workplace (DUE TO YOUR MENTAL HEALTH CONDITION/DISABILITY)?  
\_\_\_\_\_  
\_\_\_\_\_
5. How are the Job tasks mentioned in #4 affected BY your mental health condition/disability?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
6. Ideas for accommodations to address problems mentioned in #4:  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
7. If you cannot think come up with accommodations to help address your difficulties, please list what resources you've used during your search so your supervisor doesn't use them when doing their own search (e.g. websites/people/products/etc):  
\_\_\_\_\_  
\_\_\_\_\_
8. Supervisor/Manager Comments:  
\_\_\_\_\_  
\_\_\_\_\_

Signatures:

\_\_\_\_\_  
Signature of Employee      Date

\_\_\_\_\_  
Signature of Employee      Date

# Considerations for Support

- Cost-effective process (short term pain for long term gain!)
- Formal vs. informal process
- Individualize, individualize, individualize!
- Commonly provided in workplace:
  - Flexibility in work schedule
  - Productivity/organizational resources
  - Working from home
  - Headphones/Music to block distractions
  - Quiet workplace/access to private office
  - Frequent Breaks
  - JOB COACH!



# Supervision Considerations

## **A parallel learning trajectory:**

*Some young adults with serious mental health conditions are simultaneously learning to live with their mental health condition while also navigating a professional work environment for the first time.*

<http://www.pathwaysrtc.pdx.edu/pdf/fpS1310.pdf>

## **Potentially effective supervision practices:**

- Basic understanding of the mental health condition and how it affects work
- Reasonable accommodations negotiated
- Individualized and strength-based approach to supervision
- Make supervision a priority

# A Delicate Balance: Supervision versus Clinical Support



Supervisors should:

- Help manage tasks, priorities, and ensure the work gets done
- Provide a supportive environment but not provide what could be considered clinical care
- Know about an individual's mental health supports and encourage effective use of those supports in times of need OR collaborate with a separate employee in the organization that is tasked with providing that support

# PEER MENTORS AND PEER SPECIALISTS

---

# Definitions

## Peer Specialists:

- Long history within adult mental health in the United States
- Paid positions with formal trainings used within multiple service settings
- Sometimes/often reimbursable by public health insurance

## Young Adult Peer Mentors/Peer Supporters:

- Modeled after “natural” or older mentors & Peer Specialists
- Special considerations regarding Young Adulthood
- Peer can be defined as same- or near-age, with or without a mental health condition
- Diverse tasks/roles in multiple service settings, but becoming more standardized in many areas
- Paid employment opportunities for young adults

# Example #1: Vocational Peer Mentors

Test feasibility of adapted Individualized Placement and Supports (IPS):

**supported employment + supported education  
with the use of near-age vocational peer mentors**

Single group mixed method pre-post feasibility study

---

Thresholds Young Adult Program (YAP) in Chicago

**THRESHOLDS**



---

Klodnick, V.V., Sabella, K., Brenner, C., Krzos, I., Ellison, M, Kaiser, S., Davis, M. and Fagan, M. *In press*. "Perspectives of Young Emerging Adults with Serious Mental Health Conditions on Vocational Peer Mentors". *Journal of Emotional and Behavioral Disorders*. (Published online, December 30, 2014)

# Example #1: Vocational Peer Mentors

Peer qualifications:

- Self-identified as having a SMHC
- Experience in YAP or other service systems
- High school graduate with employment or post-secondary school history

40 hours of training:

- Increase knowledge of IPS model
- Learn how to share story
- Build active-listening skills



Weekly Group Meetings and 1:1 supervision



# Example #1: Vocational Peer Mentors

- **Work closely with education and employment specialists**
- Provide emotional support & **validation**
- **Engage** young people in vocational services
- **Support** young people in exploring worlds of work & school
- **Teach**, role-model, and **coach** professionalism, maintaining hygiene, and having appropriate boundaries



- 1-6 mentees per mentor
- Weekly meetings in the community

# In young people's (mentees) own words

*"[My peer mentor is]...trustworthy. I could talk to him about everything."*

*"she [peer mentor] didn't look at me differently...she didn't put on a phony act."*

*"someone who was one of us... they can talk about their life, how they get through it and show us how to do it."*

# Valued Peer Mentoring Experiences

- Receipt of advice
- Feeling related to & understood
- Opportunity to “talk” & be heard
- Relationship Building
- Trust & Safety

# Valued Peer Mentoring Characteristics

- “Strong,” “positive,” “honest,” & “trustworthy”
- Have similar life experiences and a capacity to empathize
- Having “overcome” personal struggles

# Example #1: Lessons learned

- “Peer” definition can vary
- Fully integrate peer mentors into the service team
  - Promote value and definition of role
- Develop peer mentors
  - Training and definition of role
- Support Mentee-Mentor Interactions
  - Monetary support meetings/calls
- Support Peer Mentors
  - Ongoing regular supervision (1:1 & group)
  - Support around boundaries

# Example #2:

## Peer Mentors in Mental Health Systems

- Growing in several states
- Massachusetts:
  - Young Adult Peer Mentors in 10 out of 32 Community Service Agencies that provide Intensive Care Coordination services for 18-21 year olds
  - Funded by federal grant to Massachusetts Department of Mental Health (DMH) improve services for this age group

# Example #2: Peer Mentors in Mental Health Service Systems

- *“Young Adult Peer Mentors provide **one-to-one support to young adults who are engaged in, or considering engagement in, Intensive Care Coordination services in selected CSAs.....use their own lived experience in behavioral health treatment and systems involvement to support their peers in taking positive steps toward overcoming their mental health concerns**”.*

# Example #2: Peer Mentors in Mental Health Service Systems

Struggles and considerations:

- ~2 year process to implement, still ongoing
  - Supervision structure can be tricky
  - Need to clearly define the role
  - Need full integration into team
  - Offer career growth and career track

Successes:

- Medicaid Reimbursable as Therapeutic Mentors = Sustainability!

