



A Young Adult Peer-Led Quality Improvement Project



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This publication was written by the staff and members of On Our Own of Maryland's Transitional Age Youth (TAY) Outreach Project and Taking Flight, Maryland Coalition of Families for Children's Mental Health's Young Adult Advisory Board.

WHO WE ARE

ON OUR OWN OF MARYLAND'S TRANSITIONAL AGE YOUTH (TAY) OUTREACH PROJECT

The TAY Outreach Project has been a statewide initiative of On Our Own of Maryland (OOOMD) since 2012. Its mission is to empower youth with mental health/substance use struggles to share their experiences and speak out about the kinds of supports and services they'd like to see within the behavioral health system. This project hopes to foster an understanding that the life experiences of young adults are full of unique insights and support for other young adults and that all young adult peers, joining together, can successfully advocate for a behavioral health system that honors their experiences, listens to their voices, and meets their specific needs effectively and sensitively.

The TAY Outreach Project introduces young adult peers with lived experience in mental health and/or substance use systems to the peer support, policy, and advocacy fields. The project coordinates and connects young people to social and informational events, support groups, leadership opportunities and trainings, and advocates for the inclusion of youth and young adults as equal partners in the process of system change at local, state, and national levels.

TAKING FLIGHT

Taking Flight is the statewide youth and young adult advisory council for the Maryland Coalition of Families for Children's Mental Health. Staff and members are comprised of young adult leaders, ranging in ages from late teens to mid-twenties, with backgrounds and involvement in different systems (mental health, foster care, LGBTQ, etc.) who are using their experiences to advocate for positive system changes.

Taking Flight's mission is to cultivate a group of young adult leaders who work to empower and support young adult transition and to facilitate system collaboration in an effort to promote acceptance and educate the Maryland community in order to reduce stigma. Taking Flight does this through youth & young adult speaking panels, an annual statewide art project, storytelling training, and by collaborating with the TAY Project to host an annual Young Adult Leadership Retreat.

ACKNOWLEDGEMENTS

Authors:

Lauren Grimes, Director of Network & Peer Services, OOOMD
Jordan Geddes, Youth Engagement Supervisor, Taking Flight/MCF

Contributors:

Chris Sawyer, Youth Supervisor, Taking Flight/MCF
Jayme Severn, Transitional Age Youth Outreach Coordinator, OOOMD
Christi Halpin, Youth Outreach Specialist/Operations Assistant, Taking Flight/MCF

A Special Thanks to:

Ann Geddes, Ph.D.
Jane Plapinger, Executive Director, MCF
Jennifer Brown, Director of Training, OOOMD
Yvonne Perret, MA, MSW, LCSW-C

This report represents input from 94 young adults from 16 peer-led discussion groups which were held at 15 young adult serving public service organizations in 12 counties across the state. On Our Own of Maryland's Transitional Age Youth Outreach Project and Taking Flight, Maryland Coalition of Families for Children's Mental Health's Young Adult Advisory Board are grateful to the agencies, organizations, and people who assisted with these discussion groups.

Participating Counties:

Anne Arundel County	Howard County
Baltimore City	Montgomery County
Baltimore County	Prince George's County
Caroline County	Queen Anne's County
Cecil County	St. Mary's County
Frederick County	Talbot County

Partnering Groups:

Cecil County Health Department	Maryland Coalition of Families for Children's Mental Health
Channel Marker, Inc.	Nick's Place Recovery House
Cornerstone Montgomery, Inc.	On Our Own of Cecil County
Family Services	On Our Own of Maryland
Healthy Transitions @ Humanim, Inc.	On Our Own of St. Mary's County
Healthy Transitions @ Pathways, Inc.	PDG Rehabilitation Services, Inc.
Healthy Transitions Initiative @ Waystation, Inc.	The Pathways School- Annapolis
Martylog/One Voice Wellness & Recovery Center	

INTRODUCTION

What Helps What Harms Maryland is a quality improvement project launched in August 2014 by OOOMD's Transitional Age Youth Outreach Project in partnership with Taking Flight, Maryland Coalition of Families for Children's Mental Health's Young Adult Advisory Board. This initiative is modeled from the national What Helps What Harms program endorsed by *YouthMOVE National*. What Helps What Harms Maryland was designed to infuse the youth and young adult voice into strategic policy actions and planning processes for systemic change in the state of Maryland through convening discussion groups and forums to learn about and make recommendations to address young adult peer needs. The project will use the information obtained during these discussion groups to leverage the young adult voice to inform service planning for the behavioral health service system and related public services in Maryland. The discussion forums were held with young adults ages 18-29 who have and/or are receiving services in any Maryland service system. The forums took place between August 2014 and August 2015.

The recommendations in this report resulted from the rich discussions held within these forums and groups.

EXECUTIVE SUMMARY

Young adults in Maryland who have been or are currently involved with a variety of systems (mental health, substance use, criminal justice, etc.) have unique service needs that have historically not been addressed appropriately or implemented effectively into the systems that serve them. To learn about these needs as young adults perceive them, and to develop recommendations designed to meet those needs, the staff of On Our Own of Maryland's TAY Project and Taking Flight collaborated with young adults served in behavioral health and related service settings across Maryland to listen to and discuss their service needs, past harms and helps, and to coalesce these conversations into practical and necessary recommendations. Nearly 100 young adults participated in the structured forums designed to discuss their experiences in these systems and their requests for additional and/or modified services. Most of these requests involved the desire for services which provide diverse opportunities to be involved in their own care, foster supportive and trusting relationships with both their peers and service providers, and foster credibility for their voices and opinions of young people.

