Systems and Psychosocial Advances Research Center 2017 Annual Report to the Massachusetts Department of Mental Health

Systems and Psychosocial Advances Research Center

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Executive Summary

We are grateful to the Massachusetts Department of Mental Health (DMH) for its continued support of the University of Massachusetts Medical School’s (UMMS) DMH Research Center of Excellence, the Systems and Psychosocial Advances Research Center (SPARC). We continue to leverage the DMH investment to support innovative, recovery-oriented, state-of-the-art psychosocial and systems research.

SPARC Overview

The Systems and Psychosocial Advances Research Center conducts research to enhance services, improve the quality of life, and promote recovery for people with behavioral health conditions. Our research involves, informs, and advises individuals with lived experience, their families, providers, administrators and policymakers navigating the behavioral health landscape in the Commonwealth and beyond. SPARC was created in 1993 when it was designated a Center of Excellence for Psychosocial and Systems Research by the Massachusetts DMH.

Our mission mirrors the DMH commitment to collaborating with other state agencies, individuals with lived mental health experience, families, advocates, providers, and communities. DMH and SPARC are aligned in their vision of promoting mental health through early intervention, treatment, education, policy, and regulation to provide opportunities for citizens of the Commonwealth to live full and productive lives.

Research Portfolio

Fiscal Year 2017 was a strong year for the Center.

**SPARC faculty and staff:**

- Received $9,604,667 in new research funding.
- Submitted 26 grant applications.
- Were awarded 16 new research grants and contracts.
- Submitted and published 89 research articles, briefs, book chapters, reports, and manuals.

SPARC faculty are internationally recognized in psychosocial interventions development and implementation; services and supports research; multicultural issues; clubhouse and vocational rehabilitation models; wellness and mindfulness; forensic/legal and human rights issues; child, parent and family mental health issues; perinatal mental health; Deaf and hard of hearing mental...
health concerns; transition-age youth/young adults; and co-occurring disorders. We collaborate across UMMS Departments of Psychiatry, Family and Community Medicine, and Preventive and Behavioral Medicine, Commonwealth Medicine, other UMass campuses, and other national and international institutions to optimize our resources and relationships to build a bigger and stronger SPARC to help meet the many challenges faced by DMH and its stakeholders.

**SPARC Funding Sources FY 2017**

The SPARC continues to provide a positive return for the DMH investment:

Every $1 invested by DMH this year yielded a return of $9.87 to the Commonwealth to fund research, training, technical assistance, and service delivery.

**New SPARC Initiatives**

We are very excited about a number of new SPARC initiatives this year. These include:

1. Our visits to several DMH Area Offices to ensure DMH leadership across the Commonwealth are familiar with SPARC, to learn about specific Area Office needs and environments, and to discover what types of technical assistance and information would be helpful to their DMH workforce.
2. The development of a Communications Division to expand our capacities to share research knowledge and put it into the hands of DMH stakeholders in readily used formats.
3. A Participatory Action Research (PAR) Initiative to increase the voice of persons with lived mental health experience in our research.
4. An increased emphasis on making all of our SPARC written materials accessible to individuals who speak other languages or are Deaf/hard of hearing.
5. The development of a video for the American Psychiatric Association highlighting our collaborations with DMH and with persons with lived mental health experience in the co-production of research that is relevant and meaningful to the needs of the DMH provider workforce and the individuals they serve.

**DMH Area Office Visits**

Our SPARC Director and Deputy, Maryann Davis and Kate Biebel, met with DMH leadership teams in both Western and Central Massachusetts during FY17. After initial visits with each Area Office, SPARC ensured DMH staff were included on all SPARC external communications re: new products, upcoming trainings targeting DMH workforce, and knew about the capacity
to request technical assistance via the SPARC website. In the Central Area, we now have quarterly meetings with Sue Sciarafa and her leadership team to work in partnership on identified priority areas (e.g., transition-age youth and young adults) and potential joint projects.

Development of the SPARC Communications Division

SPARC consolidated the communications efforts of the MHARN and the Transitions to Adulthood Center for Research (Transitions ACR) Knowledge Translation team into one singular entity - the SPARC Communications Division. This combined effort streamlines all SPARC and Transitions ACR’s communication efforts, including, but not limited to:

- SPARC has developed two new monthly electronic newsletters – one focused on SPARC and one on the Transitions ACR. Inaugural newsletters were released in the spring. Each newsletter includes sections on Advancing Research, Improving Practice, Changing Policy, Empowering Action and highlights a featured SPARC researcher. The newsletters are designed to appeal to a broad audience.

- To ensure that the work of SPARC is disseminated as quickly and effectively as possible and to speed the translation of research findings about effective psychosocial interventions into actual practice in the community, we have developed state-of-the-art dissemination strategies including web-based and social media campaigns.

  Highlights from these activities include:

  » Seven webinars for over 350 participants. Webinar topics included maternal mental health, Trauma-Focused Cognitive-Behavioral Therapy for children, how to navigate clinical interactions with Deaf American Sign Language users, strategies to increase meaningful young adult involvement in organizations, and an overview of a provider toolkit to support employment of young adult peer mentors.

