

MOVING FORWARD

Fostering Youth Leaders in the Mental health Community

Amanda Costa, BS

Lisa M. Smith, BA

NAMI National Convention, 2015



The Learning and Working During the Transition to
Adulthood Research and Training Center

Acknowledgements

The Transitions RTC aims to improve the supports for youth and young adults, ages 14-30, with serious mental health conditions who are trying to successfully complete their schooling and training and move into rewarding work lives. We are located at the University of Massachusetts Medical School, Worcester, MA, Department of Psychiatry, Systems and Psychosocial Advances Research Center.

Visit us at: <http://labs.umassmed.edu/transitionsRTC/index.htm>

The contents of this presentation were developed with funding from the US Department of Education, National Institute on Disability, Independent Living, and Rehabilitation Research, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (NIDILRR grants H133B090018 and H133B140040). Additional funding provided by UMass Medical School's Commonwealth Medicine division. The content of this presentation does not necessarily reflect the views of the funding agencies and you should not assume endorsement by the Federal Government.



The 5 Questions We Will Answer:

1. How do we define leadership?
2. Why is youth leadership important?
3. What are important qualities in a youth leader?
4. How do we build leadership opportunities?
5. Bringing youth leadership to the wild web!

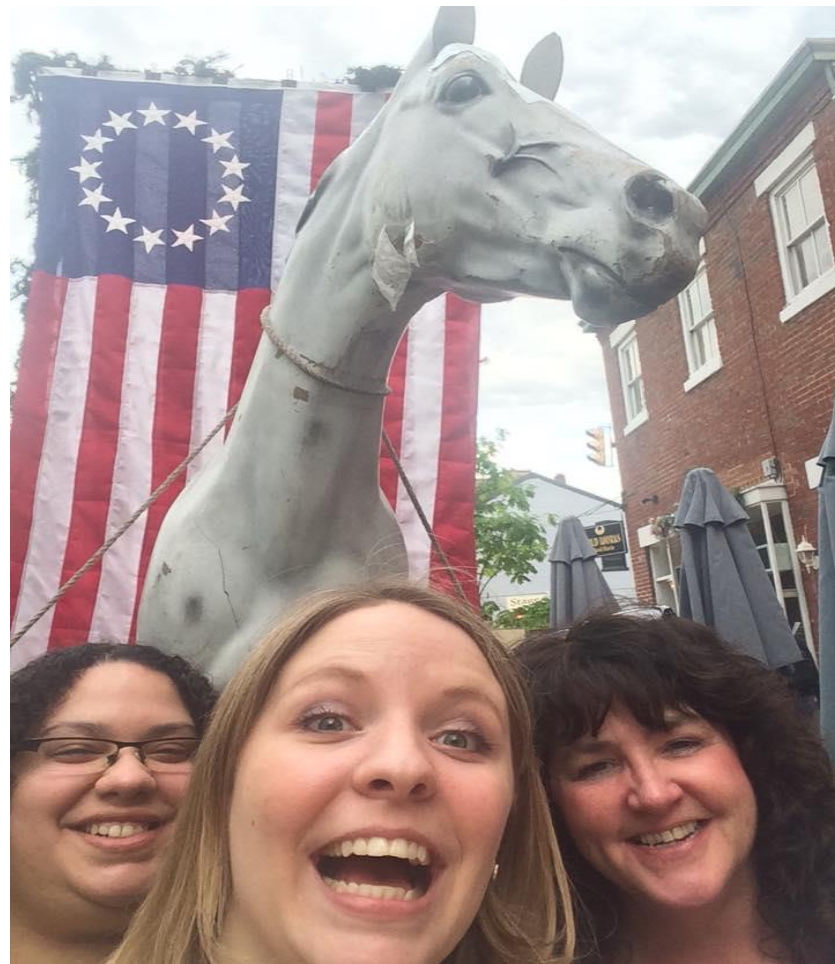




Who Are These Strangers?!



The Transitions RTC Team



Tania Duperoy, Amanda Costa, Lisa Smith

What is the Transitions RTC?

National Center that aims to:

- Improve supports for the successful completion of schooling and movement into rewarding work lives among young people, ages 14-30, with serious mental health conditions (SMHC)

How do we do that?