The purpose of this report is to offer recommendations across the systems and services with which youth and young adults have the most contact: education, employment and independence, psychiatric hospitals, law enforcement and police, mental health services, substance use services, and staffing within all these systems and organizations. Additionally, the critical component of engaging youth to inform the implementation of these recommendations is highlighted, as well as the importance of young adults having an enduring role in their own recovery and in systems change.

Several common threads inform these recommendations:

- (1) Successful systems must engage with, listen to, and address service needs before situations deteriorate and young adults' lives worsen
- (2) Young adults know what will help them improve their lives. They simply need to be heard and treated with respect, dignity, patience, and attention
- (3) Young adults want their lives to improve, however they often lack the information or resources to know what to do and the support of someone with whom to process information about resources and opportunities
- (4) Punishment and harshness cause harm and do nothing to promote recovery or empowerment
- (5) Service systems need staff who understand behaviors that are a means of expressing need, hurt and pain rather than viewing all behaviors as requiring management and control.

The perspectives of young adults are the most important element in development of the new service models being designed and implemented across the country for youth transitioning to adulthood. The engagement of young adults as equal partners is also increasingly being recognized as an integral component of systems change. Young adults nationwide are being supported to take roles which influence, inform, and improve the organizations and administrations that serve them. Those roles include program development, policy and planning, peer support and direct service delivery, outreach and stigma reduction, clinician and family member education, and quality improvement/evaluation. Consumer involvement and the corresponding reciprocity in relationships with their service systems, which have historically offered one-directional recipient roles to young adults, also promote and enhance personal well-being and empowerment.

For Maryland to improve services for its young adult population there need to be significant systems and organizational changes informed and driven by young adults themselves. The recommendations in this report are offered as a roadmap in order to begin making those changes. Youth and young adults should be engaged as equal partners to ensure that all steps taken focus on recovery, wellness, empowerment, and a successful transition to adult life, and so that the opportunities to be engaged in this process are accessible and attractive to them. Ultimately, that is the challenge and opportunity contained in this report's recommendations and in Maryland's ongoing endeavors to create successful outcomes for youth and young adults.

METHODOLOGY

The What Helps What Harms Maryland Project utilized a simple discussion prompt during these groups to facilitate a free-flowing conversation that participants directed. The prompt asked:

"Of all the systems and services you have been involved with (education, mental health, physical disability services, juvenile justice, peer-run services, supported employment/education services, etc.),

- 1) *What about its set-up, services, and service delivery has helped you move forward (into adulthood, recovery etc.)?*

- 2) *What has harmed you or created barriers for you moving forward?*
- 3) *What changes would you make that would have benefitted you in reaching your goals for your recovery and your adult life?"*

All of the discussion groups held under the What Helps What Harms Maryland Project were led by young adult peers in the same age bracket as the participants (ages 18 and 29.) Group leaders were staff of On Our Own of Maryland's Transitional Age Youth Outreach Project and Taking Flight, Maryland Coalition of Families for Children's Mental Health's Young Adult Advisory Board, who self-identify as having experiences within the mental health and/or substance use systems. This design was chosen with the hope that the common lived experiences of the group leaders and group participants would promote trust within the group and provide a safe space for truly open and authentic dialogue.

Recommendations in this report are grouped into categories that evolved out of the group discussions and that were discussed as major areas of concern for the groups' participants. An attempt has been made to call particular attention to critical areas for young adults' transition to adulthood that are part of or related to the behavioral health system. Yet, many of these recommendations are also relevant for other systems and services that work with and assist youth and young adults.

Participation in the discussion groups was entirely voluntary and no stipends or compensation of any kind was given to the participants.

FUNDING

The What Helps What Harms Maryland Project was made possible by funding from On Our Own of Maryland and the Maryland Coalition of Families for Children's Mental Health. These organizations are funded in part by the Behavioral Health Administration of Maryland and by the Substance Abuse and Mental Health Services Administration.

HOSPITALIZATION

RECOMMENDATION: HOSPITALIZATION

1 Eliminate the use of seclusion and restraint.

What Helped:

There were no comments from any of our focus groups that indicated any good came out of seclusion and restraint measures used on youth.

What Harmed:

- Seclusion and/or restraint being the first response
- Situations being ignored or mishandled until they escalated and seclusion and/or restraint were used
- Neglect and/or ridicule after being put in seclusion and/or restraints
- Lack of support in dealing with traumatization or re-traumatization caused from the use of seclusion and/or restraints

Quotes:

"I was going to the quiet room one time, willingly going down there, on my way, and they put their hands on me. When I'm that angry I don't want to see you, and I don't want you to touch me, so I was dealing with it the best way I knew how and going down to be by myself in the quiet room. I told them not to touch me, a direct warning, and they went to grab me anyway, and I went off. Then they got the men, so now I have, like, a football player-sized guy who slams me to the ground and lays on top of me. I have a rape history and I told you not to touch me. I warned you fair and square. You're just asking for my reaction, and then you have a huge guy hold me down. Especially if you're a man, you should never touch me more than you need to, if at all. If I'm willing to go willingly, then let me. I even understand if you want to follow me to make sure I'm ok and that I get to the quiet room, but there was no need to get rough with me."

"They grab you like you are a coffin or a body bag and throw you in the bed. It's humiliating to be there and have to call for everything. I shouldn't have to scream for 10 minutes just because I have to pee."

"Restraints are supposed to be used as a last resort, but I've been restrained just for yelling so many times."

"I was too scared to move most of the time. Like if I made any sudden movements, they'd stick me with a needle. So I just sat as still as possible. If was to go back to that hospital again, like tomorrow, I would kill myself."

RECOMMENDATION: HOSPITALIZATION

- # 2** Transform seclusion and/or quiet rooms and the policies surrounding them into voluntary sanctuary/comfort rooms. Have youth involved in the creation of these rooms.