  » SPARC and Transitions ACR websites received 11,758 visits from over 5,759 unique visitors in FY17. This is an increase from FY16 where our websites had 10,934 visits from 5,502 unique visitors.

  » Product downloads from our websites and our Psychiatry Information In Brief and Journal of Parent and Family Mental Health e-journals totaled over 21,010, and increase of over 28% from FY16.

  » Facebook pages reached 874 “likes,” an increase of more than 100 “likes” from FY16.

  » Twitter pages currently have 1,212 followers, an increase of over 450 followers.

  » YouTube videos had 27,876 views.

  » email listserv reached 3,185 members, which is almost 600 more members since the previous fiscal year.

Participatory Action Research (PAR) Initiative

For many years SPARC has focused on engaging end-users in our research to ensure research findings and dissemination materials are relevant to the populations whom are directly impacted. SPARC conducts this work using Participatory Action Research (PAR) principles. Beginning in October 2016, SPARC launched the PAR Initiative to enhance
SPARC’s use of PAR, and ensure that PAR and PAR principles were being used where relevant in research and communications efforts across all of SPARC. This effort, led by Kate Biebel and Amanda Costa, has developed a comprehensive PAR implementation work-plan, including goals and benchmarks, for the coming year. They have surveyed SPARC staff to identify current PAR efforts, “levels” of PAR activities, barriers to implementing PAR activities, and strategies to encourage PAR across all SPARC work.

They have developed a 3-year strategic plan that targets:

1. Increasing faculty/staff knowledge of PAR and “fidelity” to PAR processes within SPARC.
2. Increasing SPARC’s organizational capacity, resources and supports to conduct PAR.
3. Broadening and strengthening local/statewide collaboration specific to PAR.
4. Increasing national and international recognition of our PAR efforts.

Updates on these PAR efforts will be included in future DMH monthly reports.

### Accessibility of SPARC Written Products

FY17 brought a new emphasis on ensuring our written materials were as accessible as possible to speakers of different languages. Now all of our written products are routinely translated into Spanish. Our collaboration with the Southeast Asian Coalition in Worcester led to the development of one new written product and the translation of 4 existing SPARC products into Vietnamese. Finally, in collaboration with Melissa Anderson and the SPARC Deaf Advisory Board, a number of our Psychiatry Information in Brief products have been translated into American Sign Language.

### APA Video

In partnership with DMH Commissioner Joan Mikula, SPARC faculty and staff created an informational video about SPARC for this year’s American Psychiatric Association’s annual meeting in May, 2017. The theme of the video is “Partnership.” The video highlights our partnership with DMH, and with individuals with lived experience of mental health conditions, in the conduct of research.

The video was shown at the APA meeting and is posted on the SPARC and Transitions ACR websites, and our YouTube channels.
Research Highlights

**Kate Biebel** received funding from the Jed Foundation - *Promoting Mental Health in the Transition from College to the Workplace* - to examine what is known about emotional wellness of young adults during the transition from college to the workplace. This is a high-risk time fraught with emotional/developmental challenges and stressors that can lead or contribute to mental health problems such as depression. Graduating students who have a positive history of depression may be at particularly high risk of relapse.

The final report will be released by Jed in the Spring of 2018, and will include recommendations for campus leadership as well as employers about how to best support young adults during this transitional time.

**Ekaterina Pivovarova** recently received an University of Massachusetts Center for Clinical and Translational Science Mentored Career Development (KL2) Training Program award for her *The Impact of Health-Related Quality of Life on Retention in Drug Treatment Courts* study, which evaluates the applicability and feasibility of Quality of Life measures in Drug Treatment Courts populations; assesses whether Drug Treatment Courts produce improvements in Quality of Life and other psychosocial factors such as social support and self-efficacy about drug and alcohol abstinence; and examines whether Quality of Life can predict attrition from Drug Treatment Courts.

This three-year project builds on findings from a pilot study funded through a SPARC seed grant. This seed grant was a feasibility study to a) determine if clinicians could be used as a source of recruitment for probationers enrolling in Drug Treatment Courts and b) to obtain pilot data about what capacities clinicians believe are necessary to have the appropriate understanding and appreciation of enrolling in Drug Treatment Courts. This research agenda strives to improve Drug Treatment Court processes by increasing retention rates in treatment and decreasing relapses of substance abuse.

**The U.S. Deaf community** – a minority group of 500,000 people who use American Sign Language – is one of the most understudied populations in biomedical research. **Melissa Anderson** received NIH funding for the *Deaf ACCESS: Adapting Consent through Community Engagement and State-of-the-art Simulation* project to help address this knowledge gap.

In partnership with Deaf community members, Melissa will adapt informed consent procedures to make them more Deaf-friendly, and then use medical simulation to train research assistants how to appropriately recruit and enroll Deaf research participants.

They aim to:

1. Identify the barriers and facilitators to Deaf people’s engagement in biomedical research, with an emphasis on the informed consent process.
2. Develop a training intervention in which Deaf community members teach research assistants to deliver culturally appropriate informed consent using an American Sign Language interpreter.