## Example #3: Peer Support Specialists, Singapore

- Peer support in Singapore's Early Psychosis Intervention Programme started in 2010, having evolved from support groups ran by staff
- Peer Support Specialists became paid staff with roles mainly in peer support and as advisors in service improvement



## Example #3 cont..

- Some Peer Support Specialists then took on new roles in effecting systems change
  - Taken up executive roles in hospital's patient advisory committee, and advocacy roles in other non-profit organizations > act as a bridge
  - Employed as full-time staff in Singapore's National Council of Social Services' mental health division (implementation of social service plans affecting individuals with mental health conditions)

# PARTICIPATORY ACTION RESEARCH

---

# PAR at the Transitions RTC

Active involvement of young adult staff with serious mental health conditions (SMHC) in **all phases of research and knowledge translation** from defining the problem to disseminating results

- 7 PAR staff working 14-40 hours/week
- College internship program
- Engaging local and national community

**YOUTH  
DECIDE**



# Learning to Do Research

## *Interview Training*

- Qualitative Interviewing
- Developing a research question
- Safety and research protocols
- Data analysis



# The Young Adult College Study

## *The Academic Experiences and Perspectives of Young Adult College Students with Mental Health Conditions*

- Secondary Analysis of Data from the “National Survey of College Students With Mental Illnesses”
  - survey by Mark Salzer, PhD.



- Created the research questions
- Analyzed data using SPSS Statistical software
- Interpreted Findings
- Developed publications

## Breaking New Ground (Yrs 1-3)

5 Per-diem YA positions

Generalized job description

Separate YA meetings

Supervisor = main support

Internal Youth Voice

## Steering towards Success (Yrs 3-now)

PAR staff on career trajectories

Strengths based job descriptions

Culture Shift

Supervisor & Career Coach

National Youth Voice

# Successes & Benefits

## Research Team

- More authentic/rich interviews
- Engaging young adult research participants
- Stronger connection to media/technology
- Strengthened relationship with local mental health community

## PAR Staff

- PAR staff transitioning into professional roles
- Strength based work environment
- Increased self-efficacy & self-advocacy skills
- Strengthened youth voice

# Tip Sheet Feedback

**My "Must Have" Papers**  
Community of Practice, Northeast Massachusetts 2011

There are some papers that everybody must have. Here are some tips about keeping and protecting your important personal records and information.

**Get a Binder or Folder to Keep Important Documents** - an "accordion folder" works really well

**What to Keep in Your Wallet or Purse**

- State ID or Driver's License
- SNAP Card
- Health Insurance Card
- Important numbers
- Appointment Book / Calendar
- ATM Card (only if you need it)
- Who to call in case of emergency
- List of medications & what dose you take

**Essential Documents to Have**

These documents can help you get the other information you may need. You only need 2 of these to get a job and fill out the necessary paperwork.

- Birth Certificate
- Social Security Card
- State ID or Drivers License
- Passport: This document can...

**Telling Your Money What to Do: The Young Adult's Guide**  
Community of Practice, Northeast Massachusetts 2013

Has it ever felt like your money, or the lack of it, is telling you what you can or can't do if you take control of your money and spending, you can find ways to do more with what you have. This sheet provides tips on how this can be done.

**Top Money Tips**

Tell your money what to do by following these tips.

- Track your money for one or two weeks to see where your money is going - then develop a basic budget to set goals for spending. You can use the one on this tip sheet.
- Check your checking account and make sure you understand your bank's policy on overdraft checks. fines for overdrafts can be costly. You may want to punch use overdraft protection.
- Use credit cards carefully. To avoid this pay as much of your bills as you can each month.
- Can you use your emergency line or health care, unexpected medical expense, traffic tickets, etc. (payback is a great start)
- Consider a V.I.E.T. expense - cooking at home can save you a lot of money.
- Draw a budget and see expenses. Make sure to include them in your budget.
- Friends or family can add stress to your relationships. If you have to borrow money you may want to plan to pay it back.
- Don't add stress to your relationships. Family and friends love financial stress too, so they may not want to help you.

**Do I Tell My Boss?: Disclosing My Mental Health Condition at Work**  
TRANSITIONS BYC

**What Should I Say About My Mental Health Condition at Work?**

Every young adult with a mental health condition will face the decision of whether or not to tell others about, or "disclose" their condition at work. Typically the reason for disclosure is to ask for an accommodation in order to perform better at your present job. An accommodation is modifying a job, the job itself, or the way things are done in order to enable a qualified individual with a disability to have an equal opportunity for employment. The following information can provide some guidance in helping you make an informed decision.

**Some Reasons to Disclose Having a Mental Health Condition on the Job:**

- To obtain protection under the Americans with Disabilities Act (ADA)
- Required in order to request job accommodations
- To serve as a role model and educate others
- Reduces stigma

**Some Reasons Not to Disclose Having a Mental Health Condition on the Job:**

- There is no need for accommodations negatively affected due to stigma
- To protect your privacy
- Fear of:
  - Negative employer or coworker reactions to you or your work
  - People not respecting your privacy and confidentiality (others in community/ workplace will be told)
  - Being held to a different standard, i.e., less will be expected of you

**Getting Accommodations at College: Tools for School**  
TRANSITIONS BYC

If you are having trouble with school due to mental health, your school is obligated to provide extra supports and services to help you succeed. These supports and services are called accommodations and they can make a difference! Your school may also make some modifications to the courses at your request.

**What Accommodations or Modifications Can I Ask For?**

- Preferred seating
- Be able allowed during class
- Voice recorded lectures
- Classmate acts as a note-taker
- Text and syllabus available in advance
- Breaks allowed throughout test
- Frequent feedback on ongoing class work
- Alternate formats for assignments

**What Do I Need During Exams?**

- Exams in alternate formats such as written, oral, or electronic
- Extended time for test taking
- Exams given one-on-one
- Breaks allowed throughout test
- Testing in a room with limited distractions
- Allow exam to be taken in 2-3 sessions throughout the span of a few days

**What Do I Need Completing Assignments?**

- Extended time to complete assignments without lateness affecting grade
- Advance notice of assignments
- Textbook available on tape
- Assistive technology available for assignments
- Working in pairs on in-class assignments
- Help with assignments during hospitalization

**In General?**

- Reduced course load (being a full time student without having to be signed up for the normally required 12 credits)
- First choice for signing up for classes to make a less stressful schedule
- Textbook given in different format (non-computer on tape)
- Incomplete given instead of failure if relapse occurs
- Assistance with filling out financial aid registration forms
- And more!