1. Conduct cutting-edge rigorous research that tests or informs interventions
2. Develop and translate knowledge to multiple stakeholders
3. Infuse Participatory Action Research (PAR) into all RTC activities



How Do We Define Leadership?



What Do You Think of When You Hear the Word Leader?



What is a Leader, Exactly?

“A person who can enlist the support of others to accomplish a common task”

“A boss says “go” a leader says “let’s go”- E.M. Kelly

“Someone who is open to new experiences”

“The ability to translate vision into reality”- Warren Bennis

“A leader is best when people barely know he exists, when his work is done, his aim fulfilled, they will say: we did it ourselves.” —Lao Tzu



Youth Voice

Empowerment

Civic Engagement

Change Maker

Decision Making



Why is Youth Leadership Important?



Youth Leadership in Service Delivery

“We are the experts on ourselves”

- Ensures programming is young adult friendly and culturally appropriate
- Improves decision-making on key young adult issues
- Generates discussion, action plans and solutions most relevant to young adult’s needs and preferences



Benefits of Youth Leadership in Guiding Individual Care Plans

- Young adults are more engaged and committed to services that they had an active voice in
- Valuable life skills gained: negotiation, effective communication, advocacy
- Increased self-efficacy/self-determination leads to: optimism, better coping skills, increased mental health, healthy habits



Benefits in the Peer Community

- Providing peer support
- Serving as role model to others on path of recovery
- Advocating for services that serve the needs of youth first and foremost

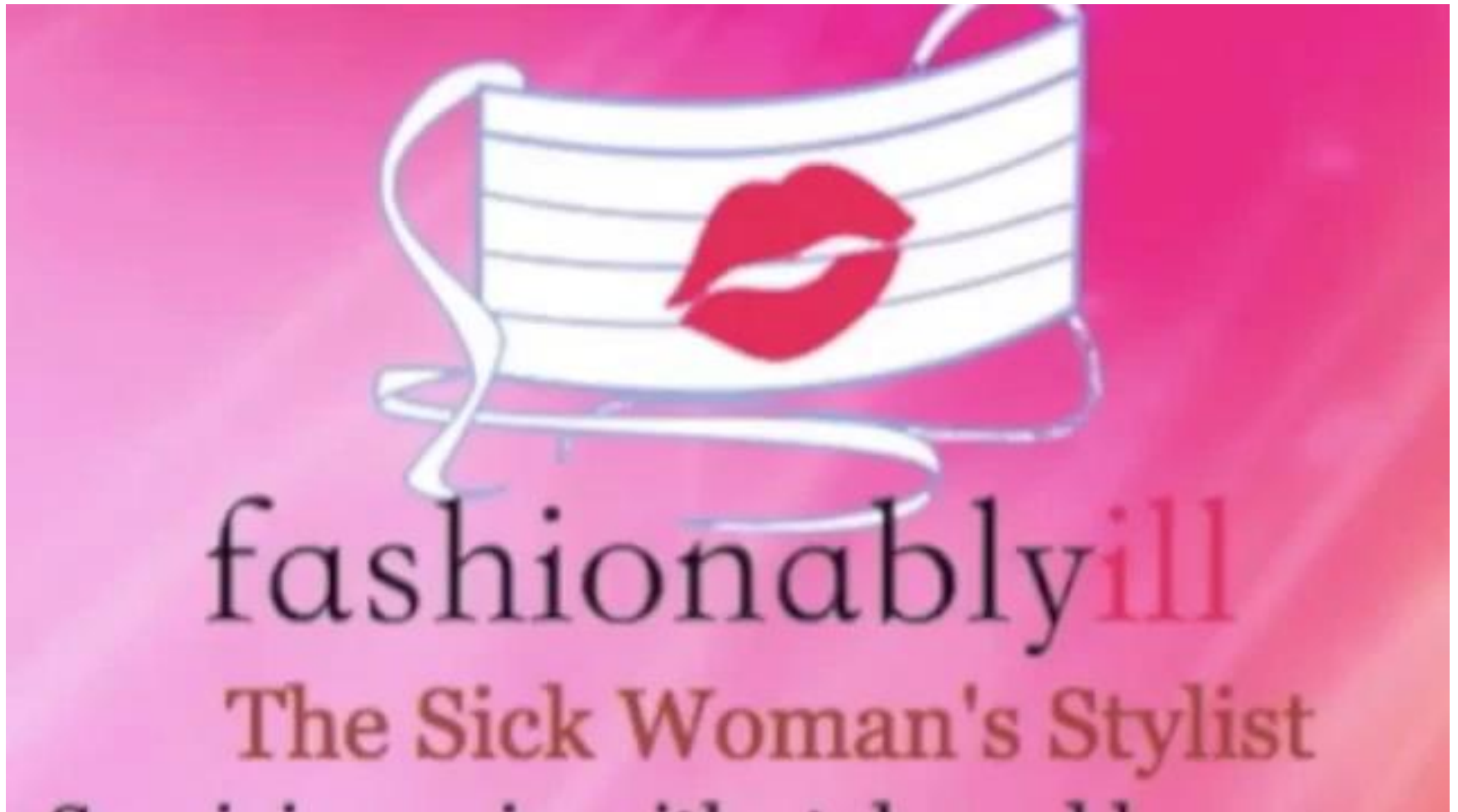
Youth are the next generation the NAMI leadership community!