3. Test the feasibility and acceptance of the intervention during simulation-based training sessions.

- Childhood anxiety disorders are common and parents may be a valuable asset in improving treatment outcomes for anxious children. However, there is scarce evidence supporting interventions with parent training. Phoebe Moore was awarded a SPARC seed grant to examine Augmenting Treatment Adherence in Parents of Children with Anxiety Disorders using Mobile Technology. This seed grant will enhance her open trial of an innovative, 6 week group-delivered caregiver treatment program: Acceptance and Commitment Therapy for Parents of Anxious Children (ACT-PAC). The project will evaluate the feasibility and acceptability of a wearable watch as a prompting augmentation for ACT-PAC, and collect pilot data on how watch use affects frequency of ACT-PAC technique use. The study team predicts that use of the watch will increase use of ACT-PAC techniques overall, and that this new technology can be used to increase the effectiveness of the parenting intervention.

- Gina Vincent was awarded a SPARC seed grant for her Trauma Symptoms and Addiction among Adolescents: A Neuroimaging Study to conduct a secondary data analysis of neuroimaging data from two adolescent samples that were generated from her NIDA K01 grant, Neuroimaging Youth with Callous-Unemotional CD and Co-morbid Substance Abuse. The broad purpose of this project is to use these samples to examine the association between trauma-related symptoms and substance abuse among youth with and without histories of stimulant (cocaine or methamphetamine) abuse. Gina Vincent will use results of her seed grant study in conjunction with results from the primary analyses in her K01 to apply for a R34 to develop an adapted addictions treatment for adolescents that is trauma informed.

- Nancy Byatt, Kate Biebel, and Tiffany Moore Simas were awarded a grant from the National Institute of Mental Health (NIMH) to develop, implement, and evaluate an online module to improve obstetric providers' knowledge, skills and practices regarding perinatal depression. The team will develop a state-of-the-art, training module, The Basics of Addressing Perinatal Depression, which will be delivered online and take into account the different mental health resources available in other states across the US. The online module will support obstetric providers to: 1) implement depression screening; 2) assess depression and comorbidities; 3) triage and refer complicated cases to psychiatric providers; 4) treat women with less complicated illness; and 5) consider risks and benefits of different treatment modalities. If shown to be effective, the training module will help obstetric providers implement depression screening and develop the processes they need to respond appropriately when women are depressed, thus getting women the care they need.
Lived Experience Contributions

Input from and partnership with persons with lived mental health experience is critical to all work at SPARC. Within SPARC, individuals with lived experience are actively involved in all phases of research, from defining the research questions to developing survey instruments and collecting data to disseminating the results. The voice of individuals with lived experience is infused into all SPARC research, training, and dissemination activities. As part of this work, SPARC relies on the direction and guidance of two advisory boards – the Mental Health Experienced & Years of Understanding (MHE & YOU) Advisory Council, and the Transitions ACR’s Youth Advisory Board (YAB).

Highlights of contributions from persons with lived experience include:

» The MHE & YOU Advisory Council, in collaboration with SPARC’s Communications Division, successfully completed the 2017 May is Mental Health Awareness Month campaign. The campaign produced several video PSAs and received artwork and poetry submissions created by individuals with lived experience focusing on the theme of “What Recovery Means to Me.” All submissions can be viewed on the MHE & YOU Advisory Council’s new website (http://mheyou.weebly.com/).

» The Youth Advisory Board (YAB) has 2 young adult Co-Chairs and 8 active members, 1 of whom is a Massachusetts’ resident and 1 of whom is a Massachusetts-based college student. In FY17 the YAB reviewed 4 tip sheets and 4 research projects. In conjunction with the SPARC Communications Division, the YAB developed a tip sheet to help explain recent federal legislation that has financial implications for individuals with disabilities, the ABLE Act (the Achieving a Better Life Experiences Act).

» A SPARC staff member who is also a member of the NAMI National Young Adult Advisory Group presented at a workshop session—Youth and Young Adults: A Key to Building a Movement—at the NAMI National Convention in Denver, CO.

» MHE & YOU had an active social media presence in FY17 with 93 likes on its Facebook page, 50 followers and 10,459 impressions (views) on Twitter and 1,037 views on its YouTube Channel in FY17. Sixty-five (65) percent or 578 video views were from Massachusetts.

» Our MHE & YOU Advisory Council had an article posted in the April 2017 edition of DMH Connections, reflecting on the experiences creating a video with DMH Commissioner Joan Mikula. All MHE & YOU videos are available on the MHE & YOU Advisory Council’s website (http://mheyou.weebly.com/)
Communications/Community Engagement Highlights

To ensure that the work of SPARC is disseminated as quickly and effectively as possible and to speed the translation of research findings about effective psychosocial services into actual practice in the community, we have developed state-of-the-art dissemination strategies including web-based and social media campaigns. Highlights from these activities include:

- **Jonathan Delman** and **Vanessa Klodnick** developed the *Toolkit for Effectively Employing Young Adult Peer Providers*. This toolkit was developed specifically for provider organizations that employ or want to employ young adult peer workers and offers direct guidance on how an organization can enhance their capacity to sustain and grow a young adult peer workforce.
  