**How to Keep a Job: The Young Adult's Guide**  
Community of Practice, Northeast Massachusetts 2013

Starting and keeping a new job can be stressful for anyone. There are healthy ways to deal with this stress. This sheet has tips to help you to be more prepared to start and keep a new job, and hopefully be a little less stressed.

**You Are Not Alone**

Make sure you have people to talk to. Create a list of your supports. These people can be your problem solvers, family, teachers, role models, counselors, church members, or friends. How many people can you count on to help you when you are feeling right now?

**Know the Rules Before You Begin**

Most companies have a clear policy or handbook on many of these questions. Take the time to read your handbook and ask questions if any part of it is not clear before you begin working.

**Questions to ask:**

- Cell Phones - Are they allowed at work? Is it a phone banking?
- Computer Use - Facebook, Twitter, and other social media sites are popular but not appropriate while at work, check the policy.
- How do I request or schedule time off?
  - How long do you have to work before you can use personal time?
  - How long do you have to find someone to cover for you?
  - Do you have to call a certain amount of time before your shift?
  - Do you need to call a certain number to take time off? What are the rules?
- Breaks - When do I get these? Where do I take them? What are the rules?
- Is there a union or dues owed?
- Overtime - What are the rules? Is it in the handbook?
- Trainings - What are the guidelines for workplace relationships?
  - Is there orientation or training where policy and procedures are reviewed?
  - Mandatory vs. voluntary - (What trainings do I have to go to and which are optional?)
  - Are there ways to advance your career?
  - What trainings are paid for by the company? What trainings are non-paid?
  - What trainings are paid for by the company? What trainings are non-paid?
- Harassment - What is it and what is the policy?
  - How is it defined?
  - How is it reported?
  - Prevention Period - What does this mean? How long is it?
  - Prevention Period - What does this mean? How long is it?

**How to Succeed Once You Begin**

Here are suggestions to help you keep your job and avoid some mistakes people make when they start a new job.



# YAB



## Diversity

- Child Welfare
- MH Services
- Foster Care
- Juvenile Justice
- Racial Minority
- College Student
- Homelessness

## National Voice

- Youth MOVE
- Home for Little Wanderers
- NAMI National
- Youth Voice Colorado

# Ty's Perspective



“Being a part of the YAB, I could see my comments put to good use. My thoughts and opinions felt important and I was treated with respect.”



# The Power of PAR



# Breakout Activity #2

**How to Achieve your goal: Identify the biggest action step needed to achieve your goal**

1. What do you perceive to be your biggest obstacle?
2. What are the needed steps to achieve the goal?
3. What is the most strategic step?



# Lunch Time! 12:30-1:30



# EFFECTIVE APPROACHES

---

## Part 2: Unpaid Youth Worker Positions

Ashley Tritt

M.D.,C.M. Candidate (Class of 2019, McGill University)

[ashley.tritt@mail.mcgill.ca](mailto:ashley.tritt@mail.mcgill.ca)

# Acknowledgements

Thank you to:

Alicia Raimundo  
Olivia Heffernan  
mindyourmind  
CAMH  
Tyson Herzog  
Aiden Harrison



**camh** Centre for Addiction  
and Mental Health

**mindyourmind**  
reach out get help give help

...And our great youth contributors who provided input/feedback to this presentation

# Preparing youth

- Be clear on youth roles before engaging them
  - What are you looking for?
  - How do you envision youth fulfilling that role?
  - What roles do youth want?
  - What are they looking to gain from their experience?
- Decide on a mutually agreed upon role: develop the role together
- Allow young people the opportunity to decide what role(s) they see themselves in



