the national 2009 youth summit report

PRIORITIES:

1) drafting a Mental Health Youth Bill of Rights

2) increasing the use of individualized and youth-directed care plans

3) creating additional supports for youth transitioning from child to adult services

4) increasing awareness of medication and treatment options

5) creating opportunities for peer-to-peer supports

TABLE OF CONTENTS

research & training center portland
ON FAMILY SUPPORT AND CHILDREN'S MENTAL HEALTH

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FUNDERS

The 2009 Portland National Youth Summit Report is a publication of the Research and Training Center on Family Support and Children's Mental Health. This publication was developed with funding from the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, and the National Institute on Disability and Rehabilitation Research, United States Department of Education (NIDRR grant H133B040038). The content of this publication does not necessarily reflect the views of the funding agencies.

CARING FOR EVERY CHILD'S MENTAL HEALTH
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NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH
NIDRR

SUGGESTED CITATION

Strachan, R., Gowen, L. K., & Walker, J. S. (2009). *The 2009 Portland National Youth Summit Report.* Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University.

The 2009 Portland National Youth Summit Report

INTRODUCTION

The following report outlines the planning process, the agenda, and the outcomes of the 2009 Portland National Youth Summit. The purpose of the Youth Summit was to invite systems-experienced youth (e.g., those who have been involved with the services such as mental health, child welfare, and/or juvenile justice systems) together to create a "Call to Action" that outlines positive solutions to improve the mental health services they receive. This Summit took place in conjunction with the Research and Training Center's (RTC) Building on Family Strengths Conference, Monday, June 22, 2009. A Youth Summit Advisory Board comprised of four young members partnered with a Youth Summit Coordinator, RTC staff and support allies to identify the goals of the event, create an application for participation, recruit applicants, create an event agenda, and facilitate activities during the event.

Thirty youth and young adults, ages 16-25, were invited to attend the Summit and contribute based on their activities as leaders and advocates within their own communities, and on their experiences with mental health services, foster care, homelessness, residential treatment, hospitalization, and/or the juvenile justice system. During the Youth Summit these participants, led by the Summit Advisory Board, identified five priority areas of change within youth services. They presented these outcomes in a Call to Action Plan. (See section six of this report.)

PHILOSOPHY

Purpose and Goals of the Youth Summit. In an effort to increase meaningful youth participation in mental health and social services, the RTC set out to facilitate a youth-driven event in the summer of 2009 to translate the perspectives of "system-experienced" youth into specific priorities and activities. This event, the 2009 Portland National Youth Summit, took the form of a one-day gathering of 30-35 youth and young adult leaders from around the nation. As a group, these young leaders would be asked to identify key areas needing improvement within systems serving young people ages 16-25 years old with emotional or mental health conditions. The group would brainstorm initial action steps on how to implement these improvements. Additional goals included encouraging youth to provide input, and planning for a series of presentations based on their findings. Among these presentations was the keynote address for the Building on Family Strengths Conference, held in Portland during the days following the Summit. The final goal of the overall project was to describe the planning process and intended outcomes of this youth-led-and-attended event, so that others use what we had learned in their own efforts to increase youth influence on research, policy, and/or practice.

The Importance of Youth Voice. Sociologist Roger Hart discusses the various degrees of youth involvement within organizations in his text Children's Participation: The Theory of Involving Young Citizens in Community Development and Environmental Care (Hart, 1997). Hart's "Ladder of Participation," a visual diagram that represents the increasing stages of youth involvement with rungs on a ladder, is a useful tool for gauging how effectively an agency is facilitating or encouraging youth involvement (see Figure 1).

THE PLANNING PROCESS

The Youth Summit Advisory Board. Because the Youth Summit was to be a youth-driven event, the first step in the planning process was to hire a young adult who had personal experience with mental health services to act as the Youth Summit Coordinator. The Coordinator, with support from RTC staff, led a process to recruit "systems-experienced" young people for the Youth Summit Advisory Board, which would help plan the Youth Summit. The Advisory Board was appointed to identify specific goals and desired outcomes for the Summit, initiate recruitment for youth and young adult participants, oversee the creation of a participant application process, and plan the Summit agenda.

Recruitment of Youth Summit Board members began with a request for potential Board members circulated nationally to youth leaders, youth coordinators, and adults connected to systems of care. Identified and interested young people submitted resumes and cover letters sharing their experiences with mental health services, foster care, residential treatment, homelessness, and the juvenile justice system, and stating why they wanted to become a part of the Youth Summit Advisory Board. Applicants were then selected based on their experiences as youth leaders, their passion for making improvements within youth services, and their availability. In return for their involvement, Board members would receive compensation for time spent on conference calls ($20/hour), funds to travel to and stay in Portland, Oregon, and a waived registration fee to attend the Youth Summit and the Building on Family Strengths Conference. An additional stipend upon completion of the Summit would also be awarded ($250). The Youth Summit Coordinator and supporting RTC staff felt it was important to provide mon-

FIGURE 1. HART'S LADDER OF YOUTH PARTICIPATION

Step 8 Youth/Adult Partnerships:
Youth initiate projects and decision-making is shared with adults

Step 7 Youth-Led Activism:
Youth initiate and direct projects while adults are in the supportive role

Step 6 Participatory Action Research:
Adults initiate projects, but decision-making is shared with youth

Step 5 Youth Advisory Councils:
Youth provide feedback on projects that are initiated and run by adults

Step 4 Community Youth Boards:
Youth are assigned project roles by adults and are informed how and why they are being included

Step 3 Tokenism:
Youth appear to be included, but really they have little or no choice in how they participate in adult-initiated projects

Step 2 Decoration:
Youth are used to help with adult-initiated projects in an indirect way

Step 1 Manipulation:
Youth are included to create the appearance of youth-inspired projects that are in fact run by adults

(Adapted from "Ladder of Participation" from "The FreeChild Project Youth Voice Toolbox" www.freechild.org)

etary compensation to Board members to recognize the value of their time and contribution and to encourage their full participation.

Once a team of eight young leaders was chosen to form the Board, the planning process was underway. Due to the fact that Board members were spread out across the country, representing Oregon, California, Texas, New York, and Massachusetts, the Youth Summit Advisory Board depended primarily on conference calls and email communication to plan the Youth Summit. With a commitment to creating an atmosphere where Board members felt heard and valued, the Youth Summit Coordinator sent meeting agenda items to members before conference calls and solicited agenda feedback and modifications.