What Helped:

- Having a colorful, pleasant room designated as a voluntary space to use for calming down
- Having activities, music, and other comforting things available in the room

What Harmed:

- Being secluded in a room with blank walls and no stimuli
- Having the same room used for involuntary seclusion and restraint be the voluntary space in which to calm down

Quotes:

“The quiet room should be colorful, not just a blank wall. The one at [hospital] is too small, but it’s remodeled and there are toys and a mural. [One of the centers] has little things to keep your hands moving and relax you. A couch and music, and I would be fine. A TV with a remote and I’d be fine.”

“I hate the quiet room because the walls are white. There’s nothing in there and all I do is think about things that make me anxious and it makes me want to kill myself. It’s so dumb, they stick you in there to calm down (or so they say), but I come out worse than when I went in every time. I wish they would just listen. I may not always be able to tell you what will help, but I can certainly tell you what doesn’t and being locked up in a small white room by myself doesn’t help.”

RECOMMENDATION: HOSPITALIZATION

- # 3** Implement training, policies, and protocols that address and remediate neglect, threats, and ridicule by staff working in hospitals *and* institute a responsive mechanism by which young adults can lodge concerns and complaints.

What Helped:

There were no comments from any of our focus groups that indicated that any good came out of the use of neglect, threats, and/or ridicule.

What Harmed:

- Being ignored while expressing a need or emotion by staff who are intentionally not making themselves available
- Being put in seclusion and/or restraint and then left alone for long periods of time
- Being threatened with seclusion and/or restraint
- Being threatened with removal of therapeutic activities
- Staff breaking confidentiality
- Being intentionally humiliated or ridiculed by staff
- Being provoked and/or antagonized by staff when in crisis

Quotes:

“Actual patients tended to help each other in that program more than the staff would. I had my first panic attack when I was put in there the first time. I was on the floor, hyperventilating and crying. The nurses just stared at me. The other patients were the ones who came over to me and told me to breathe and put their hand on my back.”

“The nurses don’t pay attention. They don’t care. When they are required to come check on you, they don’t even look in. They just knock and yell in to see if you are alive.”

“Stop calling us names. This may be funny to you but this is our lives. The last time I was on the eating disorder unit, they would call me Starvin Marvin, like, ‘Send out Starvin Marvin.’

RECOMMENDATION: HOSPITALIZATION**# 4 Make hospitals more recovery-oriented.****What Helped:**

- Being linked to recovery and peer support resources when leaving the hospital
- Having recovery and life-planning be part of conversation during hospitalization
- Focusing on how to be mentally and physically healthy

What Harmed:

- Having important parts of recovery be treated as privileges such as seeing family, showering, time outside, and permission to wear your own clothes
- Having coping supports taken away, especially things that make youth feel comfortable and functional, like smoking, art, music, make-up etc.
- Being punished for not making progress

Quotes:

“The staff felt like if they were dictating our every move, they were doing their job. We existed on a set of unhealthy rules. If you didn’t make weight, you couldn’t shower or see your family. These were seen as privileges, not ways to maintain yourself and get better. It’s like I was being punished without doing anything wrong.”

“You can’t build any kind of relationship with the counselors. They told me once, “This is a holding pen. This isn’t a place where you get treated. Go to therapy when you get out of [the hospital] if you want to get treatment.”

“He was begging [the nurse] to go out for a cigarette because he was feeling really upset and she refused to let him. She gave him no other options, so he just kept begging. Then she got angry with him and started raising her voice, and so he started getting angry and raising his voice and kind of rolling around on the ground, and then she called the cops on him. The point though, is that the nurse not only wasn’t validating a tool that this guy was trying to use as a coping mechanism to deal with his emotions, she also gave him no other options to help, and then got angry and escalated a situation that didn’t have to be a situation at all.”

MENTAL HEALTH

RECOMMENDATION: MENTAL HEALTH

- # 1** **Actively involve youth in the decision-making process about medication - every time, every change, every new symptom.**

What Helped:

- Being educated about the right to make decisions about what goes into their own body
- Being an active participant in deciding *if and what* medications to take
- Receiving full transparency from doctors about medication changes, interactions, and side effects

What Harmed:

- Being forced to be on medications
- Having medications prescribed/used as first treatment option
- Having complaints about side effects ignored by staff
- Being overmedicated
- Being prescribed medication without other supports
- Having medications added to deal with the side effects of other medications
- Lack of mental health treatment options for those recovering from addiction who don't want to take medications

Quotes:

"The hardest thing for me was having doctors just shoving pills down your throat just to see what works. They just want to get you on the next prescription and move on. Assessments aren't used to get to know you, what happened to you or why you do the things you do."

"I took Paxil when I was younger. I told them I didn't want to be on it any longer, and they told me that I'd have to be on that the rest of my life. So I tapered myself off of it. It's bad when your doctors don't hear you."

"If you find the right medication, it could be helpful. I have found the right medication now and that has helped me a lot too."

"They know what's wrong, but they do the same thing each time. Just put you on medication that makes you so lethargic. Instead of dealing with the symptoms and problems, they just make sure you live through it."

"My parents took me to see a psychiatrist and they diagnosed me with depression and ADHD, and then they gave me Ritalin and a bunch of other meds. I sat down with this lady for two minutes and she just gave me all these pills without even talking to me."

RECOMMENDATION: MENTAL HEALTH

2 Increase access to alternative therapies and community involvement initiatives for youth.

What Helped:

- Having access to alternative therapies (i.e. art, music, and yoga) in schools and hospitals

What Harmed:

- Lack of hands-on activities that promote wellness, recovery, and community-building

Quotes:

“I think music has really saved my life. I think there needs to be a bigger push in hospitals to have music therapy. There was an art therapist in every day of the week and they had a drum person come in on the weekends. They had someone put on beats to write to. The ability to be able to write and express myself in that way really saved my life, and I wish there was more like that during hospital stays.”