  It includes: 1) a manual for the organization, 2) interactive worksheets and self-assessment forms, and 3) examples of useful workplace policy approaches and job descriptions.
  
  This toolkit was developed in consultation with an advisory board composed of young adults diagnosed with serious mental health conditions and experts in transition-age youth mental health.

- **Melissa Anderson** helped plan and coordinate the 3rd Annual Worcester Recovery Center and Hospital Deaf Symposium. This year’s topic was “Substance Use and Mental Health: Dual Recovery in the Deaf Community”. In addition, Melissa presented *Treating Trauma and Addiction in the Deaf Community: Using Seeking Safety and Adapting within the Model*.

- In December 2016, SPARC introduced our new *Research Seminar Series*. This series features leading scholars presenting their research, discussing emerging policy implications, and identifying future directions regarding mental health research. This series will serve as a forum to develop a cross disciplinary dialogue and establish collaboration with the aim of developing methods to improve the mental health of all citizens in the Commonwealth of Massachusetts and beyond. We are actively working to ensure that all interested DMH stakeholders (i.e., administrators, providers, family members, those with lived experience) are on our listerv announcing upcoming seminars. Seminars are held at SPARC and we are exploring strategies to stream seminars to DMH sites in the upcoming fiscal year.

- **Gina Vincent** presented at the “Challenges with Implementing Objective Risk Screening & Assessment Tools” breakout session during for the Massachusetts DYS-sponsored Juvenile Detention Alternative Initiatives Conference.

- SPARC staff attended the *DMH Statewide Young Adult Council* in December 2016 to present on current research studies with a youth and young adult focus. Additionally, we received feedback on potential recruitment materials to be used as part of the SAMHSA-funded multi-site “Now is the Time” study, to ensure recruitment efforts were young adult inclusive and culturally competent.

- **SPARC faculty and staff** began work with Anh Vu Sawyer and Boa D. Newgate from the Southeast Asian Coalition to develop psychoeducational mental health products...
specifically geared towards Southeast Asian immigrants and refugees in Central MA. This partnership resulted in a new written product called *Tips for Mental Health Providers Working with Southeast Asian Immigrants/Refugees*, which is available in Vietnamese and English. Additionally, four existing SPARC/Transitions ACR products were selected by Ms. Sawyer and Mr. Newgate for translation into Vietnamese.

These include:

- Disclosing My Mental Health Condition at Work
- My Mental Health Rights on Campus
- Participatory Action Research and Transition-age Youth
- Vocational Peer Mentors for Emerging Adults with Serious Mental Health Conditions

✦ All above products were available at the May, 2017 Asian American Mental Health Forum, held at Clark University.

✦ Rosalie Torres Stone presented *Undocumented College Students, Social Exclusion, and Psychological Well-Being* at the Sociology at the MLK Racial Justice Teach-In held at Clark University in Worcester, MA.

✦ SPARC and Transitions ACR faculty and staff presented multiple research studies at the 30th Annual Research & Policy Conference on Child, Adolescent, and Young Adult Behavioral Health in Tampa, Florida in March 2017.

✦ SPARC collaborated with the Harvard Commonwealth Research Center to develop and implement the 2017 DMH Centers of Excellence Conference – “Targeted Community Outreach & It’s Impact on Service Engagement.” There were 100 attendees at the conference, including persons with lived experience, family members, clinicians, researchers, and policy-makers/administrators. Feedback from the conference was very positive with over 86% of participants rating the conference above average or excellent.
Dissemination of Materials at Massachusetts Conferences

- Total number of SPARC products disseminated at MA Conferences: 2,023
- Total number of MA conferences SPARC staff attended to distribute materials: 7
  - 2016 Annual NAMI Massachusetts Convention
  - UMMS/DPH sponsored 3rd Annual Health Fair
  - 8th Annual Asian American Mental Health Forum
  - Parent/Professional Advocacy League 7th Annual Conference & Celebration
  - 1st Annual UMass Center for mHealth and Social Media Conference
  - SYAC 10th Anniversary & Young Adult Peer Leader Recognition Event
  - 40th Annual Wellness and Recovery Summit.

Collaborations with DMH and Other State Agencies Highlights

We recognize that partnerships are more critical than ever, especially in light of the increasingly collaborative and multidisciplinary nature of services research. SPARC faculty and staff collaborate with DMH and other state agencies to further the missions of our organizations and meet the needs of the citizens of the Commonwealth.

Examples of collaborations and activities include:

- In July 2016, Rob Walker (DMH’s External Consumer Engagement Liaison for the Office of Recovery and Empowerment) and colleagues visited SPARC/Transitions ACR to discuss DMH projects that could benefit from SPARC/Transitions support and guidance.