During the first conference call in December of 2008, members voted on which day of the week and time of day future calls should take place. Members were encouraged to lead team-building "ice-breaker" exercises at the beginning of each call to help them establish a positive rapport with one another. Because members had many existing commitments, they received reminders about conference calls through emails, individual phone calls and text messages one or two days before each call. For those youth who could not attend certain calls but could communicate electronically, a group website was created through Google Sites to facilitate comments on planning and application materials, as well as to provide access to previous meeting agendas and minutes. Most importantly, youth were asked to (and they often did) speak up if the language being used in any of the communication was not clear and understandable.

Advisory Board Conference Calls. Over the course of seven months, the Youth Summit Advisory Board and supporting RTC staff met for eleven conference calls, which took a total of ten and a half hours. Although each of the eight original Board members was very dedicated to amplifying youth voice in systems of care, four of these youth were not able to commit the time and energy that was necessary to be a Board member. Therefore, the Youth Summit Advisory Board shrank to four members representing three states: Massachusetts, New York, and Oregon.

Online Surveys. As work was being done to select possible topical areas of focus for the Youth Summit, Board members decided that it was important to hear from a broader spectrum of young people. To do this, RTC staff members created an online survey to see what sorts of changes in youth mental health services young people with mental health conditions were the most eager to see.

A list of potential topics was created, using recommendations drawn from other local- and state-level youth summits (or equivalent events) along with suggestions from the Youth Summit Advisory Board. Two RTC staff members, assisted by the Youth Summit Coordinator, narrowed down these recommendations to 28 items that were grouped into five categories: 1) Medication and Treatment; 2) Therapy Relationships; 3) Youth Advocacy, Peer Support, and Peer-to-Peer Services; 4) "Aging Out"/Transitions; 5) Specific Settings/Systems (Gowen & Walker, 2009).

Through RTC email lists and viral forwarding of an online survey announcement, participants were invited to take the survey. A total of 73 youth (26 years of age or younger) and 193 adults (over 26 years of age) responded. Youth respondents identified the most important topics to be discussed at the Youth Summit as "the importance of life skills training for youth," "the lack of support for young adults transitioning out of social service systems," "mental health training for juvenile justice workers," "the lack of training and education youth need to get meaningful employment," and "the need to fund youth advocacy organizations." Over half the youth respondents also thought that medication- and treatment-related options were a "top priority" that should be discussed at the Summit (Gowen & Walker, 2009; see Appendix A for more detailed results).

YOUTH SUMMIT PARTICIPANTS

Applications. Before beginning the recruitment of Youth Summit participants, the Youth Summit Advisory Board first had to identify what type of participant would be able to contribute to the Youth Summit. The Board wanted participants to network and have a good time, but they also wanted participants to contribute by sharing their stories, brainstorming thoughtfully, exploring new ideas, and problem solving as a team.

It was decided that although the voices of young people from all levels of leadership experience were important to improving mental health services, youth that had experience supporting other youth in their communities, in addition to experience within mental health and social service systems, would best fit the one-day structure of the Youth Summit. Therefore, it was determined that young people who could demonstrate leadership skills would be ideal participants for the Summit.

The Summit Advisory Board defined "youth" as being between the ages of 16 years and 25 years old. The Board also considered that youth would be traveling out of their familiar community to a new environment and that abilities to travel independently and be comfortable and adapt to an unfamiliar setting were important.

When creating the Youth Summit participant application, the Board did not want to limit youth to one type of application style. In recognition of the many different ways of expressing leadership, the application included several short answer questions, a request for a recommendation letter from whomever the youth would like to select, and an invitation to submit art, writings, or any other type of expression the youth felt represented himself/herself. One youth applicant sent a collection of poems with her application, while another sent a local newspaper story featuring his transition from his past life of gang involvement and time in corrections, to his current work as a hospital volunteer and his goal of becoming a nursing student. By reading these materials, the Youth Summit Coordinator was able to get a clearer picture of each applicant's personal story, leadership experience, and goals for improving youth services.

The organizational sponsor of the Youth Summit, the RTC, was able to award a handful of youth applicants financial assistance. Scholarships included travel to and from Portland, hotel stay, and registration fee for the Building on Family Strengths Conference. Youth were asked to identify in their applications if they were requesting financial support, and if they would still be able to attend if they did not receive a scholarship. Of the youth that applied, all the individuals who indicated that they would not be able to attend without financial support received a scholarship. Eight total scholarships were awarded.

Recruitment. The Youth Summit application was converted into an electronic PDF file that included a cover page introducing the purpose of the Youth Summit, the application itself, and a recommendation form for whomever the youth selected to write on their behalf. This completed packet was disseminated electronically through RTC email lists of youth coordinators, grant sites, and organizations that serve or advocate for children and youth; forwarding of the application was encouraged.

The Youth Summit was also publicized via a web page on an online social networking site (MySpace). The Youth Advisory Board designed and maintained the page. Information about the Youth Summit could also be accessed through the RTC website. All materials related to the Summit were posted on both these online resources. All publicity materials and outside correspondence included a link to the Youth Summit web pages.

Youth coordinators (often the first to receive news of the Youth Summit call for participants) reacted with interest and enthusiasm. Ongoing communication about the Youth Summit with these coordinators and other adult allies occurred through phone conversations, email correspondence, and face-to-face interactions. Applicants were asked to send their applications to the Youth Summit Coordinator electronically through email, fax, or through physical mail. Initially youth were given three weeks to complete and return the application, but the deadline was later extended an additional week.

Thirty youth were invited to participate in the 2009 Portland National Youth Summit. These youth were ages 15-25, 19 female and 11 male. Twenty-six had received mental health services, 6 had been in foster care, 16 had spent time at a residential treatment center, 7 were a part of the juvenile justice system, 5 had been hospitalized for a psychiatric concern, and 11 had experienced homelessness. Youth were given the option of reporting their race. Of the 24 that did report race, 14 identified as White, 4 as Asian, 4 as African-American, 1 as Mexican and Aztec, and 1 as Multi-racial.

The selected participants were sent a congratulatory letter via email along with a welcome letter of introduction from a Youth Summit Board member. Of the individuals who submitted applications, only a few were not invited to attend the Summit. These

few did not fit the identified age range, or did not have mental health or social service systems experience.

Pre-Summit Communication. The Youth Summit Advisory Board members and planning team wanted to maintain the enthusiasm exhibited in the youths' applications during the two-month gap between receiving acceptance letters and the Youth Summit event in June. One idea suggested pairing youth participants with a Board member in a pen-pal relationship. While this was a well-supported idea, Board members were not able to commit the time to communicate with five or six youth several times. It was therefore decided that the Youth Summit Coordinator should create electronic newsletters to keep youth engaged and excited during the lead-up to the Summit. The newsletters included information about Board members, important reminders about preparing to attend the Youth Summit, and information about national organizations dedicated to youth voice. Two newsletters were created and sent to youth participants. Youth participants were invited to submit information for the newsletters. Two participants wrote pieces about their personal experience within mental health services and their desired goals for the Youth Summit.