“These therapies, like touch therapy, can help get people comfortable in their own skin. These are all looked at like luxuries, but it’s prevention and recovery and pain management. A lot of people I know started with addiction because of Percocet after an injury. They go straight to medications; not physical therapy, not massage therapy. Acupuncture is effectively used for detoxing people. Things like that can also keep people from finding drugs in the first place.”

“Like we did a park clean-up on Earth Day, and we’ve done some anti-stigma work in the community, which is great, and sometimes we’ll do fun stuff or groups here, like with the TAY Project, but it’s so infrequent that it’s not enough to keep people engaged, especially young people. We want something to look forward to. Every week, every day even, something to get up in the morning for.”

RECOMMENDATION: MENTAL HEALTH

3 Implement policies which address and seek to lessen the impact of staff turnover on youth.

What Helped:

- Being involved in the hiring of new staff
- Having previous staff keep in touch with program/clients
- Having new/unfamiliar staff be introduced by experienced/familiar staff

What Harmed:

- Having to retell personal stories and build relationships with new service providers
- Feeling rejected and neglected when staff leaves suddenly
- Feeling uncertainty and fear when no transition plan is made

Quotes:

“The trust thing comes in when you have to switch doctors constantly, too. I have had like 45 therapists in the past few years and having to rehash my story again and again really sucks, and the burden to build that relationship always seems like it is on the patient.”

“We got to interview the people applying to take [the director’s] job. The one lady I met and I was like oh no, she’s [stuffy] and doesn’t get us at all. It was kinda cool to be involved even though we all knew we wanted [current staff member] to move up into [director’s] place.”

“They change counselors every time, so every time you’re talking to someone new. You’re telling your same story again, and usually they don’t even remember what you have said. You can’t build any kind of relationship with the counselors.”

SUBSTANCE USE

RECOMMENDATION: SUBSTANCE USE

1 Implement realistic drug education in middle and high schools.

What Helped:

- Early exposure to substance use education
- Hearing real and personal stories about substance use, *especially from young people*
- Being provided education about and connections to peer support and fellowship programs

What Harmed:

- Abstinence-only approach and the absence of information on where to go or what to do once a youth has already begun using substances
- The absence of realistic information on the dangers, consequences, and realities of substance use
- Lack of education and resources for youth living with family members with substance use issues

Quotes:

“I think one of the biggest things missing in the education system is real, non-sugar-coated facts about alcohol, drugs, and what they do to you...to your body and to your life, your family, your person. I think starting in middle school, when they start teaching kids about sex, and health issues, they need to start talking straight about drugs and alcohol.”

“They do the whole DARE ‘Just Say No’ thing, but what if that doesn’t work, and I don’t say no, and I use? What then? I have no more information.”

“They drill into your head the illegality of the drugs but don’t explain the real reasons why that is...the way it can undo people and families. They should touch some on the ugliness, the vomit and shit, and organs shutting down, and your teeth falling out, and you acting like something you’re not.”

“They need drug and mental health counselors to come into classes and make themselves known and available to the kids, not just guidance counselors who help you fill out applications. The burden should be on them to create that opening and access so kids know about this kind of help if they need it and so they feel safe enough to seek it out.”

RECOMMENDATION: SUBSTANCE USE

2 Implement staff training, policies, and protocols to address and remediate the use of punishment over treatment and help.

What Helped:

- Compassion and understanding for the idea of recovery as a process and not a linear one
- Being treated as someone in need of support rather than as a bad person
- Language that is positive and recovery-oriented

What Harmed:

- Viewing addiction as a moral failure
- Being kicked out of treatment for relapse - essentially getting punished for being sick
- The pass/fail nature of substance use treatment
- Punitive treatment language (e.g., “fail” “dirty urine”)
- The shame that keeps people from getting help because of the risk of punishment and fear of stigma
- Lack of treatment resources available as alternatives to forensic involvement

Quotes:

“If someone gets help with their drug problem, they flip everyone’s room upside down searching for drugs and then make us clean it up.”

“I grew up in Calvert County, and first the pills came in, but now it’s harder and harder to get pills so they went to dope. There’s one [Narcotics Anonymous] meeting once a week. In the middle part [of the county] there’s nothing at all. They have cops kicking down peoples doors looking for this stuff, but there’s no help for them.”

“They know what’s going on all the time but they don’t come at you as a boss. They come at you with advice and support.”

RECOMMENDATION: SUBSTANCE USE

3 Increase linkages to recovery supports and harm reduction resources before, during and after treatment.

What Helped:

- Having links to peer support, 12-step programs, self-help groups (especially age-specific ones)
- Getting involved in sober communities and activities
- Having mentors, sponsors, and alumni to introduce youth to recovery communities and offer ongoing support
- Having links from rehab or hospital to community treatment
- Needle exchange programs
- Long term recovery houses

What Harmed:

- Lack of discussion, acknowledgement and general awareness of recovery, especially in medication-assisted treatment (MAT)
- Insufficient attention given to transition plans
- Lack of recovery resource options built into transition plans
- Disruptions or absences in the continuum of services that form a step-down process towards sobriety and recovery

Quotes:

“People are going to come and get the free needles [at the needle exchange program], so anything you can put into the needle wagon, people are going to take it. Maybe they can put an NA pamphlet or other stuff about recovery in the needle bag. I don’t know that hearing about it will change anything, but I know that once I did it, it helped me. Even if they throw it out the next day, they’ve seen it, they know it’s an option, and they can come back to that knowledge when they’re ready.”

“Most methadone clinics are privately owned, so I guess you can’t force people to put information out on a rack, but there’s like zero information on recovery.”