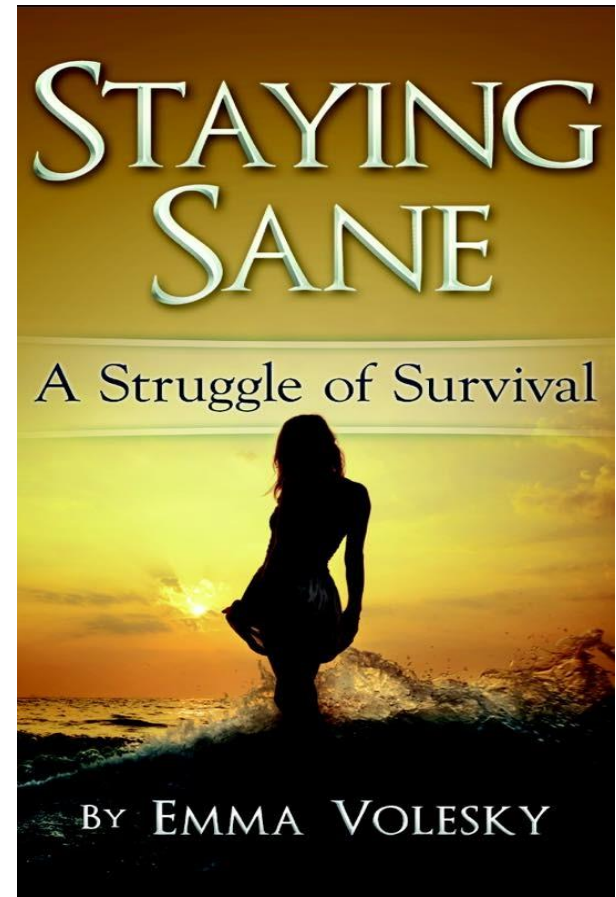
What Are Important Qualities In a Youth Leader?



What do YOUTH Think?



Emma Volesky



Purchase Emma's Book Here: <http://www.amazon.com/Staying-Sane-A-Struggle-Survival/dp/1512209538>



How Do We Build Youth Leadership Opportunities?