In addition to the two online newsletters, participants were invited to follow the Youth Summit online through becoming friends with the Portland National Youth Summit MySpace page. Some youth did not have access to the internet, or did not feel comfortable using a computer, so the Youth Summit Coordinator attempted to reach them by telephone several weeks before the Summit to congratulate them again on being selected to attend the Youth Summit.

THE EVENT

The Identified Goals of the Youth Summit. When planning the Youth Summit agenda, the planning team felt it was crucial to: 1) create a welcoming, respectful, and youth-driven event; 2) maintain a "safe space" during small and large discussion groups, meaning that individuals were not judged based on their personal stories, different opinions were respected, and each idea was valued; and 3) provide each participant with a chance to contribute in a way that felt comfortable.

Youth Summit Facilitators and Allies. The team recognized that some individuals might prefer sharing in small group settings, while others would become motivated and energized when working with a large group. They also recognized that there was limited time—as this event was planned for one day only—and that while the agenda should foster fun activities and chances for networking, it also had to include times for meaningful discussions that would result in a plan for action. For these reasons, planners formatted the day to include small group discussions, as well as large group activities.

It was decided that small group discussions should be facilitated by a member of the Youth Summit Advisory Board and an older adult "youth ally." While the youth facilitators would be asking their small group members to share stories and participate in brainstorming ideas, the older adults would provide additional support by taking notes, making suggestions, and offering additional emotional or physical support to the youth facilitators and/or participants.

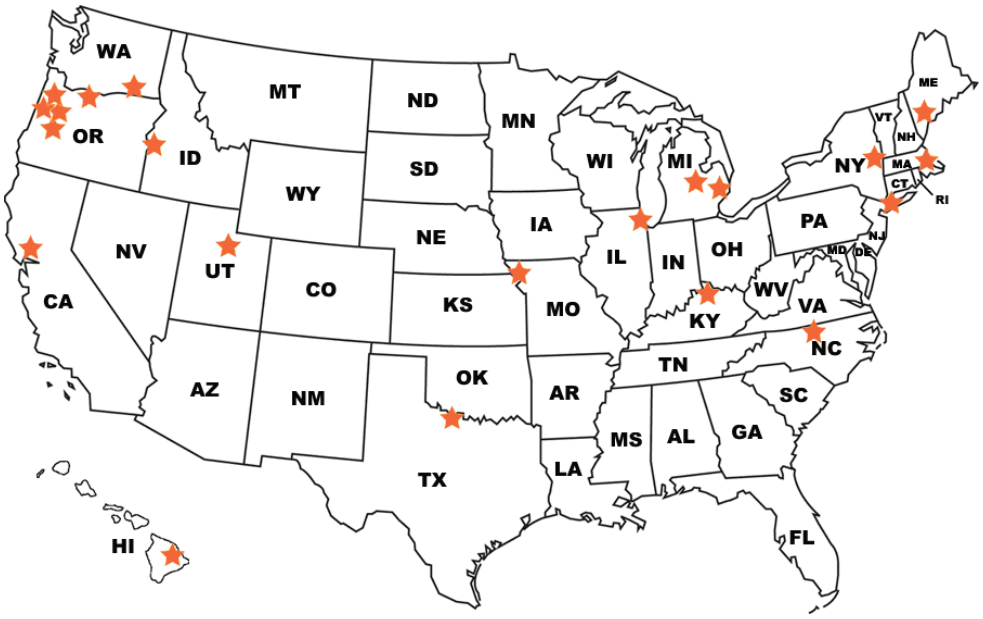
Ideally, Youth Summit Advisory Board members would have liked to have two youth facilitators and one support person in each group, but there were only four Board members and three identified support facilitators. To obtain the minimum additional facilitators needed, the Youth Summit Coordinator recruited one Youth Summit participant to be an additional youth facilitator, and two youth coordinators who were traveling to Portland in support of a youth participant.

Sunday Welcome Celebration. The Youth Summit event kicked off the evening before the actual event with an open house Welcome Celebration. Youth participants and their sponsors were invited to attend, have dinner, and get to know other youth. Approximately 20 people attended over the span of three hours. Youth and older adults sat at three round tables covered with bright paper, markers and crayons, and were encouraged to show off their art skills as they got to know one other.

To facilitate introductions, a version of the ice-breaker activity "Find Someone Who" was created

that could be completed in a relatively unstructured format. Youth and sponsors alike visited with one another, discussing their current community youth projects, what they hoped to accomplish the next day, and how long they had to wait in line with their shoes off at airport security. It was many youths' first time traveling to Portland or the West Coast, and the activity helped familiarize the attendees with each other and their new environment.

FIGURE 2. YOUTH SUMMIT PARTICIPATION MAP



Monday Morning Activities. The welcoming event was open to invited youth, their allies, and sponsors, but the Portland National Youth Summit on Monday, June 22nd was open only to youth and specially invited "youth allies." Of the 34 young people (30 participants, 4 Board members) that were invited, 27 youth attended. In addition to these 27 youth, six youth allies served as support facilitators.

Advisory Board members and the Youth Summit Coordinator opened the Youth Summit by introducing themselves, while participants enjoyed a continental breakfast and coffee, made nametags, and looked through their Youth Summit Participant folders.

In these folders participants were given an agenda of the day, a list of those in attendance, a map highlighting the location from which each participant traveled (see Figure 2), a map of the hotel where the event was being held, an information sheet outlining events at the following Building on Family Strengths Conference, a Subject Multimedia Release form (so that pictures of the event could be used by the RTC and the youths' organizations), and a Participant Evaluation Form.

Next, participants brainstormed as a group and created a list of ground rules meant to ensure all those involved remained respectful, supportive, and on topic throughout the day (see Community Norms, Figure 3); one of the Board members led this activity.

Once ground rules were established, youth facilitators led two different ice-breaker activities in an effort to begin building relationships and trust. The first activity, "Circle Up," asked youth to introduce themselves, and to state where they were from and what their favorite movie or TV show was. The second activity, "Step to the Other Side," led youth through a series of questions that challenged them to think about their past experiences within men-

FIGURE 3. COMMUNITY NORMS

tal health support services and social services. Examples: "Have you ever felt discriminated against?" and "Have you ever gone out of your way to support a peer?"

After these introductory activities, Youth Summit participants divided randomly into five different groups, three groups of six and two groups of seven. Each of these "experience discussion groups" was led by a youth facilitator and a support ally. Groups dispersed to breakout rooms and worked to identify three areas where change was needed within mental health services by sharing positive and negative examples from their own involvement with mental health services and other social services. This personalized approach was intended to create more participant engagement, and to validate the importance of sharing personal experiences in strengthening youth services.