“They don’t tell you ‘go to a meeting’ or ‘try this to help.’ [The treatment providers] just want you to do methadone until you die. You have all these people coming in who don’t know about meetings at all.”

“We all have to find our own thing and I think that is a big part of getting clean. For me, it was the peers in the 12-step program that helped me find my own thing and teach me how to live as a responsible member of society and I only found that through others who gotten clean before me and showed me.”

RECOMMENDATION: SUBSTANCE USE

- # 4** Increase age-specific resources, access points, outreach strategies, and treatment options.

What Helped:

- Having a wide array of options to suit different recovery styles
- Attending 12-step meetings with younger members
- Having staff at treatment facilities be younger and easier to relate to
- Being able to make sober friends close in age and be part of sober communities
- Being involved in creating outreach strategies and identifying access points for other young people in recovery

What Harmed:

- Feeling disengaged and disconnected from sober communities because of drastic age differences
- Lack of resources and access points in schools and other places young people spend time

Quotes:

“There should be more places directed at young people. Ten years ago was the first time I went into rehab and I was the youngest by at least 10 years. The older guys were in a completely different space than me and it was hard to connect. It wasn’t anything like the energy and the support you get here.”

“I think the halfway houses with strict rules wouldn’t have been good for me because if someone tells me what to do, like when to be home, it makes me want to not do that. I liked the places that helped you learn stuff, like drive my car. I also liked it when we had fun events, like to meet new people. I had to learn to have fun again.”

“I was in a house where there wasn’t a lot of structure and that was helpful for me but I know that can hold some people back. I was one of the people that needed to practice having control over my life from the get-go. They were set up with kind of a democratic system for making choices for the house.

“I didn’t really have friends and didn’t want to make them, but being here kind of forced me to. I had burned bridges. That’s what I did. I didn’t want to be friends with any of you, but this place broke down a lot of barriers for me. I learned how to make bonds with other guys. This was the first group of guys I ever trusted. I would say I didn’t want to hang out but they would force me in a way, it got me out of my stuff. It helped me build healthy relationships with other men my age which I didn’t think I’d ever have. I needed that camaraderie because I would get stuck for so long.”

EDUCATION

RECOMMENDATION: EDUCATION

- # 1** Provide individualized, person-centered options in all aspects of education.

What Helped:

- Having alternative and hands-on classes that kept students physically engaged
- Being allowed, encouraged and supported to be active participants in their education planning

What Harmed:

- Rigid teaching and testing protocols
- Lack of accommodations and/or rigid accommodations for learning and mental health difficulties

Quotes:

“Why can’t schools use the self-directed care concept that some mental health systems use? Some kids are not good test-takers, and quizzes and tests make up too much of the final grade so that they end up failing or doing poorly. Intelligent kids are falling through the cracks.”

“I’m intelligent, but...with my memory, school is hard. Because I don’t learn ‘that way’ I’m falling behind. It’s the teacher’s preference of teaching, not the student’s [preference].”

“Teachers didn’t give any specialized attention. I felt left out all the time. I didn’t get seen unless I was acting up. “

RECOMMENDATION: EDUCATION

- # 2** Train and support students to be active participants in the Individualized Education Plan (IEP) process. Provide students the opportunity to have a young adult peer assigned as an advocate for them during the IEP process.

What Helped:

- Having an advocate in IEP meetings
- Being encouraged and supported to articulate needs and preferences

What Harmed:

- Being dismissed when attempting to contribute to the discussion or planning process
- Being spoken about as though not in the room
- Focusing entirely on negatives in the IEP meeting

Quotes:

“In IEP meetings, you really don’t get to be involved. All of these decisions about your life other people are making for you. I can’t tell you how many times I heard, ‘I think this is best for you.’ It didn’t matter what I wanted.”

“The day you hear ‘You have an IEP meeting today’, that’s the day you want to kill yourself. You sit in a room with all these people who look at your files instead of at you and rehash all the things you’ve ever done and want to forget. Your grades, your mistakes, the things that weren’t mistakes but they talk about in a bad way anyway because they don’t bother to ask.”

“This all goes back to not being heard, not bothering to speak up even when they ask you to because you feel like it’s pointless. They stare at you and take notes like you are a zoo exhibit, and you’re afraid to speak up because you’re afraid they’ll use it against you later. Or even worse, that they’ll dismiss what you say as usual, you get angry, and then you have another strike against you.”

“I had the option to share [at IEP meetings] but at the time I didn’t have the confidence to speak up.”

RECOMMENDATION: EDUCATION**# 3 Require ongoing quality, trauma-informed mental health and crisis training for teachers.****What Helped:**

- Staff reacting calmly and without fear when someone was in crisis
- Staff debriefing with witnesses after a crisis situation
- Staff responding to students with help rather than punishment

What Harmed:

- Staff ignoring students whose mental health issues were not obvious or who were not actively disrupting class
- Staff using punitive measures on everyone in the vicinity of an incident
- Staff failing to respond directly and immediately to bullying

Quotes:

“I was an isolator because I didn’t feel like they got me. They didn’t know what was wrong with me or understand what I was putting out there. At lunch I would sit alone and listen to music and then in the halls no one talked to me.”

“When I was sent into the special education schools after they got rid of me [from public schools], it was a scary mess. The teachers need so much more help and more training. They are there to help and they just can’t. If there wasn’t blood or someone didn’t leave in handcuffs, it wasn’t a normal day.”

“I remember when they restrained one girl in front of me, I didn’t know what to do and this memory haunts me. There is no discussion after a takedown for the people who saw it to make sure that they are ok, but that’s a big trauma.”