- Our colleague Vanessa Klodnick worked with Heidi Holland, DMH STAY Project Director, and Bonny Saulnier, DMH consultant for the STAY Together Grant, regarding young adult therapeutic peer mentor supervisor trainings and developing a community of practice. The SPARC webinar team provided the platform and support for the delivery of two 2-part webinars on the topic of effective clinical supervision of young adult therapeutic peer mentors to the clinical supervisors of therapeutic mentors across Massachusetts. The implementation of young adult peer mentors across Massachusetts represents an effort to sustain services that were initially delivered as part of a SAMHSA System of Care STAY grant and the long-term success of this model will partly depend on the ability of the clinical supervisors to effectively support the young adult peer mentors in their role.

- In November 2016, at the request of Michael Stepansky, the director of employment for DMH, Marsha Ellison provided a presentation on adapting Individual Placement and Support for transition-age youth at a DMH Individual Placement and Support Trainers/Community of Practice meeting. Marsha spoke about current research on how supported education efforts are being incorporated into the Individual Placement and Support model of Supported Employment.

- In early May 2017, Marsha Ellison and Maryann Davis collaborated with Heidi Holland of DMH to examine literature related to the effectiveness of supported education that they could use to validate a program at Bridgewater State University for support services and housing for DMH and DCF young adult students. Marsha forwarded Heidi Holland a supported education report she and Kate Biebel wrote for the federal Office of the Assistant Secretary for Planning and Evaluation.

- Staff from the Transitions ACR attended the May 2017 10-year Statewide Youth Advisory Council Anniversary event in Marlborough; several Transitions ACR staff received awards at this event.
Rosalie Torres Stone began working with the Worcester Division of Public Health and the Southeast Asian Coalition of Central Massachusetts, Inc. to develop a model of care targeting immigrant and refugee mental health.

**SPARC Grant Support Team**

The SPARC Grant Support team is a group of faculty and staff who review and offer their expertise on the development and submission of grant proposals. All SPARC investigators are encouraged to meet with the Grant Support Team as they are working on their grants, to ensure developing proposals receive as much input and review as possible prior to submission. The Grant Support Team helps with the submission process and tracks grant proposals that have been reviewed, submitted, and funded. The Grant Support Team is led by Drs. Gina Vincent and William McIlvane. In Fiscal Year 2017, the Grant Support Team provided support with 14 grant reviews and 12 grant submissions, 5 of which were funded. Examples of proposals reviewed by the Grant Support Team include:

- Addressing Gaps in Psychiatric Care for Pregnant and Postpartum Women with Bipolar Disorder – **Nancy Byatt and Kate Biebel**
- Online Training for Addressing Perinatal Depression – **Nancy Byatt, Kate Biebel, Tiffany Moore Simas**
- Digital Storytelling for Preventing Depression Among Pregnant and Postpartum Women – **Nancy Byatt**
- High-risk Offenders with Substance Use Disorders: The Impact of Targeted Interventions on Re-Offending and Relapse – **Dara Drawbridge**
- Meaningful Engagement of Transition-age Youth with Serious Mental Health Conditions – **Kate Biebel and Amanda Costa**
- Optimizing Psychiatric Treatment In MAternal mental health (OPTIMA) Center – **Nancy Byatt**
- Pilot Studies to Detect and Prevent Suicide Behavior, Ideation and Self-Harm in Youth in Contact with the Juvenile Justice System – **Gina Vincent**
- Predicting Attrition from Drug Treatment Courts Using Quality of Life – **Ekaterina Pivovarova**
- Preventing Prenatal Stress and Depression in Low-Income Families – **Nancy Byatt**
**Nancy Byatt** was the recipient of this year’s UMMS Women’s Faculty Committee, Women in Science and Health Achievement Award. Nancy was one of six UMass Medical School faculty recognized for her individual achievements and contributions to the advancement of women in science and health care in the areas of community service, education, clinical practice, mentorship, science and health, and early career development at the 2017 Women’s Faculty Awards luncheon. Nancy also received the 2016 American Congress of Obstetricians and Gynecologists Council of District Chairs Recognition Service Award on the behalf of MCPAP for Moms, and the American Psychiatric Association 2016 Psychiatric Services Achievement Gold Award for MCPAP for Moms. The Gold Award recognizes creative models of service delivery and innovative programs for persons with mental illness or disabilities. MCPAP for Moms is a DMH-funded program to support health care providers in addressing mental health concerns of perinatal women.

**Melissa L. Anderson** received the 2017 Bellflasher Award at the American Deafness and Rehabilitation Association Conference. The Bellflasher Award honors the most outstanding and thought provoking biennial conference presentation, as determined by the scores and comments on evaluations and “buzz” generated by breakout conference sessions.

**Rosalie Torres Stone** received the Oliver & Dorothy Hayden Junior Faculty Fellowship Award for 2016-17, presented to an outstanding junior faculty member who personifies the Clark University ideal of excellence in teaching and excellence in research, scholarship, or creative work.
Fulfillment of the DMH Contract

Fiscal Year 2018 is off to a great start. A number of new grants have already received funding, and we continue to explore innovative opportunities to help us diversify our funding portfolio. We continue our commitment to the shared DMH and SPARC goal of providing the best, state-of-the-art recovery-oriented, patient-centered care to all citizens of the Commonwealth. We look forward to another productive year of partnering with DMH.

Research Activity

These numbers represent both ongoing and new SPARC research during Fiscal Year 2017.