After identifying a variety of areas for change that they felt should be addressed within youth services, groups rejoined and presented their ideas to the large group. As breakout group members presented, common themes emerged among their presentations and discussions. A consolidated list of 17 priorities was compiled onto a large piece of paper (see Figure 4). Many of the identified priorities corresponded with the priorities recognized through the previously administered online topics survey (see section three of this report). Thus, although the priorities identified were determined by a small group of youth, these priorities reflected the wider perspectives of systems-experienced youth.

All youth were then asked to select the top five topics they felt were most important and that warranted more discussion during the afternoon Call to Action sessions. Each participant was given five small dot stickers and then asked to physically place stickers under the listed priorities they felt were the most important. Youth could divide up their five sticker votes any way they wanted to. For example a young person could place one sticker by five different priorities, or place multiple stickers by one or two different priorities.

Monday Afternoon Activities. At this point in the day, participants broke for lunch while facilitators counted the number of votes for each priority. The top five priorities, as voted by the Youth Summit members, became the topics about which action plans were to be crafted during the afternoon. These were: 1) drafting a Mental Health Youth Bill of Rights, 2) increasing the use of individualized and youth-directed care plans, 3) creating additional supports for youth transitioning from child to adult service programs, 4) increasing awareness of medication and treatment options, and 5) offering opportunities for peer-to-peer supports.

After a well-deserved break, Youth Summit participants rejoined as a group. Facilitators then presented the five top areas selected during the voting process. Youth were asked to select which topic, of the five listed, they felt the most passionate about discussing further, or that they felt the most connected to due to their own experiences.

Once youth selected a topic, participants broke into "action coalitions" led by one of the previously

FIGURE 4. ALL IDENTIFIED PRIORITIES

- Increase peer support
- Increase family support
- Opportunity for youth voice
- Self-directed care/individualized care plans
- Cross-system collaboration and trainings
- Updated information on current supports
- Medication options
- Alternative services emphasized
- Resources for youth transitioning
- Housing for youth transitioning
- Changing Individual Education Plans (IEP) and diploma requirements
- Separation of social support and education supports in school
- Mental health labels
- Sharing information about diagnosis
- Peer support constitution
- Mental Health Bill of Rights for youth
- Job Corps

formed youth facilitator/support ally teams. These five different action coalitions congregated in five different meeting rooms to brainstorm strategies to overcome current barriers, possible resources and supports, and action steps. Youth facilitators led the coalitions through a series of questions to assist them in brainstorming ideas and creating an action plan for improving their selected topic area. These questions addressed ideal contexts, barriers to implementing successful solutions, and steps to action. For example, the action coalition that focused on creating opportunities for peer-to-peer supports discussed: 1) what peer-to-peer supports would look like in a perfect world, 2) barriers to currently achieving that perfect world, 3) action steps to begin making changes, and 4) available resources for increasing peer supports.

After addressing barriers and exploring possible solutions, each action coalition wrote a "call to action" and prepared a 15-minute presentation. These call to action plans identified their priority of change, outlined their plan, and incorporated suggestions and feedback from the large group. The results from the five presentations are discussed in the next section.

Closing Ceremony. At this point in the afternoon, it was clear that youth and ally participants were exhausted mentally and emotionally. When finalizing the agenda, the Youth Summit Advisory Board had considered the importance of ending the event in a way that allowed for reflection and some amount of closure. To commend their efforts and acknowledge the value of their participation, Youth Summit participants received a certificate, signed by the Youth Summit Coordinator and the Chief of the Child, Adolescent and Family Branch of the U.S. Department of Health and Human Services Center for Mental Health Services, which funded the Summit.

For their final activity of the day, youth and facilitators participated in a closing ceremony that asked individuals to share what they enjoyed most about the Summit, what they wished had gone differently, and how they planned to implement the ideas and voices from the Youth Summit in their own communities.

CALL TO ACTION PLANS

As noted previously, Youth Summit participants identified five areas needing improvement within youth services through sharing stories of personal experiences within systems of care, brainstorming in small groups, compiling brainstormed priorities,

and voting on what they identified as top priority areas in need of change.

Participants selected the five highest priority topics as:

1) drafting a Mental Health Youth Bill of Rights,

2) increasing the use of individualized and youth-directed care plans,

3) creating additional supports for youth transitioning from child to adult services,

4) increasing awareness of medication and treatment options, and

5) creating opportunities for peer-to-peer supports.

Each of these top five priorities was then assigned to one small group, or action coalition, consisting of four to five youth, a youth facilitator, and a support facilitator. These action coalitions were asked to think about what the ideal implementation of their priority in youth services would be, to identify current barriers to the ideal vision, and to brainstorm the strategies needed to move forward to make the ideal a reality. Action coalitions formatted their discussions and ideas into a Call to Action Plan and presented to the other group coalitions.

The following sections outline the presented Call to Action Plans by: 1) defining each priority item, 2) identifying what the ideal implementation of each priority is or what services would be like "in a perfect world," 3) identifying the current barriers in incorporating each priority, and 4) outlining possible action steps to break through, work around, or work with identified barriers.

Priority One: Drafting a Mental Health Youth Bill of Rights

Definition: A Mental Health Youth Bill of Rights is a document meant to inform counselors, psychologists, doctors, social workers, and other service providers how to effectively and appropriately work with youth receiving mental health support. It reflects the importance of providers' focusing on the strengths of the youth, using clear language, sharing possible options, and creating opportunities for youth input and leadership while creating a plan of care. The Bill of Rights outlined by this team also speaks to the other four identified priorities included in this report.

In a Perfect World: Every youth ages 14-25 would have the right to:

i. Be fully informed by her/his medical provider of any known possible side effects of recommended medications, how long the medical provider thinks that s/he will need to take any recommended medication, possible alternatives to taking recommended medications, how to deal with unwanted side effects of medication, and the best way to express dissatisfaction with her/his prescribed medication.

ii. Evaluate the treatment plan created by his/her medical provider or counselor and to make recommendations for how to improve his/her plan.

iii. Understand the language used by service providers and be provided the chance to ask for clearer explanations.

iv. A supportive transition in services, whether s/he is changing service providers, transitioning from child service programs to adult service programs, or exiting services completely. A supportive transition includes, but is not limited to: an opportunity to receive closure with current providers, receiving information about a new provider or a new service center if possible, and a willingness on the part of closing providers to meet with new providers at the youth's request.

v. A positive environment that is focused on her/his strengths and successes versus focusing on her/his areas of needed growth and struggles. This positive environment can be represented in the way providers communicate, the amount of opportunities youth have to ask questions or voice ideas, or even in the way an office or center is decorated.