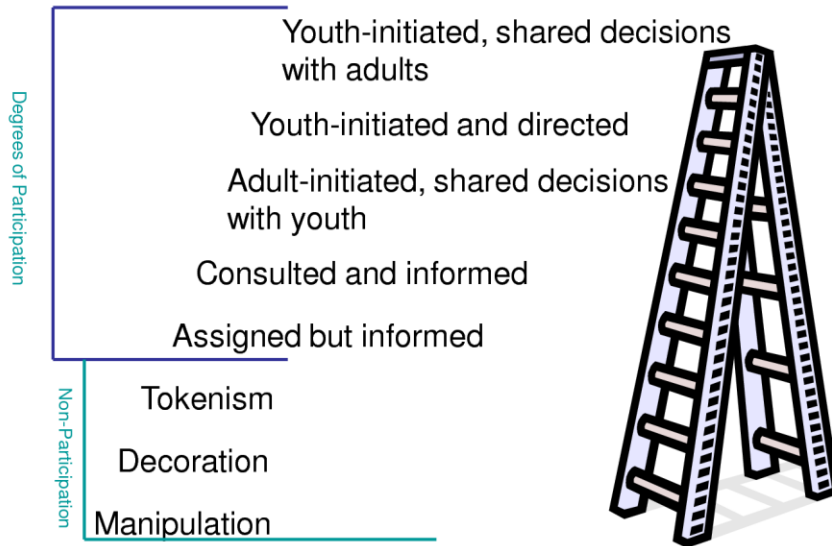


Step 1. Define Involvement

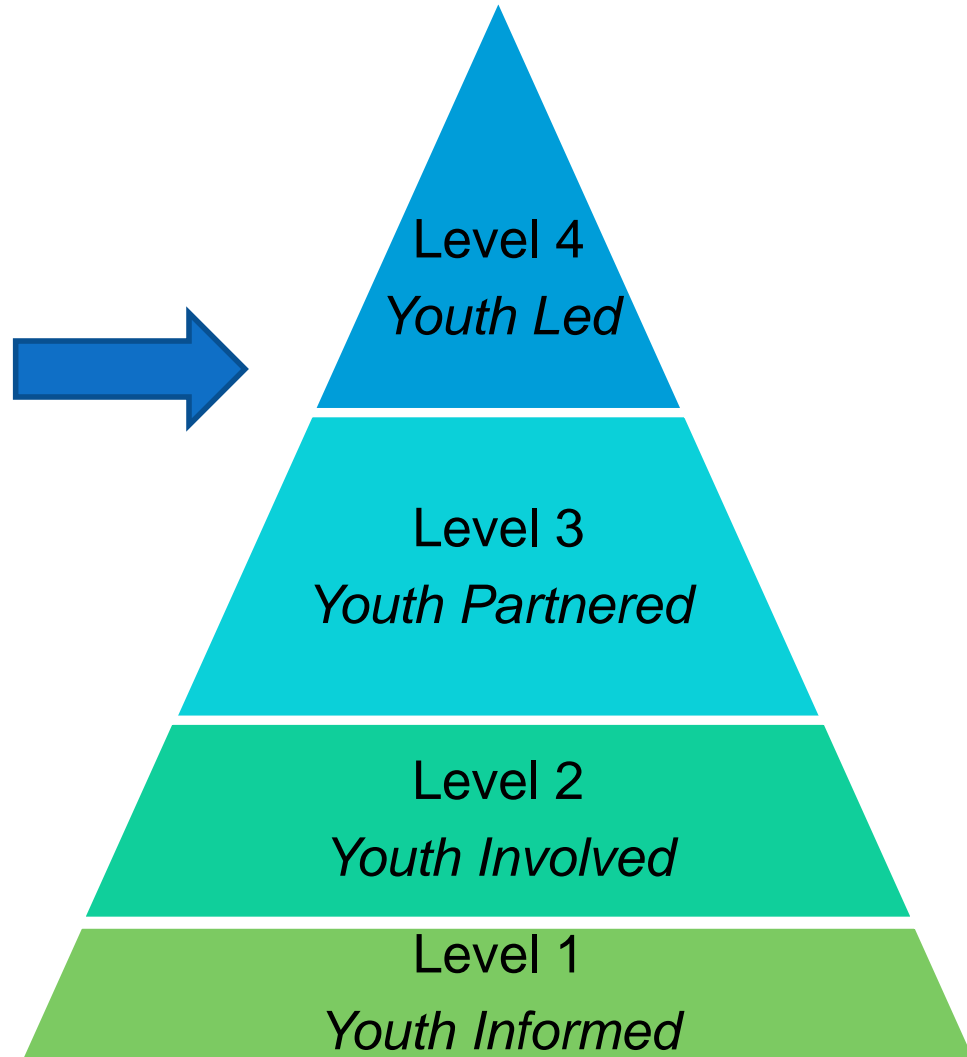


Creating Meaningful Involvement

Ladder of Youth Participation



Adapted from Hart, R. (1992). *Children's Participation from Tokenism to Citizenship*
Florence: UNICEF Innocenti Research Centre.