<table>
<thead>
<tr>
<th>Performance Measure</th>
<th>Accomplished in Fiscal Year 2015</th>
<th>Accomplished in Fiscal Year 2016</th>
<th>Accomplished in Fiscal Year 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of research projects approved by DMH(^1)</td>
<td>46</td>
<td>37</td>
<td>39</td>
</tr>
<tr>
<td>Number of research proposals submitted &amp; approved by an IRB(^2)</td>
<td>12</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>Number of grants submitted(^3)</td>
<td>28</td>
<td>24</td>
<td>26</td>
</tr>
<tr>
<td>Number of grants approved for funding(^4)</td>
<td>16</td>
<td>19</td>
<td>16</td>
</tr>
</tbody>
</table>

\(^1\) The number of ongoing SPARC research projects during the fiscal year.

\(^2\) The total number of projects that received initial IRB approval during the fiscal year.

\(^3\) The total number of grant applications that SPARC submitted during the fiscal year, regardless of their approval status. Some submitted grants may have received funding during the fiscal year, some may receive funding next fiscal year, and some may receive no funding.

\(^4\) The total number of new grants that either received money during the fiscal year or are approved for funding in the upcoming fiscal year.

Summary of New Grant Funding

The ongoing financial support provided by DMH confers SPARC the ability to leverage monies from a variety of other sources in support of research and training. The figure reported below includes the portion of each grant/contract awarded in the 2017 Fiscal Year, not the total funds for life of the grant. The total is inclusive of both direct funds (monies which go directly to the project) and indirect funds (monies that support overhead on the project, the operation of SPARC, the UMass Department of Psychiatry, and the University of Massachusetts Medical School)

<table>
<thead>
<tr>
<th>Performance Measure</th>
<th>Accomplished in Fiscal Year 2015</th>
<th>Accomplished in Fiscal Year 2016</th>
<th>Accomplished in Fiscal Year 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>External Funding Obtained</td>
<td>$6,825,040</td>
<td>$9,839,498</td>
<td>$9,604,667</td>
</tr>
</tbody>
</table>
Summary of Publications

SPARC faculty and staff publish in a variety of different venues. Although the majority of publications appear in peer-reviewed journals, SPARC faculty and staff also publish books, book chapters, monographs, reports, conference papers, and reviews of academic manuscripts.

<table>
<thead>
<tr>
<th>Performance Measure</th>
<th>Accomplished in Fiscal Year 2015</th>
<th>Accomplished in Fiscal Year 2016</th>
<th>Accomplished in Fiscal Year 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of papers submitted and accepted for publication</td>
<td>76</td>
<td>53</td>
<td>89</td>
</tr>
</tbody>
</table>

Summary of Other Dissemination Efforts

SPARC continued to conduct trainings and give presentations at a wide variety of venues throughout Fiscal Year 2017. The following numbers represent the efforts of SPARC to distribute and disseminate information to DMH state and provider clinical workforce as well as individuals with lived experience and family members.

<table>
<thead>
<tr>
<th>Performance Measure</th>
<th>Accomplished in Fiscal Year 2015</th>
<th>Accomplished in Fiscal Year 2016</th>
<th>Accomplished in Fiscal Year 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number and types of forums used by SPARC to share information with DMH State and provider clinical workforce, individuals with lived experience &amp; family members</td>
<td>107</td>
<td>65</td>
<td>59</td>
</tr>
<tr>
<td>Number of state and provider workforce members, individuals with lived experience and family members with whom research information was shared$^5$</td>
<td>4,636</td>
<td>4,537</td>
<td>2,508</td>
</tr>
</tbody>
</table>

$^5$ This represents the number of individuals attending SPARC faculty and staff presentations at conferences and trainings in Massachusetts during FY17. This does not include Massachusetts individuals accessing research information through other SPARC mechanisms (i.e., website, listservs, and social media).
Appendix A

New SPARC Funded Research

Augmenting Treatment Adherence in Parents of Children with Anxiety Disorders using Mobile Technology

PI: Phoebe Moore, Ph.D.
Funding: Systems and Psychosocial Advances Research Center (SPARC seed grant)
Budget: $10,000
Time Frame: 7/1/2016-6/30/2017

Description: Childhood anxiety disorders are common and parents may be a valuable asset in improving treatment outcomes for anxious children. However, there is scarce evidence supporting interventions with parent training. This seed grant is part of an open trial of an innovative, 6 week group-delivered caregiver treatment program: Acceptance and Commitment Therapy for Parents of Anxious Children (ACT-PAC). Wearable biosensing watches will provide immediate reminders to parents who are in distress to use their ACT-PAC techniques in a community setting with their children. Newly emerging technologies make this possible. Wearable biosensors measure electrodermal activity, a physiological biomarker of sympathetic nervous system activation. These watches generate a notification on smartphones when parents’ physiological stress levels are rising, at precisely the moment when ACT-PAC techniques are most needed. The project aims to evaluate the feasibility and acceptability of the wearable watch as a prompting augmentation for ACT-PAC; and to collect pilot data on how watch use affects frequency of ACT-PAC technique use. The study team predicts that use of the watch will increase use of ACT-PAC techniques overall, and that this new technology can be used to increase the effectiveness of the parenting intervention.