Current Barriers:

- Youth are often left out from taking part in making decisions about whom they receive services from, how long they receive services, and what the desired outcomes are for their lives.

Action Steps:

- Present this Bill to conference participants during the Building on Family Strengths Conference Tuesday keynote, a separate 90-minute symposium presentation, and a visual presentation.
- Post the initial version of this Bill of Rights online and circulate for feedback via free electronic message boards: Yahoo! Answers, Twitter, and Blogspot.
- As feedback is given, make appropriate revisions to the Bill.
- Format the final version of the Bill into an attractive document, listing the purpose of the Bill, how it was created, and its content. Send this final version, with a letter of introduction requesting sponsorship, to the Research and Training Center on Family Support and Children's Mental Health, Portland State University School of Social Work, the National Institute on Disability and Rehabilitative Services, the Substance Abuse and Mental Health Services Administration, Youth Motivating Others through Voices of Experience (Youth MOVE), and the Oregon Family Support Network.

Priority Two: Increasing the use of individualized and youth-directed care plans

Definition: Treatment plans are written reports that traditionally outline identified problems or issues, goals for addressing those issues, what methods will be used to reach goals, and the timeline for the completion of goals. They are often used to monitor progress of treatment and the "effectiveness" of services.

Individualized and youth-directed care plans are created and monitored by not only the care providers, but the youth receiving services as well. These types of plans should highlight youth strengths, include goals identified by the youth and realistic strategies that are youth-driven, list people the youth has identified as his/her positive support network, and state how frequent the provider plans to meet with the youth for plan revisions.

In a Perfect World: Mental health providers working with youth would:

- Explain the purpose and process of creating a treatment plan.
- Share with the youth who will have access to his/her treatment plan.
- Invite youth to share his/her goals for the future.
- Collaborate with youth to brainstorm possible strategies that directly address the goals identified by the youth.
- Present to the youth several age-appropriate and culturally respectful treatment options, regardless of perceived cost or availability.
- Encourage youth to frequently evaluate and update his/her treatment plan with the provider.

Current Barriers:

- Providers are uncomfortable changing the "provider knows best" model.
- The belief that youth are not capable of being active members of their treatment plans due to their age or emotional state of mind.
- The use of confusing and specialized language that is intimidating to youth.

Action Steps:

- Create youth advisory councils within national agencies, such as the Substance Abuse and Mental Health Services Administration, National Association of Social Workers, American Psychological Association, and American Counseling Association.
- Increase research that evaluates the effectiveness of Wraparound teams within youth mental health services.
- Share the importance of youth voice in care plans with legislative offices on national, state, and local levels.
- Request that state and national grant administrators require agencies receiving grant money to implement models of individualized care.

Priority Three: Supports for youth transitioning from child to adult services

Definition: Once young people reach a certain age (usually between 18 and 21, depending on state of residence), they are no longer eligible to receive mental and financial support from child and youth social services, such as state custody or foster care. These "transition-age youth" are left with limited resources and often must navigate housing, education, health services, and emotional wellness on their own.

In a Perfect World: Each community would have a center specifically targeted toward transition-age youth. Centers would:

- Be accessible and visible.
- Provide free access laundry facilities, showers, bathrooms, and kitchens.
- Offer employment support, life skills education, financial management counseling, emotional and social peer support, and basic health care.
- Be planned, guided, and led by a council of transition-age youth.

Current Barriers:

- Lack of funding for the development needed to establish and maintain these resource centers.
- Lack of research about the difficulties of youth transitioning out of services.
- Lack of visibility of the resource centers that are currently serving transition-age youth.

Action Steps:

- Agencies that serve youth 16 years of age and older provide the above supports and resources to their youth in preparation for transition.
- Create community youth advisory councils to research and advise on the needs of transition-age youth.
- Employ youth receiving supports in resource centers to take part in maintaining their center in return for classes, resources, and counseling.
- Increase research initiatives that focus on youth transitioning from child welfare programs to adult programs or leaving social services.
- Encourage state and federal social service funders and partners to create funding opportunities for youth-led resource centers.
- Include youth-driven staff development training at centers serving children, young adults, and adults.

Priority Four: Increasing awareness of medication and treatment options

Definition: Youth may be prescribed psychotropic medications meant to address a mental health concern by their primary care physician or psychiatrist. These medications often carry many unexpected side effects and effects such as increased depression, weight gain, restlessness, insomnia, tremors, or seizures. It is ethically important that youth are counseled about all possible side effects and effects before they begin to take medications, and are made aware of other options.

In a Perfect World: Youth and medication dispensers would:

- Work together to explore treatment options, possible medications, and alternatives.
- Discuss positive and negative medication effects and side effects in a clear language.
- Frequently monitor medication use and effects.
- Include a support person chosen by the youth in all medical visits.
- Can count on medical assistance programs and insurance companies to reimburse alternative methods of treatment if requested.

Current Barriers:

- Medical providers and therapists use confusing jargon when talking about medications.
- Youth do not have a choice in their medication options, or they perceive that they do not have a choice.
- Youth are often unsure how to ask questions about their medication options.

Action Steps:

- Train therapists and doctors how to talk to youth and families about their medications.
- Partner with organizations such as the Bazelon Center for Mental Health Law to rally for expanded insurance coverage.
- Collect personal stories from youth about their experiences taking prescribed medications and share stories with funders, medical groups, and clinical providers.
- Create education empowerment classes for youth and families so they know what their rights are and how to ask for more information.

Priority Five: Creating opportunities for peer-to-peer supports

Definition: A mental health support model in which a system-experienced youth is partnered with an incoming youth to help the latter effectively navigate the mental health system.

In a Perfect World:

- At least one paid peer support position is a part of every organization that provides direct services to youth.
- Youth receiving emotional and social support have the opportunity to partner with a peer that has experienced similar struggles.
- The peer-to-peer support role is clearly defined and the relationship understood by all involved.
- There is a national network for youth engaging in peer-to-peer support that provides training and resources.

Current Barriers:

- There is no nationally acknowledged description of what a peer-to-peer support relationship must entail.
- There is a widespread belief that youth struggling with their own mental health challenges cannot safely nor effectively provide support for other youth.
- There is limited research evidence supporting the benefits and describing the challenges of providing peer-to-peer support.

Action Steps:

- Collect research and data from current programs to assess the effectiveness of peer support programs.
- Hold a national peer support summit of youth and allies to create a clear definition of what peer-to-peer support is.
- Create a best practices model of the peer support role in addition to a tool to measure quality, accountability, and outcomes of the peer support model.
- Gather personal testimonies of youth effected by peer-to-peer supports.
- Encourage youth to get involved on a local, state, and national level in order to promote the use of peer support.