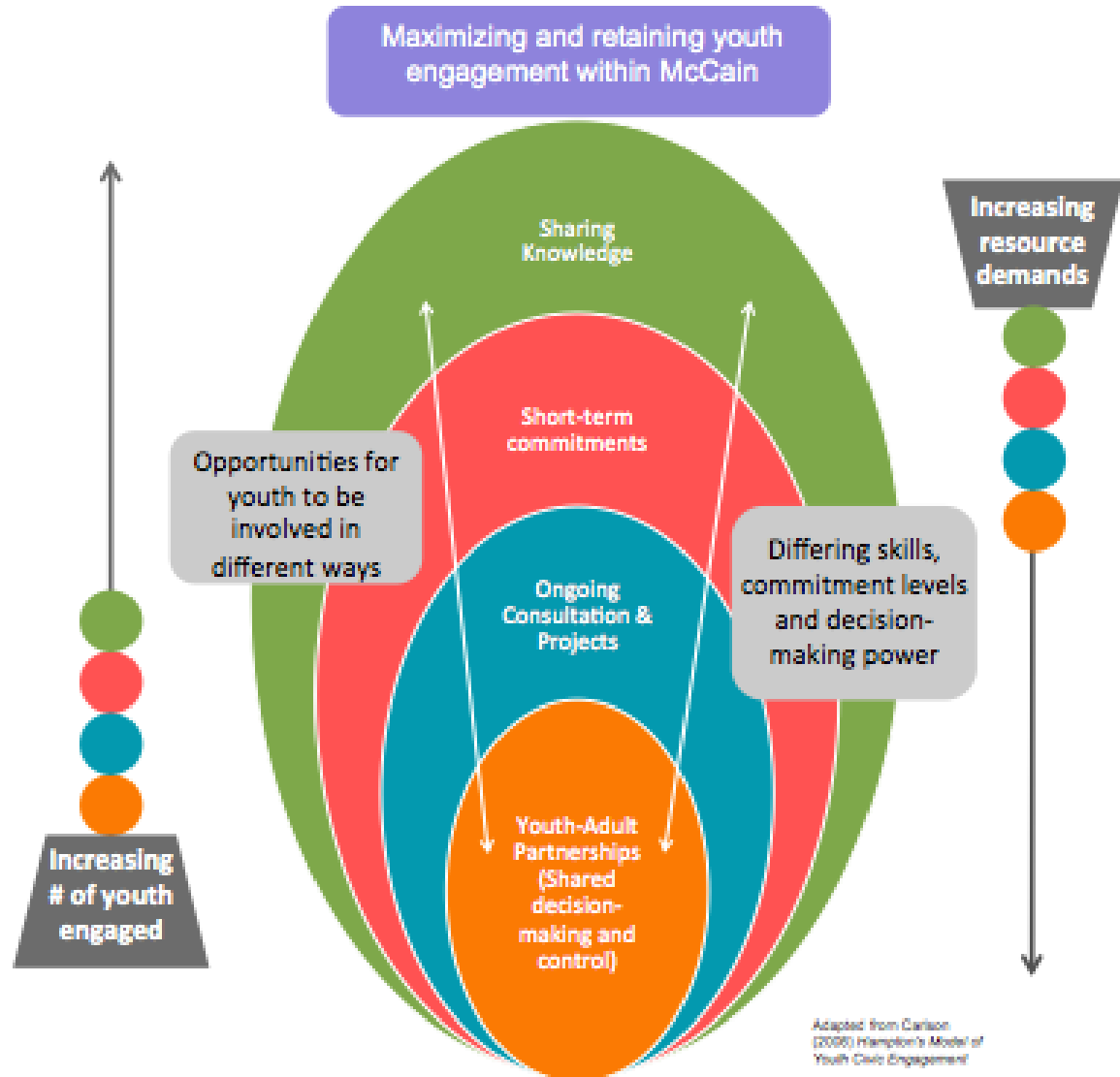
# Examples: spectrum of roles

- **Advisor/Consultant**
  - Programs or initiatives are already developed, but asking opinions of youth
- **Developer/Collaborator**
  - Youth are helping to create programs/initiatives, but less of a direct role than creator
- **Co-Creator/Decision-maker**
  - Youth are helping to create programs/initiatives (usually from the beginning stages) in a more direct role, have decision-making power
- **Youth-Led**
  - Youth are primary leaders in project, adults help facilitate youth' goals

# Examples: spectrum of roles

Herzog, Heffernan, Chaim, & Henderson. Next Level Youth Engagement: Strengthening research through youth-adult partnerships. 2015 Poster Presentation.

Consider:  
Skills involved  
Time commitments  
Resources required  
Targets and goals  
And so forth...



# Examples: spectrum of roles

- “[The importance of] gating involvement. There is a good balance between having an overly selective group to a completely open group. **I have actually felt more tokenized in big groups of youth because I felt like part of a collection being advertised to funders than actually owning any part of what was created.** Being selective is difficult but accepting everyone can also be quite tokenistic.”

# Examples: spectrum of roles

- ***“Nothing for us without us”***
- Ideally, co-creation and involvement that is equal and meaningful
  - This means investing time and money into learning from youth engagement experts on how to do this well
  - Includes all stages of work, i.e., administration, development, etc.
- Equal means understanding that the youth bring a perspective that's equally important
- **“They [youth] have to be respected as experts in their own lives - they need to be partners.”**

# Preparing youth

- Ensure mutual expectations are clear from the get-go
  - What can they expect from you?
  - What can you expect from them?
  - Be clear on possible outcomes and feasibility of youth participation
- Be careful with wording used to describe youth roles and expectations
  - e.g. “Youth led” implies youth are making decisions; “advisor” opinions may or may not lead to change
  - If expectations are unclear from the beginning, it could lead to disappointment and frustration on behalf of the young person (and the organization!)

# Preparing youth

- Establish mutually convenient communication methods and meeting times/places
  - Is the young person in school 9-5?
  - Do they prefer to receive phone calls, or emails?
  - Do they have access to long distance communication?
  - Is your office really far for them to travel to?
  - How often can you expect to hear from each other?
  - Who should youth contact for different matters?
  - Who will pay for big ticket items (e.g. travel expenses)?
  - And so forth...
- Little things may not seem important to a seasoned professional, but can make all the difference to a young person (unanswered emails, considerations for youth' out-of-pocket expenses, etc.)
- Establish confidentiality (if appropriate)

# Preparing youth

- Most importantly, establish feedback platforms or channels, both formal and informal
  - Anonymous surveys provide a great, safe way to evaluate how young people feel
  - Can be really hard for young people to express grievances, make sure to be supportive, non-judgmental and encouraging
  - Do something with the survey results (or youth will feel further disengaged) – you want to show them their voices matter and that you take their opinions very seriously

An organization's youth engagement is only as good as their youth say it is.

# Considerations for Unpaid Youth

- There are other ways to remunerate young people other than money. There are many ways to show appreciation. Be creative!
  - If no funds for regular payment → other goodies (food, cupcakes, movie tickets, reference letters, money for school books, and so forth...)
  - Volunteering is of course encouraged, sense of giving back



# Paid/voluntary

- “[...] So to speak to the paid part: paying youth is a **discussion of equality**. The adults are usually paid by an organization to spend time working on a project. If a youth is volunteering they can't have as much say in it. When you ask someone to volunteer: understand that **you are on their time**. Traditional meetings might not work, especially if they are balancing work and school. Figuring out other means like Facebook groups, etc., are great alternatives.”

# Employee vs Paid Consultant

- Depending on the nature of the young person's role, paying young people for their time doesn't mean they are now "employees"
- Young people can feel uncomfortable accepting money, and thus may feel like they "owe" something for it
- Reinforce that they are partners, they deserve to be remunerated for their expertise and what they have to offer – express how valuable they are and show it!
- Encourage them to feel good about their work and that typical "work" dynamics don't apply here

# Paid Consultant vs Volunteer Consultant

- If paying youth, make sure expectations are clear (role descriptions developed together can help set this up)
- If youth are volunteering:
  - Should feel as if they can leave at any time
  - Put strategies and processes in place to ensure transitions and continuity of work
- Regardless of volunteer vs. paid, always ensure flexibility
  - Set up mechanisms should youth need a break, have other things going on, etc.
  - Encourage the young person to be honest if they have a prior engagement, like an exam, etc.
  - They should not feel penalized for taking time off (they may feel bad enough already to ask for it!)
  - Encourage self-care, wellbeing and the importance of stating one's needs

# Genuine/tokenism

- Tokenism:
- Having youth just to say you have youth
- Having one youth who is approached for everything youth-related
- One young person doesn't represent the voices of all young people
- All youth members should be approached equally for opinions and decisions
  
- “I think [that] if people feel like there is a token youth who people always listen to/approach for things, and they aren't willing to listen or approach other youth because it's not as convenient, the young adults just won't show up.”
  
- “[...] When a group knows what they want to do, and they just want to check a box that says youth engagement so **they try and convince youth of their ideas rather than listening.**”

# Genuine/tokenism

Young people had a lot to say about tokenism...