Bridges to Health Information for Individuals with Serious Mental Illness

PI: Elaine Martin, Ph.D.
Site PI: Kathleen Biebel, Ph.D.
Funding: National Library of Medicine
Budget: $112,873
Time Frame: 9/30/2016-9/29/2018

Description: Through our sub-contract with the Harvard Medical School, we will continue work on the Bridges project to meet the health information needs of individuals with serious mental illness, an underserved health disparity population. We will develop a dynamic, interactive, wide-reaching, web-based platform that promotes access to information regarding physical as well as mental health. In year 3, we will develop and test a training module to promote health literacy, and a website platform to facilitate access to health information.

Deaf ACCESS: Adapting Consent through Community Engagement and State-of-the-art Simulation

PI: Melissa Anderson, Ph.D.
Co-I's: Jeroan J. Allison, Ph.D., Jennifer Tjia, M.D., MSCE
Funding: National Institute on Deafness and other Communication Disorders
Budget: $475,952
**Time Frame:** 7/20/2016-6/30/2018

**Description:** The U.S. Deaf community is one of the most understudied populations in biomedical research. One reason is the frequent use of research methods that are not accessible to Deaf people (for example, telephone surveys). In addition, researchers often aim to “cure” or “fix” hearing loss, while Deaf people, however, do not view themselves as needing to be “fixed,” but as members of a rich culture with shared experience, history, art, and literature. These barriers have resulted in systematic mistrust of researchers and reluctance to participate in biomedical studies. The Deaf ACCESS project will facilitate the adaptation of informed consent procedures to make them more Deaf-friendly, and then use medical simulation to train research assistants how to appropriately recruit and enroll Deaf research participants. We aim to: (1) identify the barriers and facilitators to Deaf people’s engagement in biomedical research, with an emphasis on the informed consent process, by holding four Deaf community forums and three focus groups at Deaf community cultural institutions; (2) develop a training intervention based on lessons learned from Aim 1, in which Deaf community members teach research assistants to deliver culturally appropriate informed consent using an American Sign Language interpreter; and (3) test the feasibility and acceptance of the intervention during simulation-based training sessions with five hearing research assistants who currently conduct informed consent at UMass Medical School (and who have no prior experience working with Deaf individuals). Results will support a larger trial of Deaf ACCESS and will produce training products with much potential for distribution and replication. This work will lay the foundation for a sustainable program of research that shifts how we approach and engage the Deaf community, increasing the number of Deaf people who participate in biomedical research studies and encouraging more Deaf people to become actively engaged in the research world.

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**Evaluating Brain Injury Clubhouses and Their Effects on Neurobehavioral Functioning and Participation**

**PI:** Colleen McKay, M.A., CAGS  
**Funding:** Commonwealth of Virginia/Community Brain Injury Services (sub-award)  
**Budget:** $119,928  
**Time Frame:** 4/1/2017-3/31/2020

**Description:** Approximately 1.7 million people in the United States sustain a traumatic brain injury (TBI) each year; in 2013, about 2.8 million TBI related emergency department visits, hospitalizations, and deaths were reported. The cost of traumatic brain injuries in the US is over 48 billion each year, and the cost of caring for a survivor of severe TBI is between $600,000 and $1,875,000 over a lifetime. Persons with brain injury due to trauma, stroke, and other acquired causes often transition from rehabilitation to home and community settings with multiple, chronic impairments, with the majority requiring assistance or supervision. The Clubhouse Model of service delivery has the potential to meet the long-term, well-being of people with brain injury-related disability and their families through skills development, support, and advocacy. The Evaluating Brain Injury Clubhouses project will evaluate the Clubhouse Model’s potential to serve the unmet needs of Virginia’s citizens with brain injury-related disability and improve their quality of care. The project will implement a program level data collection system (the Clubhouse Profile Questionnaire) and other measures to standardize data concerning the injury and sociodemographic characteristics of people served, the level and duration of services provided, and outcomes generated by Virginia’s Acquired Brain Injury Clubhouses. We will also describe and evaluate the effectiveness of Acquired Brain Injury Clubhouses in meeting Virginia’s citizens’ needs. This project will compare the persons treated, services provided, and the outcomes generated by Virginia’s Acquired Brain Injury Clubhouses to 3 Acquired Brain Injury Clubhouses in the US and Canada to identify strengths and opportunities for growth.
Let’s Talk about Parenting

PI: Kathleen Biebel, Ph.D.  
Co-PI: Joanne Nicholson, Ph.D.  
Funding: Massachusetts Department of Mental Health  
Budget: $93,991  
Time Frame: 7/1/2016-6/30/2017

Description: The majority of adults in the U.S. who experience mental illness during the course of their lifetime are parents. This includes those who meet criteria for the most serious of mental illnesses, who are likely to be receiving public sector services. Decades of research support the finding that children of parents with mental illness are at increased risk to develop behavioral and emotional issues. The cost of not supporting individuals living with mental illness as parents is significant, both for adults themselves as well as for their offspring. Providers often express concern that they are ill prepared to work with these parents and families, and lack the necessary skills to identify and meet their needs. We propose to develop and evaluate Let’s Talk About Parenting (LTP), and to train a group of providers, peer specialists and champions in LTP principles, practice and implementation approaches. The goal of the LTP project is to increase the capacity of individuals working with adults with mental illness to explore and deal with their clients’ experiences, needs and goals as parents, and to improve the quality of service delivery and care for these adults. Year 2 of this project focuses on developing the Let’s Talk about Parenting intervention in partnership with DMH CBFS providers, and testing it in two community-based mental health agencies.