MOVING FORWARD

Presentations. After the Youth Summit event, the Youth Summit Coordinator and RTC staff members were left with the important question of how to move forward with the outcomes and action plans presented at the Youth Summit. In an initial effort to spread awareness of needed changes within youth service systems to a larger audience, the Youth Summit Coordinator and Summit Advisory Board members presented summaries of the Call to Action Plans during the Building on Family Strengths Conference keynote presentation, a 90-minute symposium presentation, and an open-house poster session.

2009 Portland National Youth Summit Report. Next, the Youth Summit Coordinator organized pages of notes, brainstorming sessions, and presentation outlines written during the Youth Summit into electronic documents. These documents were used to create this document, the 2009 Portland National Youth Summit Report.

Mental Health Youth Bill of Rights. Of the priorities presented at the Building on Family Strengths Conference, the Mental Health Youth Bill of Rights

generated the most interest from youth and conference participants. A former Youth Summit Advisory Board member took on the task of editing the initial Mental Health Youth Bill of Rights presented at the Youth Summit. He first posted the Bill on sites such as Twitter and Yahoo! Answers to solicit edits from other youth. In an additional effort to receive feedback, the Youth Summit Coordinator created an online survey. This survey asks participants to rate the language used in the Bill, and the relevance of each point.

Finally, the RTC reported on the Mental Health Youth Bill of Rights in the Featured Discussion section of its website (www.rtc.pdx.edu/FeaturedDiscussions/pgFD66.php) to solicit additional comments. All of this feedback was compiled and resulted in a revised version of the Mental Health Youth Bill of Rights, which can be found on the back cover of this publication.

A summary of the action coalition priorities is also featured on the RTC's Youth Summit webpage (www.rtc.pdx.edu/conference/pgSummit2009.php). This Call to Action represents a starting point for others to utilize in their own efforts to improve mental health services for youth. We encourage people to take our Mental Health Bills of Rights and other action priorities back to their stakeholders to get local input in order to best meet the needs of their communities.

Evaluation of the Youth Summit. Following the Youth Summit event, participants were asked to complete a short evaluation form which asked them to both quantitatively and qualitatively assess their experience participating in the Youth Summit and the organization of the event. Thirteen youth returned their anonymous evaluation forms.

Overall, participants offered positive ratings of the event. In the qualitative portion of the evaluation, youth were asked to name the most important impact of the Youth Summit. Many respondents referenced the importance of "youth voice" and "getting the word out" when it comes to improving mental health services. One participant stated that the Summit gave "lots of insights into our own sights." The social aspects of the Summit, including "meeting people," "networking," and "the socialization," were by far the most common responses to the question, "What did you enjoy most during the Youth Summit?"

Quantitative evaluation results indicate that the Summit had the most positive impact on youths' interest and enthusiasm for being a leader, and their interest in working with youth needing mental health support and services. Summit participants rated the Ice Breaker Activities and Morning Session in which they shared their personal experiences as the most important aspects of the Summit. See Table 1-3 for more detailed evaluation results.

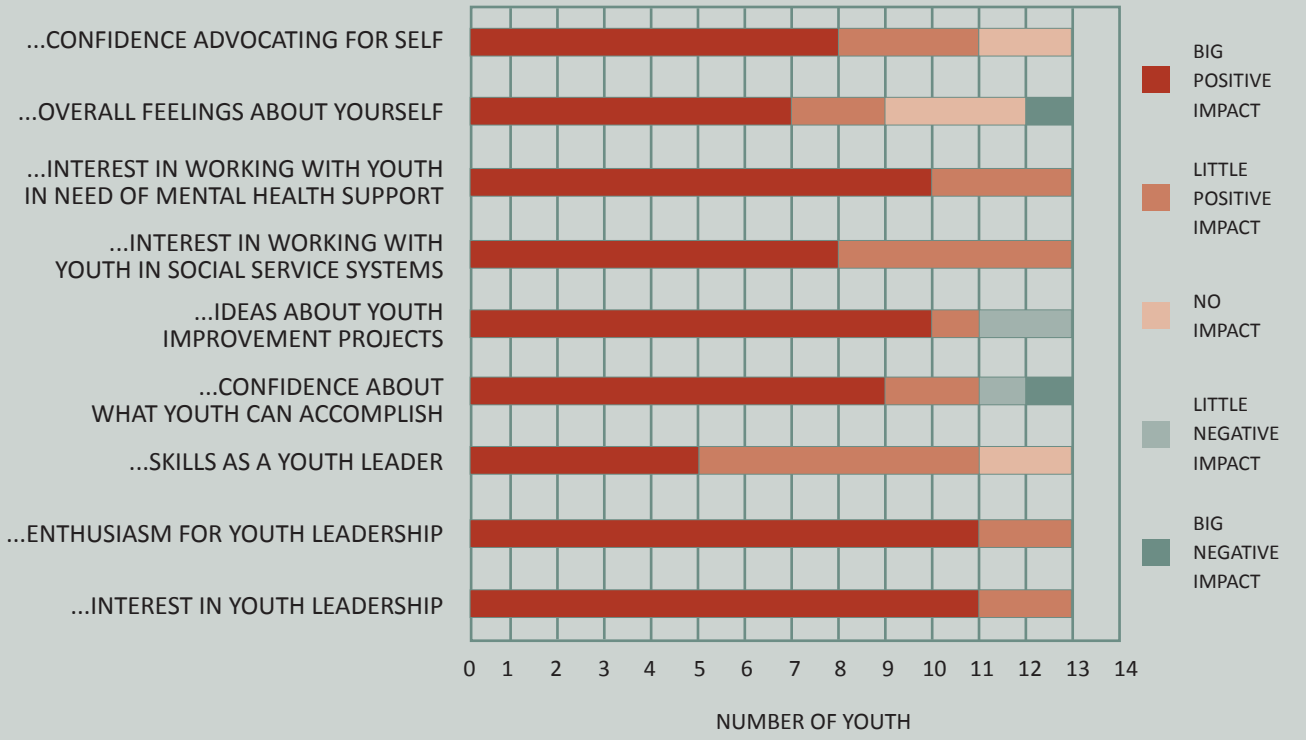
In rare instances, youth stated that the Summit had a negative impact. Although many youth stated that they felt their voice was heard and valued, one participant stated "I felt no one wanted to empower me, just get what we need[ed] to do done[—]that's right." Two participants responded that the Summit had a negative impact on their confidence regarding what they can accomplish in this arena (in contrast to eleven who said the Summit had a positive impact). When participants were asked if there was anything they wished had gone differently, the few who offered suggestions primarily stated that they felt the day was too packed and that in the future such events should take place over two days.