Step 2. Identify Challenges & Develop Solutions



Identify Challenges

Commitment
From Team

- Fear of minimizing rigor
- Lack of clarity of roles

Youth Culture

- Media Driven
- Viewed as “inferior”

Lack of
Professional
Experience

- Imbalance in knowledge
- Lack of advocacy skills

Develop Solutions

Commitment
From Team

- Top down commitment from leadership
- Clear understanding of role

Youth Culture

- Thinking outside the box
- Empowerment
- Strength-based

Lack
Professional
Experience

- Mentoring and modeling
- Clear Guidelines

Mythbusters:

What makes a good leader?

1. One Personality trait fits all

- Charismatic/Extrovert/Authoritative vs. “anti-hero”

2. Leadership comes with age

- Learn from past experiences & ability to influence peers

3. Leaders should have all the answers

- Good leaders know their limitations

4. You're not leading if you don't have followers

- Leading yourself / thought leadership

5. There is a shortage of great leaders today

- LOOK AROUND YOU!



Step 3. Provide Structured Opportunities



Community Involvement



TEAMWORK



**RALLYING
SUPPORT**



Youth Advisory Boards



“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.”



Informing Products/Services

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

The Work on Work, Tip Sheet 7 TRANSITIONS ETC 2012

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 site, 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 at the Job:

- To obtain protection under the Americans with Disabilities Act (ADA)
- Inquired in order to request job accommodations
- To serve as a role model and educate others
- Reduce stigma
- Reduces the stress some may feel about "hiding" a disability
- Makes employers better able to respond to sudden symptoms or hospitalizations
- Disclosure to a supervisor is kept confidential by law

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

- There is no need for accommodations
- Hiring or promotion choices may be negatively affected due to stigma
- To protect your privacy
- Year 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

If I Want to Disclose, How Should I Do It?

- Let your employer know you have a medical disability, how your disability affects your work, and the accommodations that address those barriers. YOU DO NOT need to disclose your entire medical record, progress notes or test results.
- You will need to provide information about the existence and extent of your disability or diagnosis, how your condition may limit your functioning in the job, and the accommodations that address those barriers.
- Prepare and practice what you will say ahead of time.
- List your strengths and qualifications related to this job. You also get with a disability will positively affect your work performance.
- Share what issues you may face in the workplace due to your diagnosis, for example, "My disability requires me to take frequent breaks in order for

Applying for a Job: The Young Adult's Guide

Community of Practice, Northeast Massachusetts 2011

Things to Keep in Mind When Looking for a Job

- Type of work you would like - Restaurant, childcare, store, outdoors, office, etc.
- Schedule - What days and number of hours you can work - try to keep as open as possible
- Transportation - How can you travel to get to a job, will you get paid enough to cover transportation
- What you're good at - Your skills and abilities

How Do I Find A Job?

Online - Some examples of job search websites are monster.com, indeed.com, and craigslist.com. To find a list of these sites, go to a search engine (ex: Google) and type in keywords such as "online job search site" and you should find a list of popular sites. Also, check out company websites directly (ex: Target.com, HomeDepot.com). **Tip Sheet 8: Smartest job postings are listed under "Careers" or "Hiring Information."**

Visiting Businesses In Person - You can also visit a business in person to ask the hiring manager if they are accepting applications. Make sure you have your mock application with you in case you decide to fill out an application while you are there.

Do these appropriate clothes such as:

- Button up shirts
- Blouses
- Draw pants or khakis
- Shoes
- Short skirts, jeans or shorts
- Low cut shirts or anything too revealing
- Straight or wrinkled dresses
- Flip-flops

Career Centers/Clubhouses/Employment Supports - Job support programs will help you with all the steps involved in getting and applying for jobs. The Massachusetts Rehabilitation Commission is one vocational support in Massachusetts. Talk to your helpers (case managers, guidance counselor) for places to go.

Networking - Ask yourself: Family members, friends and neighbors may know of places that are hiring.

Filling Out Job Applications

There are a few ways to apply to a job and separate businesses ask you to apply in different ways. If you know where you want to apply, call or go online and find out how that specific place wants you to fill out an application.