- Tokenism:
- Developing entire proposals, projects, etc., and then involving youth late in the process when things have already been decided
- Getting things rubber-stamped or a seal-of-approval
- “Having youth there, but **the project is already decided and their feedback will only be listened to if it’s positive** [...] It’s honestly a waste of everyone’s time and can be really harmful to the young people [...] because it can make them feel like they do not matter and that adults don’t care about them.”
- “At one point I was working on a 'task force' to edit a policy paper. Unfortunately at the time, **I had no idea what a policy paper even was and no one stopped to explain it to me.** I was too shy to stop and ask so I gave feedback on something that I knew absolutely nothing about!”

# Genuine/tokenism

And more...

- “I was a part of a project where the group was happy to hear the voice and opinions of young people, but we didn't really have any decision making power. **Instead of letting us into the decision making and problem solving process, they would just make decisions without us** and then would tell us why they couldn't implement some of our ideas - even though they liked them. It felt pretty crappy.”
- “I was a part of something that was so meaningful to me and then, suddenly, I wasn't. [...] It's been more than a year now and I still feel so sensitive and upset about not being able to contribute. [...] I feel embarrassed that I've been so negatively impacted by it. [...] I would say that it has made me lose confidence in myself and made me consider pursuing a different career path due to this experience. [...] I think **people sometimes forget the vulnerabilities of engaging people with mental health issues and it can be a really derailing experience for them if it's not done properly.**”

# Genuine/tokenism

And more!

## The “80%” and the “20%”

- “Youth engagement **needs to access the other 80%** - not the 20% who are already invested and keen...while they are invaluable and need to continue to be a part of the process, broader perspectives are not being heard, and real change isn't happening besides what we choose to look at on the surface.”
- ““...This underlines the importance of increasing organizational capacity for youth engagement. In my opinion, to effectively engage with a truly diverse and representative group of young people (in your target population/demographic), it **requires a well-researched, well-planned, well-supported, and well-funded youth engagement strategy**. People who seek youth input **need resources to be creative, flexible and accommodating enough to capture the voices of those who aren't being heard.**”

# Genuine/tokenism

- Differentiation:
- *“We did this entire proposal... What are your thoughts?”*
  - Be willing to take time to explain each aspect, the reasoning behind each aspect, and to change/compromise on something if youth disagree
  - Give enough time for youth to look it over and really give their opinions (even if you don't like what they may have to say if it means more work for you!)
  - If you ask them to put their name on it.... They should have contributed in a meaningful way (development, creation, changes, etc.)
  - If you ask for their opinion, ensure enough time for them to actually look it over (and ask them prior what a reasonable time frame looks like)



# Genuine/tokenism

- Genuine:
- Youth feel valued, heard, and involved
- Youth feel their voices matter, they feel engaged
- They feel their participation is meaningful and impactful
- Youth voices lead to action and change
- Youth feel their expertise are respected
- They feel they are true partners
  
- “In our current funding structure, grants and funders often want to know how many youth are involved or affected by a project. This has led to the practice of collecting young people, which means that getting young people associated with the project, purely for numbers’ sake and not knowing how to engage them beyond that. **It doesn't matter if you have 100, or even 1000 young people involved if they don't feel like they have any meaningful effect on the project.** Often times, we will say we have 100s of young people involved when what we really mean is that we have 100 emails and only 8 people who are really involved. “

# Genuine/tokenism

Youth also got very excited talking about genuine and meaningful involvement!

“I was in a youth committee on mental health and it was one of the most positive experiences ever for me. [...] We organized ourselves and had young people chairing the committee. It was really powerful **as we all felt comfortable enough to discuss drawbacks and negative emotions as well as the positive sides to the projects that we were working on.** It was great to work with a strong group of people that truly believed in youth engagement - without having ego or power get in the way.”

“I was involved in a project where the people were really flexible and nonjudgmental. They took into consideration the other things I had going on at the time (university, volunteering, etc.). For example, **I wasn't made to feel badly when I showed up late to a meeting.** When I apologized for my lateness, the facilitator just smiled warmly and said "There's no need to apologize - you're right where you need to be. Welcome. We were just talking about..."”

# Genuine/tokenism

Really excited!

- Genuine:
- Importance of continuous youth validation
- “I think it's about asking youth. Do you feel tokenized? Do you feel like this project is allowing you to feel ownership of it, like it matters to you? [...] Do you feel like people are only engaging youth who talk, act, and believe like them? **Are they keeping youth engaged who make things messy by disagreeing with them?**”
- There is a major difference between:

*“We engaged youth” and “Youth were partners”*

vs.

*Youth themselves expressing that they feel engaged and consider themselves as partners*

# Genuine/tokenism

Young people have so many positive, great ideas about engagement...

- How do we create genuine involvement? We ask!
- “A few ways: learning how to create brave spaces, where young people will feel comfortable disagreeing with you or your plan and not feel like their future involvement would be compromised.”
- Creating brave spaces means thinking about how a room is set up, what is the environment like, what are the power dynamics that need to be addressed, and listening twice as much as you are speaking
- “Always reviewing the youth engagement process and **being honest with what worked and what didn't. A lot of folks want to say they are the best, first, or only, at something** but the truth is we can all improve and learn from many others before us that have done youth engagement.”
- “I think it's about **constantly evaluating your process and listening.**”

# Genuine/tokenism

...That are waiting to be heard and implemented

- How do we create genuine involvement? We ask!
- “Building a relationship with youth - making them feel valued and important, that their opinion is something you truly do value, not just something you seek so you can put down on paper that your initiative "consulted youth" or was "youth created" **when you just threw young people into a room, let them talk, and then did what you wanted anyway.**”

# Genuine/tokenism

- Use youth opinions to generate change
- “I think if you don't fix it **people just stop showing up to your meetings.**”
- Importance of reflection, humility, compassion, and follow up
- If something goes wrong, address it as soon as possible with the young person and see what can be done to mend the relationship; do not ignore the issue!
  - If issue is ignored, or person just leaves without follow up, they may feel used/replaceable/unappreciated/vulnerable, etc.
  - To err is human – always address it, learn from it, and move on!
  - An apology goes a long way (and helps address power dynamics, allowing youth to feel more comfortable)