Challenges. Although the Youth Summit was perceived as a success, there were some challenges. In congruence with youth evaluation responses, Summit organizers also felt that the day was too rushed and that similar future events should be conducted over the span of two days. Another challenge was maintaining the enthusiasm of the group. Perhaps because of the length and intensity of the day's activities, approximately five youth did not return to the Summit after the lunch break. When older adult allies told the youth that their presence was missed, these youth stated that they were too tired from the morning's activities and needed a break. (It should be noted that the youth who did not return had traveled significant distances the day before.)

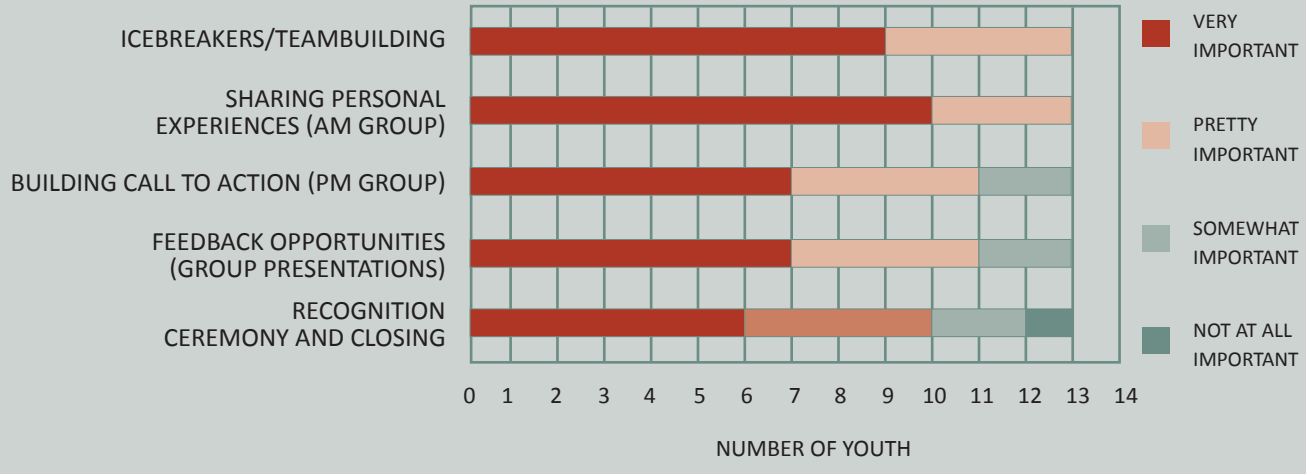
A logistical challenge identified by Summit organizers is the amount of resources it takes to successfully organize such an event. The Youth Summit Coordinator needed to work at least half time—often during late afternoons, evenings, and Saturday

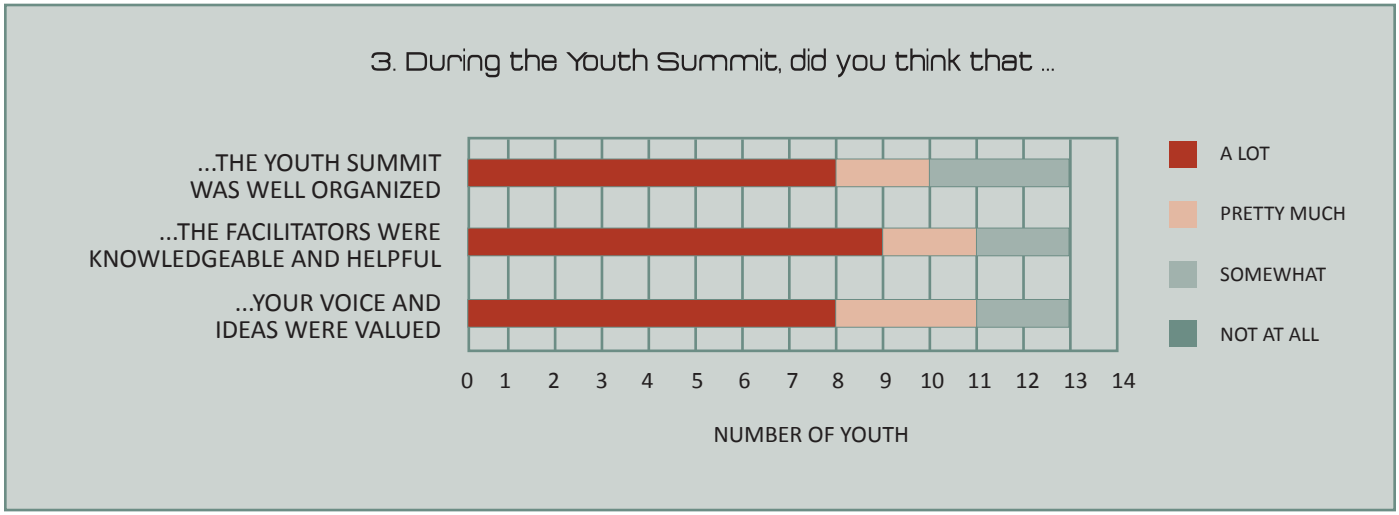
TABLES 13. YOUTH SUMMIT PARTICIPANT EVALUATION RESULTS

1. What sort of impact will your experience at the Youth Summit have on your ...



2. How important do you think each activity was toward the Youth Summit's success?





mornings—in order to communicate effectively with the Advisory Board. In addition, an RTC staff member needed to put in significant hours to oversee the process. This staffing time, plus the event itself, could not have been possible without receiving a generous grant from the Child, Adolescent and Family Branch of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

Another challenge was working on the Summit within a designated funding cycle. Coordinating the Summit to coincide with the Building on Family Strengths Conference left RTC staff with little time and resources to do a thorough follow-up of the event. Ideally, staff would have liked to follow up with the Summit participants to see how they utilized their Call to Action plan and whether the positive impact reported immediately after the Summit was sustained. Unfortunately, such follow-up was not feasible. Future events should be planned with a more thorough follow-up plan, ensuring adequate resources (both time and money) are available after the summit itself.

CONCLUSION

This report summarizes the creation and execution of a Youth Summit designed to bring youth together to generate solutions to improve their mental health services. It outlines the planning stages of the event and describes the day. It also presents five priority areas for improvement as identified by Youth Summit participants. This project demonstrates that young people can be involved in the planning of the day, and that they can have a voice in identifying needs for change in their services. It also shows that youth can present those findings to a larger group of stakeholders.

We hope that this event and its corresponding report inspire others to provide youth with opportunities to offer their voice to generate solutions to improving mental health care. Although there is still work to be done, the Youth Summit helped begin a dialogue about changing mental health services so that they best benefit the young people they were designed to serve.