*Make sure to have your mock application with you to fill out any job applications!

On Paper - Applications on paper tend to be the shortest, and you are usually allowed to take them home to fill out, and bring back when you're done. Take 2 copies of the application if possible, in case you make any mistakes.

My "Must Have" Papers

Community of Practice, Northeast Massachusetts 2011

These 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 conditions in case of any possibilities then.

What to keep in your Binder

- Education documents
- Medical information
- Housing / Utilities information
- Work information
- Financial information
- Learn more about these on the other side of this page

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 replace all of the essential documents listed above

If you need to get your birth certificate: Go to the Town Clerk or City Hall in the town/city you were born in and request it. If you were born further away you can contact the Town Clerk/City Hall (on internet or phone) and ask how to get it. Also, often there's a fee (up to about \$25). You may also ask a DCF/DHHS worker if they either have a copy or can assist you.

If you need to get a license/ID/Permit: Go to the Registry of Motor Vehicles (RMV). You will need the required ID, Massachusetts if you don't have enough forms of ID (such as a birth certificate and social security card) a letter from DMV or DCF may be helpful explaining your situation. MA.gov/RMV has more info about this. To get a social security card: You, or your representative proxy, will need to present your ID to the Social Security office and request a new card. There is a limit to the number of cards you can request in your lifetime so it is important to keep it safe! Don't keep your social security card in your wallet unless you are unemployed and applying for a job-site one somewhere else. Try to memorize the number.

Go to your local post office or check with your state's Passport Agency for details on how to get a passport. You can also visit an embassy or consulate in your home for more info on how to get a new passport, or your phone is best to call.

Telling Your Money What to Do: The Young Adult's Guide

Community of Practice, Northeast Massachusetts 2011

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 a year or two weeks to see where your money is going... then develop a budget to set goals on spending. You can use the one on this sheet.
- Monitor your checking account and make sure you understand your bank policy on overdraft checks. fines for overdraft checks can be costly. You may want to opt to have overdraft protection.
- Save and invest on credit cards can add up. To avoid this, pay as much of your bills as you can each month.
- Emergency funds can save you in emergencies like car or health costs, unexpected needs of expense, traffic tickets, etc (adding 1 to 10 to per paycheck is a great start)
- Eating out though convenient, is VERY expensive - cooking at home can save you a lot of money
- Smoking, drinking and drugs add up and are expensive. Make sure to include them in your budget.
- Borrowing money from friends or family can add stress to your relationship. If you have to borrow money you may want to pay yourself as a payment plan per pay back.
- Lending money can also add stress to your relationships. Family and friends have financial stress too, so they may not be able to pay it back.

Realities Up

One credit may not seem like much, but if you look at costs over time you see how much it takes from your wallet.

	Average Cost per Item	Average Cost per Week	Average Cost per Month
Energy Drinks	\$2.50	7 x \$2.50 = \$17.50	\$57.50
Daily Coffee	\$2.00	7 x \$2.00 = \$14.00	\$42.00
Cigarettes	\$6.25	4 x \$6.25 = \$25.00	\$100.00
Eating out	\$7.00	2 x \$7.00 = \$14.00	\$42.00
Taxi Rides	\$10	1 x \$10 = \$10.00	\$30.00
Gas	---	---	\$60.00
Dog	---	---	\$100.00

A little bit of savings also adds up over time.

Save Up

per month	Average Savings per Month	Average Savings per Year
\$20	\$20.00	\$240.00
\$40	\$40.00	\$520.00
\$100	\$100.00	\$1,200.00

Getting Accommodations at College: Tools for School

Tip Sheet 2 TRANSITIONS ETC March 2011

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... in the courses at your request.

What Accommodations or Modifications Can I Ask For?

- What Do I Need In the Classroom?**
 - Preferred seating
 - Breaks allowed during class
 - Voice recorded lectures
 - Classmate acts as a note-taker
 - Text and videos available in advance
 - Class materials available on computer
 - 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
 - Class materials available on computer
 - Allow exams 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 in-class affecting grade
 - Advance notice of assignments
 - Textbook available on tape
 - Assistive technology available for assignments
 - Working in pairs or 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 type)
 - Homework given instead of failure of class occurs
 - Assistance with filling out financial aid registration forms
 - And more!