“I know sometimes I’ve got to show restraint. But no one ever saw or acknowledged what was happening so I get madder and madder. You’re ignored and then punished for being bullied and reacting to it since no one else did.”

RECOMMENDATION: EDUCATION

4 Increase accessibility to the smaller one-on-one alternative education and treatment programs sooner.

What Helped:

- Having a smaller staff to student/client ratio
- Ability to develop close relationships with staff
- Receiving a higher level of support from programs and more individualized and self-directed programming
- Having better, more caring, and invested staff
- Being paired up students with similar interest and issues to help one another

What Harmed:

- Having to get worse before being seen as having severe enough need to access more intensive programs and supports

Quotes:

“When I was in the public school system going through awful IEP meetings, they wouldn’t tell us about [this] school. It was considered a last resort. If I hadn’t found this school I’d have dropped out entirely and I would imagine I’d be in bad shape. They need to talk about this school more because it would help so many people. In fact they just need to make more [schools like this] so it isn’t a last resort. This option should be available before things

get out of control. All four of us here seem to be cases that things totally fell apart before anyone got us here. It shouldn't be like that."

"You had to get into major trouble before you got linked with services and by that time some damage is done and it might be too late."

"I think there needs to be more places like this. What this place offered me wasn't at all what I was expecting. It was so much more than I could've gotten anywhere. They have dinner at this table four nights a week with the owners. You have this completely different feel from them because they started the house because their son died, and neither of them will hesitate to shove a foot in your ass like they're your parents. They kind of separate themselves from the day to day stuff. They know what's going on all the time but they don't come at you as a boss. They come at you with advice and with support. All of those things working together make this place work how it does."

EMPLOYMENT AND INDEPENDENCE

RECOMMENDATION: EMPLOYMENT & INDEPENDENCE

- # 1** Design and offer services to young adults assuming that they do not have transportation.

What Helped:

- Having staff come into the community to meet young adults where they lived or where they were able to get to.
- Access to services at locations easily accessed by bus or mobility transportation services

What Harmed:

- Being forced to travel to the services on their own

Quotes:

“The most helpful thing the DORS counselor did for me was consistently meeting with me every week. She’d go out into the community to have meetings with me.”

“When this office moves I will no longer be able to work here because Mobility doesn’t go to Howard County. I am losing my job because of this and having to start again at no fault of your own because of transportation issues is really hard.”

“Their services are great, but the logistics are terrible. Like, for example, you can’t make a therapy appointment and see your psychiatrist the same day. I find myself running around to eight appointments a week, and not being able to make one trip to do any of them. Transportation is a huge problem here. Most of us don’t have cars, and making it to that many appointments is hard. And when we miss one or two because of this, we often have to start all over or they drop us. And how are we supposed to hold down a job with that amount of our time being taken up going to and from appointments and treatment. There is no helpful coordination.”

“Not having transportation really holds you back if [independence] is what you need. Your options...for meetings, for friends, for other things that make staying clean possible because you’re happy...are limited because you can’t get there.”

RECOMMENDATION: EMPLOYMENT & INDEPENDENCE

- # 2** Increase access to young adult-specific supported employment programs.

What Helped:

- Agencies making an effort to keep young adults in supported employment despite hospitalizations and other extenuating circumstances
- Being met in the community and supported through job interviews, disclosure issues, job placement, and job difficulties
- Having coaching and support about disclosure to employers
- Consideration of long-term career goals when making a job placement

What Harmed:

- Long waitlists
- Needing multiple diagnoses to access supported employment
- Lack of peer interaction with other young people in the program

Quotes:

“Even with DORS and other programs that can be helpful if you get in, the acceptance process can be intense and stressful, too. You have to have three disorders to qualify or you go right to a waiting list that you remain on forever. It’s tough when you have to play up your problems or diagnoses (that you may or may not even agree with) in order to get help. I know some people who know that a therapist gave them a diagnosis just so they could get the help or the service they need. But then that sticks with you your whole life.”

“[The supported employment counselor] would go on interviews with me if I wanted, and once I got an internship, she’d check in with me at the workplace and see how I was doing. I liked having someone I could tell about the progress I was making, and it made me want to keep going.”

“I told myself I was never going to get a job, and now I have one. The job at Office Depot makes me have to talk to people, which is usually really hard for me because of my anxiety, but I don’t have panic attacks anymore doing it. I really like the feeling of being able to say “I’m going to work!” when I leave the house. I take a lot of pride in it.

RECOMMENDATION: EMPLOYMENT & INDEPENDENCE**# 3 Include hands-on life skills training in realistic settings.****What Helped:**

- Learning life skills (e.g., laundry, driving, budgeting) along with mental health and recovery skills
- Learning life skills alongside others in real life settings rather than in a class format
- Being allowed to fail and keep learning without having responsibilities taken away

What Harmed:

- Being expected to already have life-skills knowledge and feeling penalized or abandoned for not having previously learned those skills.
- Having staff do everything for youth instead of taking the time to teach them how to do it

Quotes:

“I didn’t know anything when I came here. How to do laundry, cook, and pay bills. I didn’t have a car or a bank account. I didn’t really know how to live at all. They taught me that simple stuff and made it part of my daily routine.”

“Not only do the staff guide you through you and teach you stuff, but you kind of pick up things from each other just living. I guess I feel like not only do they teach you these things but they’ll sit there, and after the first couple months, they’ll say ‘this is what you need to do, figure out how to do it, but if you have questions come talk to me.’ It pushes you to do what you need to do and then you have a sense of pride that you accomplished that, that you did it yourself.”

“Driving is a skill that makes your life so much easier, especially out of high school, but...getting the hours, passing the test, and all that stuff is so difficult. They give you these study guides and then you are pretty much on your own. You can only do so much on paper to develop a skill that is hands-on, but they don’t give you any more help.”