REFERENCES

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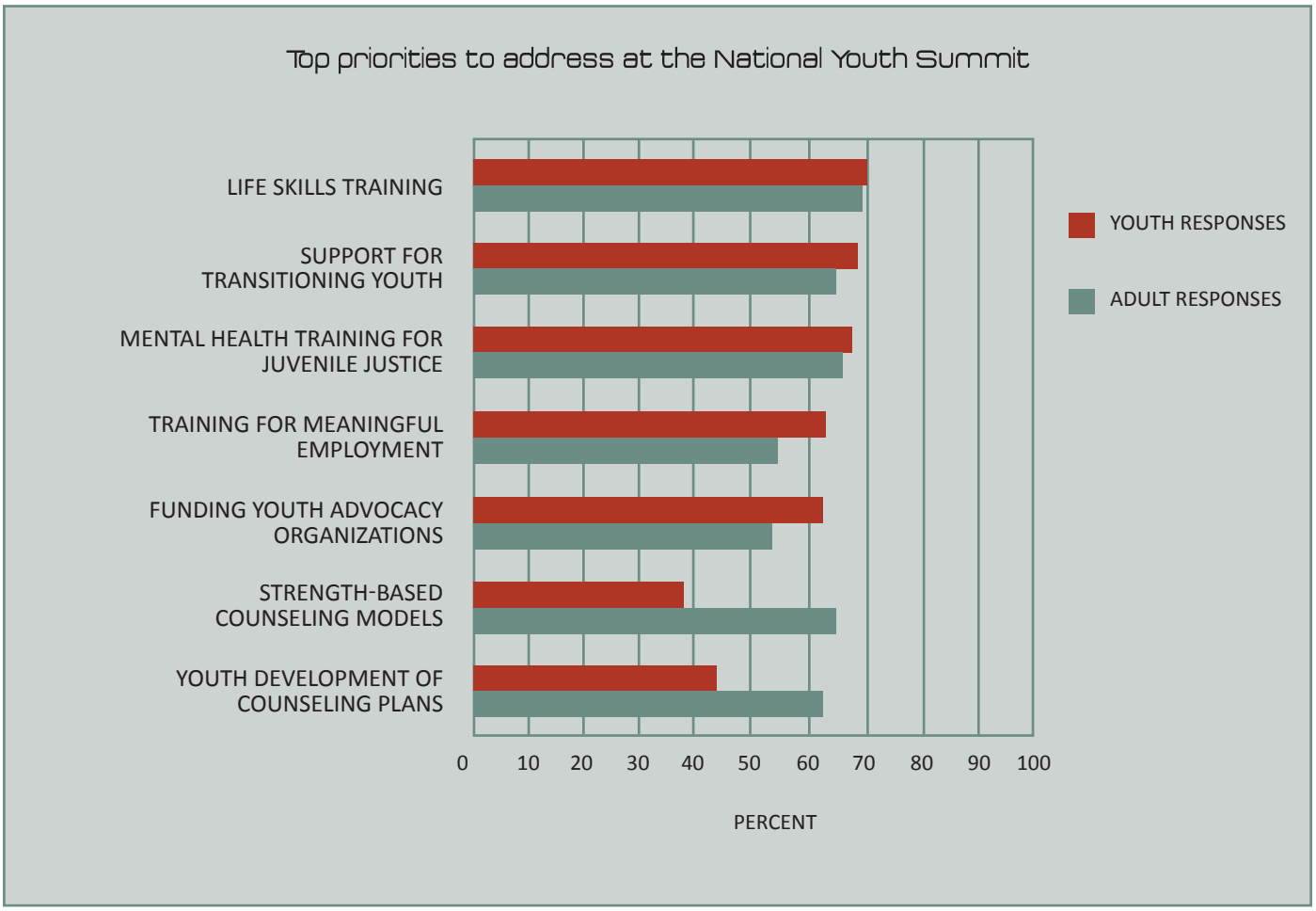
APPENDIX A.

In order to better understand the changes in children's mental health young people with mental health conditions are most eager to see, we created an online survey which was disseminated through our email lists and viral forwarding. A total of 73 youth (those who identified themselves as being 26 years or younger) and 193 adults (over the age of 26) responded.

The most common topics identified as being "a top priority" for youth were the importance of life skills training for youth (70%), the lack of support for young adults transitioning out of social service systems (68%), mental health training for juvenile justice workers (67%), the lack of training and education youth need to get meaningful employment (63%), and the need to fund youth advocacy organizations (62%). Although not rated within the top priorities, medication- and treatment-related issues were still a "top priority" for about half of the young people.

The topics most commonly identified as top priorities by adults were the importance of life skills training for youth (69%), mental health training for juvenile justice workers (65%), the lack of support for young adults transitioning out of social service systems (64%), the importance of strength-based counseling models (64%), and the involvement of youth in developing their own counseling plans (62%). As is shown in Table 4, three of the top five priorities identified were the same for youth and adults.

TABLE 4. TOP PRIORITIES TO ADDRESS AT THE NATIONAL YOUTH SUMMIT



youth mental health bill of rights

1) YOUTH HAVE THE RIGHT TO BE LEADERS OF THEIR PSYCHIATRIC TREATMENT PLANS.

Youth should be informed of the possible side effects of medications, how long recommended medications take to go into effect, and the possible long-term effects of recommended medication. Service providers should work with youth to explore possible alternatives to using psychiatric medication before medication is given. Communication between youth and all medical providers should be collaborative, clear, and with limited use of medical terminology.

2) YOUTH HAVE THE RIGHT TO EVALUATE THEIR MENTAL HEALTH SERVICES.

Mental health counselors, social workers, psychologists, and other service providers should provide opportunities for youth to evaluate the satisfaction of their services throughout the duration of care in a respectful and non-threatening manner. This includes evaluation of the relationship with the provider, counseling plans, and implemented treatment models.

3) YOUTH HAVE THE RIGHT TO THE MOST NON INVASIVE SERVICE TRANSITIONS POSSIBLE.

When youth are transitioning into new services, mental health programs should strive to make the transition as accommodating as possible for the youth. Youth should be consulted on the ways they would like to end their relationship with the current provider and whether they would like the current provider to share their file with their new provider. Providers should share if there will be any changes in the costs of services and/or insurance coverage.

4) YOUTH HAVE THE RIGHT TO TRAINED, SENSITIVE TREATMENT PROVIDERS.

Youth should have access to mental health professionals that are familiar with the unique needs and challenges of youth with mental health needs. All mental health professionals should have specialized training that fosters positive youth development and support. Youth mental health service consumers should be included in the creation and implementation of these trainings.