# Funded/independent

- For youth who may also represent/be funded by other organizations, who are they beholden to? Important to discuss!
- Should young people be independent representatives?
- How do they balance their perspectives in relation to the organization?
- “Meaningful involvement means when there is a mutually beneficial relationship between youth and the organization. The youth grows, gains connections and isn't afraid to be involved in several different projects. Too often, organizations want to keep youth "in the family" and discourage them from spreading their wings and trying out other organizations. I hope that people understand that **the most engaging experiences for me are places that encourage me to grow and try other things.**”
- **“It's not fair to try and own young people or their stories; accept the gifts they give you, don't ask for more.”**

# Balance of youth/family input

- Certain age limits to joining organizations without parental knowledge
- Look up legalities, consider risks
- Having family present can be very overwhelming for youth
- Parents = experienced, can overpower youth voices
- Youth may not feel safe/confident in presence of families (parents)
- Ask youth how they feel with family involvement in a project/group
  
- “Family members and youth are very separate groups with very different experiences. Combining them [often] means having one voice or experience shine over another. It's important to give them their own spaces and figure out how they can collaborate while not letting the parents take over. It's especially hard because a lot of youth are triggered by parents.”



# Summary

- Clear expectations
- Explicit youth-derived goals
- Youth-led projects
- Lots of choices
- Flexibility
- Young, relatable leaders
- Shared decision-making
- Evidence-informed (do your research!)
- Transparency
- Reciprocity and co-learning
- Continually evolving
- Adults as resources/mentors/allies
- Youth-friendly environment
- Opportunities for youth personal development
- Youth recognized for contributions (e.g. honoraria, wages, certificates)

Adapted from: Herzog, Heffernan, Chaim, & Henderson. Next Level Youth Engagement: Strengthening research through youth-adult partnerships. 2015 Poster Presentation.

# EXAMPLE #1

---

Lye Yin

Community Health Assessment Team  
(CHAT), Singapore

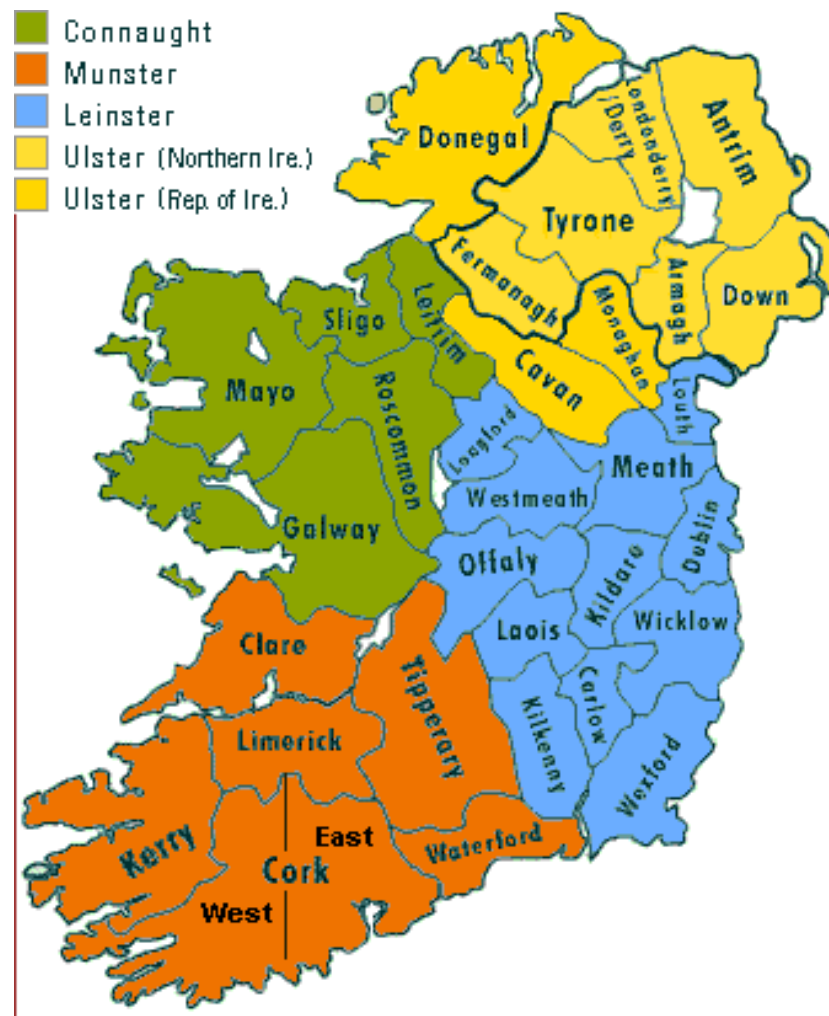
8 Oct 2015



Community Health  
Assessment Team

# Ireland

- In terms of GDP per capita, Ireland is ranked as one of the wealthiest countries in the OECD and the EU-27 as of 2008
- Ireland's National Office of Suicide Prevention reported that Ireland's suicide is 4<sup>th</sup> highest in Europe
- High rates of suicide and self-harm amongst the young





2006: founding of Headstrong – The National Centre for Youth Mental Health



Focus groups with parents, community members and governments

Large-scale survey (My World Survey, MWS) to establish national baseline of youth mental health in Ireland amongst young people aged 12-25 years