RECOMMENDATION: EMPLOYMENT & INDEPENDENCE

- # 4** **Involve young adults in shared decision-making about their lives in a way that promotes independence and dignity, and that respects their privacy.**

What Helped:

- Being a significant part of discussions involving independence, life skills, and resources
- Being supported to identify and manage your own priorities
- Having privacy and control over your body and your belongings

What Harmed:

- Rigid program rules which impeded individual growth and independence
- Feeling like nothing belongs to you
- Being treated like you are too incompetent to be a part of making choices for your life

Quotes:

“Nothing is up to us. Nothing is voluntary. We don’t get a choice and that just creates the anger, frustration, and resentment that we are trying to work on and that landed us in here to begin with.”

“If I’m not allowed to try this stuff out on my own and mess it up a few times, I’ll never get it right. I have no control over my own finances either. My [Social Security Disability Insurance] check is taken from me every month and has been since the day of my 18th birthday, and the decisions are made for me on how it will be spent. I’ll never learn to budget or make choices with my money if you never give me a chance to do that.”

“Making us all go to the same pharmacy... That’s a new policy. I don’t understand that either, because they want us to be more independent and I had been totally fine getting my prescriptions by myself. I drive and I liked running that errand on my own. But they just made it a group rule to make it easier for staff that we all have to go to the same pharmacy, and now I can’t pick them up myself. It’s like they move me backward in my independence if it’s convenient for them.”

“There’s a lady that takes pictures of our rooms. She doesn’t even ask. They took pictures of the kitchen, our bedrooms, and they don’t even tell you what they are doing or why. They just invade your space like nothing belongs to you.”

LAW ENFORCEMENT/POLICE

RECOMMENDATION: LAW ENFORCEMENT

- # 1** **Require quality mental health, substance use, trauma informed care, stigma and crisis training for all law enforcement officers.**

What Helped:

- Police taking the time to talk to the person, help calm them down, find out what happened, and find out what they need or want to do
- Police explaining ahead of time what was going to happen before cuffing them or taking them to the hospital or precinct
- Having crisis resources other than hospitals and jail be utilized by police
- Involvement of youth in police education

What Harmed:

- Unnecessary use of force and handcuffs
- Being treated like a criminal when being taken to the hospital for a mental health crisis (handcuffs, sirens, aggressive attitude, threats of arrest, etc.)
- Being provoked and antagonized when in crisis

Quotes:

"I was upset and called my counselor, and something I said must have made her feel that she needed to report that. They called the mobile crisis team, but they were busy so the police came. They said 'are you [name]?' And I said yeah, and they asked if something had happened today. I was freaked out because they were police and I started to cry because there were four police cars around me. I wasn't crying because I was crazy but because cops were surrounding me. I'm very emotional and the cops being everywhere raised my anxiety. Then, they handcuffed me and took me to the hospital. They didn't take the time to actually figure out what was going on. They didn't ask me a single question or care what I needed. They just took me straight to the hospital."

RECOMMENDATION: LAW ENFORCEMENT/POLICE

- # 2** **Implement staff training, policies, and protocols to address and remediate the use of punishment over treatment and help.**

What Helped:

- Being treated as a person in need of support rather than as a bad person
- Being able to communicate openly with officers

What Harmed:

- Having police focus their efforts into arresting young adults rather than helping them
- Lack of treatment resources available as alternatives to forensic involvement
- Being automatically assumed to have ill intent or to be a troublemaker
- Assumptions being made based on youths' race, age, appearance, etc.
- Arrests looked at as "wins" or effective measures

Quotes:

"If a kid is missing, they don't show up or do anything, but they'll ride up and down Main Street to see who they can catch with an open container."

"I grew up in Calvert County, and first the pills came in, but now it's harder and harder to get pills so they went to dope. There's one NA meeting once a week. In the middle part, there's nothing at all. They have cops kicking down people's doors looking for this stuff, but there's no help for them."

"The police harass the homeless here and there is a really high number of homeless young adults here. Because you are homeless and you exist, you must be panhandling so I'm going to arrest you. "

STAFF

RECOMMENDATION: STAFF

1

Eliminate the use of negative reinforcement and other punitive measures that create barriers to relationships, treatment, and recovery.

What Helped:

There were no comments from any of our focus groups that indicated that any good came out of these the use of these measures.

What Harmed:

- Being in constant fear of losing services
- Relationships with staff turning into a ‘them vs us’ dynamic
- Not being able to go to staff with problems for fear of being punished instead of helped

Quotes:

“They make us sign stuff all the time that I don’t understand and they tell me if I don’t I’ll get kicked out.”

“We weren’t approached, like when I was pregnant, like “ [young adult],” I noticed that you’ve got some stuff going on. Would you like to sit down and see if we can get you some resources to help you out? No, they came to me with the attitude like, “Aha! I caught you! You’re pregnant, or on drugs, or whatever the case may be.” Who wants help from that person then? Not me.”

“Once you’re admitted to this program, you’re held to a higher standard than the rest of the human race. You’re not allowed to get mad. Just because I’m having a bad day...I mean I’m human...doesn’t mean I need to be thrown to the floor.”

RECOMMENDATION: STAFF

2

Employ staff and volunteers close in age and with relatable experiences to the young adults being served and create opportunities for alumni to fill staff and volunteer positions and to utilize their lived experience.

What Helped:

- Being able to develop more trusting relationships with staff who had similar life experiences
- Having staff that related to the experiences of youth and having common interests and reference points

What Harmed:

- Feeling like staff didn't understand where they were coming from

Quotes:

"All of what providers know is based on books and stuff from their college degrees. They haven't been in the patient's shoes."