Leading Mental Health Research

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

Peer Support

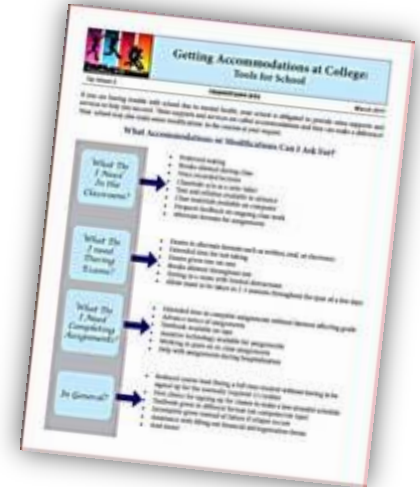
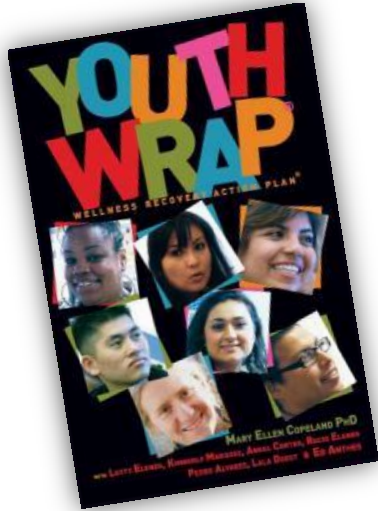
- Providing Peer Support:
 - Youth Council Leaders
 - Certified Peer Specialists/Peer Support Specialists
 - Running support groups/Trainings



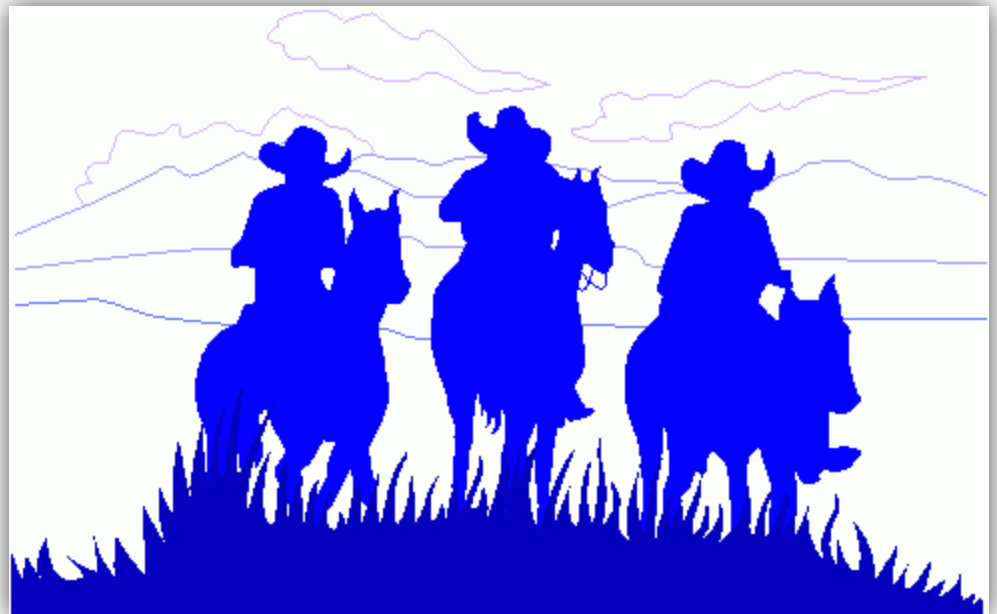
Step 4: Support, Support, Support!



Mental Health Management



Bringing Leadership To The Wild Web



Managing Social Media





- For youth by youth
- Youth leadership from the top down
- Background leadership & Spotlight leadership
- Topics chosen by youth

Engaging the Online Community



Youth Engaged 4 Change



Thank You!

Want More Information?

Amanda Costa: amanda.costa@umassmed.edu

Lisa M. Smith: lisa.smith2@umassmed.edu

Transitions RTC Website: labs.umassmed.edu/transitionsRTC