# Core values of Headstrong

<https://www.headstrong.ie/about-headstrong/>

**Respect** the voice of young people

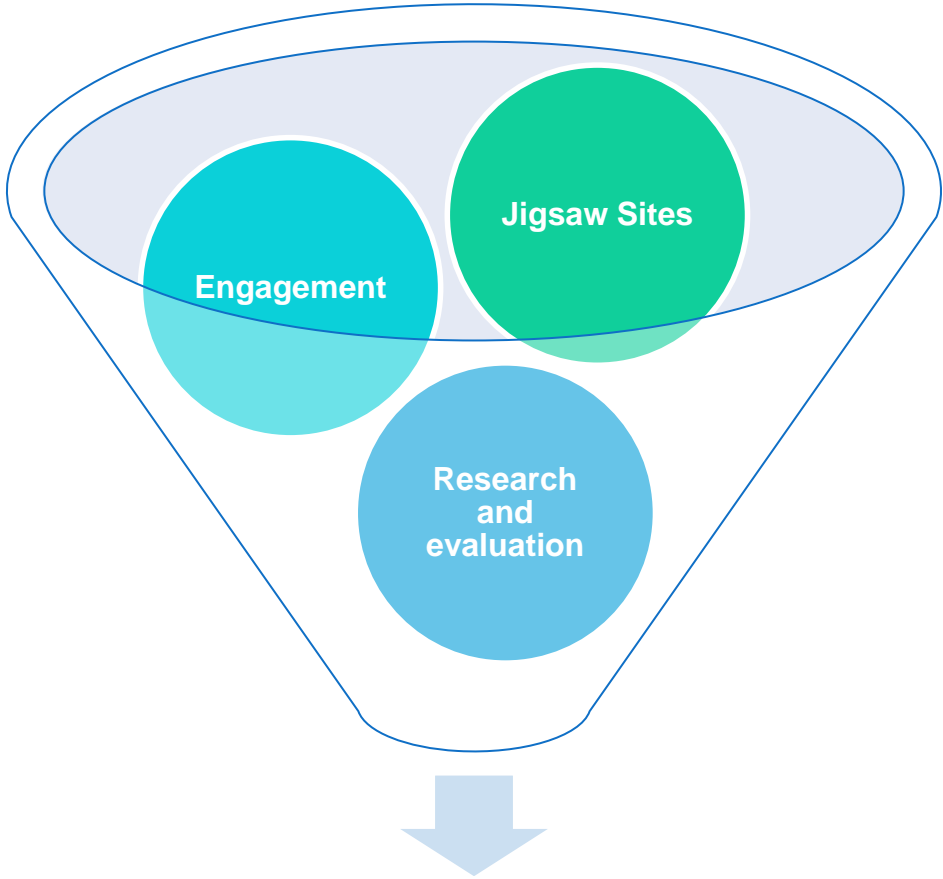
**Believe** that all young people should be given the supports they need to develop good mental health

Recognise that young people, communities and **government all have a role and contribution** in developing a supportive environment

Strive to **innovate, challenge and apply best practice** in youth mental health in an Irish context

Research and evaluate all of our activities as an **evidence-based led organisation**

# Core components of Headstrong



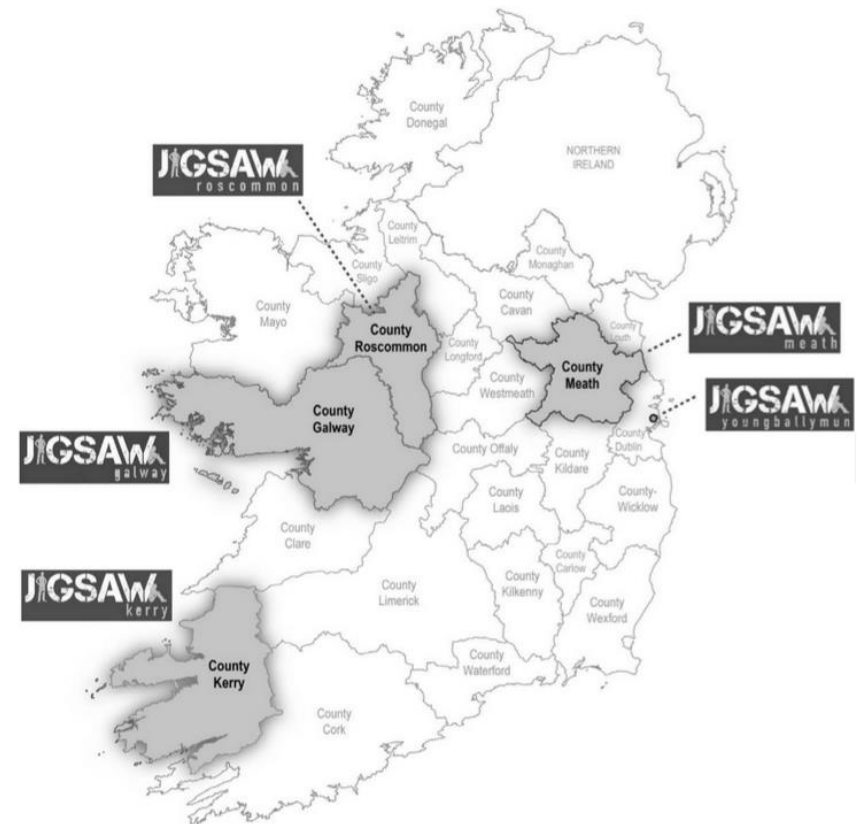
# WHERE IS YOUTH INVOLVEMENT IN SYSTEMS CHANGE?

---

# Jigsaw sites

- Where young people, their families, service providers and community agencies can engage with one another to support and intervene for young people's mental health
- Design of Jigsaw sites
- Design, implementation and review of programmes

FIGURE 1. Jigsaw demonstration sites in the Republic of Ireland.





# Engagement

- Youth Advisory Panel: advise on providing and developing our support services for young people
- Youth Learning Network



*“Hello from Ireland! Here is a picture of the Jigsaw Youth Learning Network (YLN) it brought together the Youth Advisory Panels (YAP) from all over Ireland. It was all planned by young people with the support of adults.”*