"Here you have the alumni who you look to as your friends. People who came through here and know what you're doing. We have interns here too who are going through school, and they're more clinical but still around your age and most of them are getting into it because they went through it themselves."

"The alumni come back through the years. The value of having the alumni involved is the fact that they support you because they feel that it's right. They don't have to come back here, but they do because they want to and that makes you trust them that much more."

RECOMMENDATION: STAFF

- # 3** **Implement training, policies, and protocols for staff and organizations that promote respect, credibility, and dignity for youth.**

What Helped:

- Having staff understand that most young people with behavioral health histories have been dismissed and disrespected because of both their age and behavioral health status
- Feeling like staff are really listening to what they are saying
- Feeling like staff genuinely care about their well-being
- Making a significant connection with a staff member or supporter
- Having staff acknowledge and respect youths' right to their mental, emotional, and physical boundaries

What Harmed:

- Being deemed incapable, unwilling, uninterested or too immature to be involved in decisions about their lives and their care

- Being treated as if what they say and think is insignificant, naïve, or irrelevant

Quotes:

“Point blank, they listen. They care about you, they support you, they keep tabs on you. They make sure you’re ok emotionally, mentally, and they are there for you when you think no one else is.”

“They just know and respect limits here in ways that other schools and hospitals I’ve been to didn’t. They give you choices. They encourage you to do stuff that will challenge you and have you step outside your comfort zone, but if you say “no” three times they’ll stop.”

“You have to find that one person that gets it. They are out there. There’s a zillion more who don’t or don’t want to, but if you find one that does who is willing to kind of advocate for you, it can make all the difference.”

“I’ve always really loved this Al Capone quote because I think it shows exactly what the double standard is like being young and assumed to be crazy in the hospital system and other service places. He says, ‘When I sell liquor, it’s called bootlegging. When my patrons sell it on Lake Shore Drive, it’s called hospitality.’ It’s just like with us and everything we’ve talked about, like when we act normally in response to a situations or when we have a thought or a feeling, it’s insubordinate and weird and wrong, but not when adults or doctors or the rest of the world does that same thing. That makes sense?”

YOUTH VOICE

RECOMMENDATION: YOUTH VOICE

1

Build the infrastructure for authentic and well-supported youth engagement and leadership that treats youth as equal partners at local, state, and national system levels. Build the capacity for youth peer advisory councils at organization and system levels.

What Helped:

- Being involved in organization and program policy-making
- Being involved in quality improvement and evaluation projects
- Having youth culture acknowledged and used as an asset
- Connecting and collaborating with diverse youth groups and causes
- Having statewide youth leadership who represent youth served by behavioral health and other youth-serving systems
- Having adult allies and supports that promote new youth leadership infrastructure

What Harmed:

- Being treated like you have nothing to give back or offer
- Being treated as an object or recipient rather than a resource
- Not having a community of young people with similar backgrounds with whom to make a difference

Quotes:

“Unless you are an adult, you don’t have an opinion that matters. The only opinion that matters is the most experienced one.”

“Flexibility makes everyone win. The system gets our ideas, we get to have fun, feel useful, and not get bored. My brain works better when I am not being drilled for answers and when I don’t feel forced. OOO and the TAY Project are the best because I get to make the decision that I want to be a part of each thing that they involve us in. Some things might be right for me and other not, and I get to make that decision.”

“The group decides what is best for the group at the [Wellness & Recovery] center. It’s great having numerous people in the group for brainstorming and learning, but you also feel like you were, [as an individual] part of making most of the decisions and choices.”

“We used to have meetings where we could give our input about the program but they just stopped and besides there isn’t anyone we feel comfortable talking to on the staff anymore. I’d like to have a meeting where we got an opportunity to talk about issues in the program or what we need (like help mediating roommate issues), or other stuff.”

RECOMMENDATION: YOUTH VOICE

2

Expand training for young adults in public policy, advocacy, and peer support. Increase capacity of statewide youth peer leadership advocacy projects.

What Helped:

- Being involved in advocacy and behavioral health policy-making
- Being involved in systems change
- Having a community of young people with similar backgrounds with whom to engage in advocacy efforts and make a difference
- Having identified adult allies as supports
- Feeling respected and valued as equal partners
- Having orientation, training, and ongoing support as youth advocates

What Harmed:

- Lack of provider/administrator awareness about youth role in systems change
- Being unaware of the existence of peer support and advocacy
- Tokenization of youth involvement and lack of support for authentic participation
- Overuse of the same youth advocates and their stories

Quotes:

“We’re all adults and we should be able to get together with the staff and have just as much input. We have meetings but [staff] talk, we don’t talk. We’re not allowed.”

“I am involved with all kinds of advocacy organizations and consumer training programs. I love it and they really help me with my recovery and my disability and with being a good parent.”

“This project [What Helps What Harms Maryland] was the first time I had ever heard of peer support. I’ve been in mental health treatment and supported employment for half my life and never really thought that I could help someone else with that.

“I’ve participated in system improvement and told my story about using supported employment...on a webinar teaching therapists and other people about what didn’t work for me...and I got paid because I was the expert.”

“How do I become a peer supporter? It just hit me that this is really what I want to do with my life.”

CONCLUSION

The young adults who participated in What Helps What Harms Maryland were both surprised and thrilled that someone would actually seek to elicit their opinion about their experiences and think it valuable enough to inform policy and planning for service systems. Some were energized to engage in advocacy or peer support work, a number of whom were directly connected to opportunities to do so by On Our Own of Maryland and Taking Flight staff. The focus groups made clear that youth want to succeed and have a clear idea of what their goals are, how they might achieve them, and of the things that impede or facilitate their doing so. Clearly, it is hoped that the recommendations provided in this report will be helpful in continuing to improve behavioral health systems and related services for youth and young adults.