# Research and Evaluation



**Effectiveness of  
Jigsaw sites**



**Foundation  
Papers**

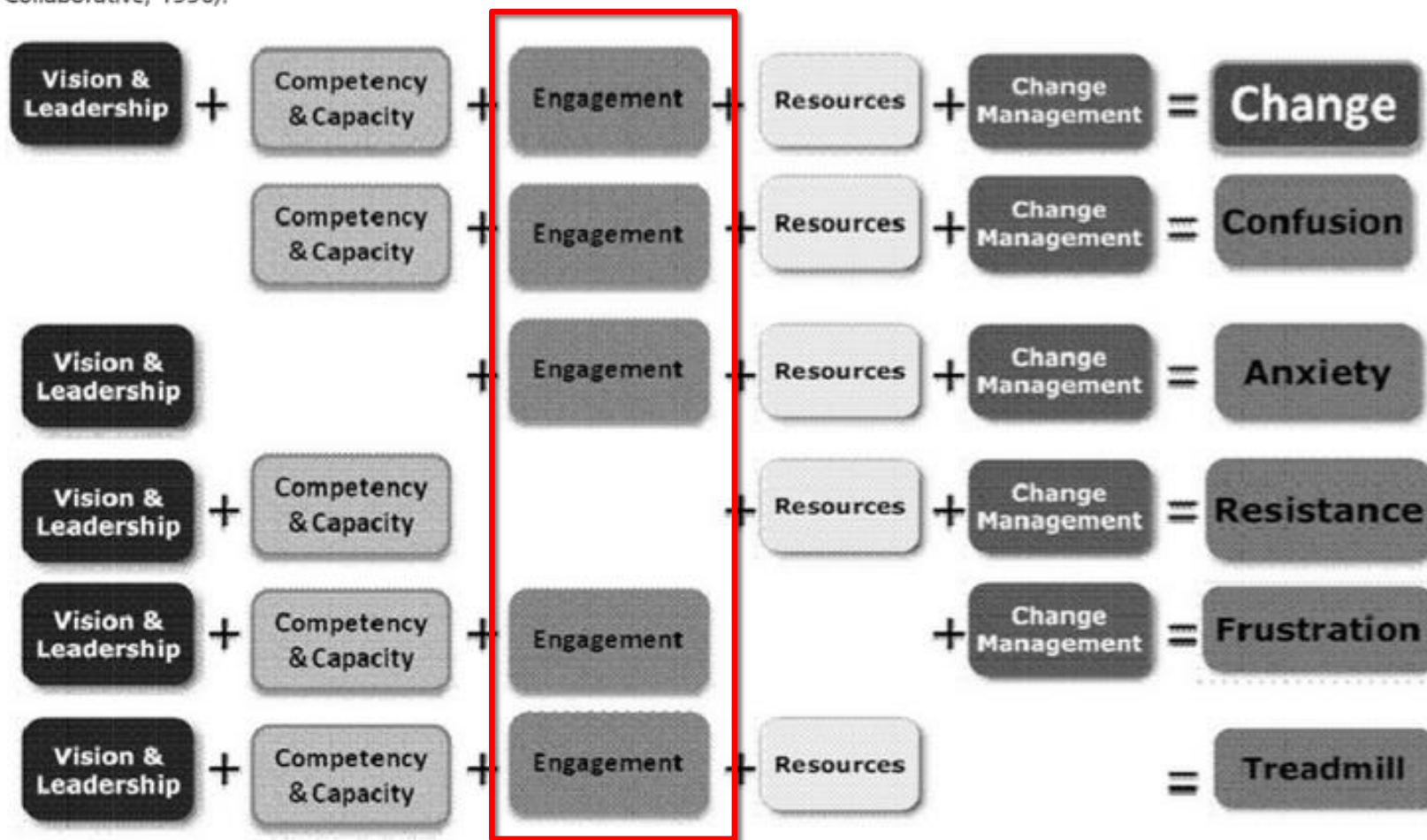


**Trends in youth  
mental health**

# What have I learnt

- Youth engagement and involvement in systems change:
  1. Young people exist in **systems!**
  2. Youth input for systems change can be **subtle** (e.g. via research surveys, feedback)
  3. **Build/ Grow** active involvement of those with lived experience

FIGURE 2. The Active Ingredients of Systems Change in Youth Mental Health (Adapted from: T. Knosler, 1991 and Human Service Collaborative, 1996).



# EFFECTIVE APPROACHES

---

Part 3: Strategies to Involve Youth in Their Own Care

# Models for 1-on-1

- Motivational Interviewing most common
- Shared Decision-making (more medical model)
- Person-Centered Planning



# Shared Decision-Making

## Key characteristics

- At least two people, acting as partners, are involved - generally, the health care provider and client/patient
- Both partners take steps in sharing a treatment decision
- The two partners share information about treatment options
- The partners arrive at consensus regarding the preferred treatment options (Charles, Gafni, & Whelan, 1997; Schauer, Everett, del Vecchio, & Anderson, 2007)

# Shared Decision-Making

- Focused on medication in MH
- <https://store.samhsa.gov/shin/content/SMA09-4371/SMA09-4371.pdf>
- <https://www.patdeegan.com/commonground>
- No approach specific to young adults





# Motivational Interviewing

- An evidence-based treatment that addresses ambivalence to change
- A conversational approach designed to help people identify their readiness, willingness, and ability to change and to make use of their own change-talk
- <http://www.motivationalinterviewing.org/>



# Components of MI Spirit

**A** = Autonomy (vs. authority)

**C** = Collaboration (vs. confrontation)

**E** = Evocation (vs. education)

# Basic MI Principles

**R** = resist righting reflex

**U** = understand client

**L** = listen to client

**E** = empower client

**MI based approaches effective in adolescents, young adults, and not-young adults**

# Team Approaches

## Achieve My Plan

- A structured process for implementing
  - Organizational commitment
  - Preparation for youth
  - During the meeting: meeting structures and interactions that promote youth participation
  - Accountability

<http://www.pathwaysrtc.pdx.edu/pdf/Webinar AMP.pdf>

# AMP Ground Rules

- Stick to the agenda (use the parking lot)
- Speak directly to each other, not about one another
- One person talks at a time
- Be respectful of everyone's voice and ideas
- No side conversations
- AJAA - Avoid Jargon and Acronyms
- Focus on strengths and solutions
- Don't assume you know what others are thinking- Ask them
- End the meeting with everyone clear about commitments and next steps

# Other Team Approaches

- Open Dialogue

[https://www.power2u.org/downloads/becomingdialogic\\_AN\\_ZJFT11.pdf](https://www.power2u.org/downloads/becomingdialogic_AN_ZJFT11.pdf)

- Transition to Independence Process (TIP)

<http://www.tipstars.org/>

- Project RENEW

[http://www.iod.unh.edu/Projects/renew/renew\\_main.aspx](http://www.iod.unh.edu/Projects/renew/renew_main.aspx)

# BREAKOUT ACTIVITY #3

---

How to Achieve your Goal: Developing a Timeline

# Developing a Timeline

Activities	Priority	Deadlines



# Tea Time 2:45-3:15



Be back by 3:15pm  
to start back up!

# BREAKOUT ACTIVITY #4

---

Timeline continued & Measuring Your Success

# Breakout Activity #4

1. Finalize your activity timeline and details from Breakout Activity #3
2. Think through how you will know when you have reached success with implementing your goal
  - Indicators of success
  - How to measure level of success

# Wrap-Up and Reporting

- What do your goals look like now?
- What resources will you look into moving forward?
- How can you keep up the stamina?



\*Slides will be made available next week via e-mail!\*