Long-Term Impact of Risk Assessment and Risk-Need-Responsivity Reforms in Juvenile Justice

PI: Gina Vincent, Ph.D.  
Funding: U.S. Department of Justice  
Budget: $499,998  
Time Frame: 10/1/2016-3/31/2019

Description: This project examines the long-term impact of one of the most prominent recommendations for juvenile justice (JJ) reform that is using valid risk and need assessment tools (RNAs) to identify low-risk youth who could be handled less formally, to match youth to appropriate treatment, and to target high-risk youth for more intensive interventions. While most states today have instituted a RNA in juvenile probation for use in case planning, there are still no long-term studies supporting its impact, examining how information from RNAs is translated into practice, or assessing whether implementation of a RNA in the JJ system is actually cost-effective. The proposed study will examine the sustainability of impact and cost-effectiveness stemming from the RNA + Delinquency Prevention Act reform effort by building on existing data and previous research from the Risk/Needs Assessment in Juvenile Probation: Implementation Study. We will gather archival cost data for the pre-implementation samples from the afore mentioned study as well as a new prospective sample from 2017 (7-year post-implementation cohort) to examine the sustainability of impact at multiple levels (intervention-level outcomes).

Preventing Perinatal Stress and Depression in Low-Income Families

PI’s: Maureen Perry-Jenkins, Ph.D., Nancy Byatt, D.O., M.S., M.B.A, F.A.P.M.  
Funding: UMMS  
Budget: $25,000  
Time Frame: 4/1/2017-6/30/2018

Description: Transition to parenthood is a challenging time for new parents. Evidence suggests that mothers/parents from low-income communities bear an excess burden of prenatal maternal stress...
and perinatal depression which has been associated with less than optimal maternal and child health outcomes. The community targeted for this study (Springfield) is one of the major MA cities at-risk for poor maternal and child health outcomes as well as parenting stressors. Early pregnancy provides opportunity to intervene and reduce the negative effects of maternal psychological and physiological stress and depression; however, few evidence-based interventions designed to reduce depression and stress during this time period exist. UMass Amherst and the UMass Medical School partnered with Square One and the Children's Trust on a pilot study to promote the mental health and co-parenting relationships of underserved, low-income parents and their partners. Investigators will adapt and test the feasibility of a group-based intervention called Choices in Childbirth & Co-Parenting (3CP) aimed at reducing depression and stress among low-income new mothers and their partners early in pregnancy. The investigators anticipate that that the results of this study will guide and inform an R34 or R01 submission to conduct a randomized control trial with adapted 3CP with low-income, prenatal parents.

**Partners in Care: Community-Based Implementation of Evidence-Based Treatment for Childhood Trauma**

**PI:** Jessica L. Griffin, Psy.D.  
**Funding:** Substance Abuse & Mental Health Services Administration (SAMHSA)  
**Budget:** $129,000  
**Time Frame:** 9/30/2016-9/29/2019

**Description:** This project will provide additional training in Trauma-Focused Cognitive-Behavioral Therapy (TF-CBT) at the Baystate Medical Center, Family Advocacy Center. Our team will:

- Conduct basic TF-CBT training for therapists and therapeutic training and support staff (TT&S) from partnering organizations who have completed the on-line version of the training
- Provide consultations in the model to therapists and TT&S workers who have completed the above basic training session
- Provide training using the Core Curriculum on Childhood Trauma and
- Expand our Centralized Referral System, LINK-KID, to include specific information related to clinicians and agencies providing trauma-focused in home therapy services in order to increase access to services and expedite the referral process for families

**Promoting the Integration of Post 9/11 Student Veterans**

**PI:** Marsha Ellison, Ph.D.  
**Funding:** Department of Veterans Affairs  
**Budget:** $72,957  
**Time Frame:** 4/1/2017-3/31/2019

**Description:** As many as 20% of returning Veterans have mental health conditions such as PTSD. However, many of these Veterans do not present themselves for mental health treatment or rehabilitation, often because of the significant stigma attached to having mental health problems. In the past year, more than 1 million Veterans or family members have used the Post 9/11 G.I. Bill to attend college. However, many of the newly returning Veterans enrolled in college face significant health challenges, and do not seek out care. One strategy to reach these untreated Veterans is the VA's Veterans Integration to Academic Leadership (VITAL) program. VITAL promotes clinical engagement by deploying a clinician to college campuses to conduct outreach activities. This project seeks to address the academic needs of student Veterans who are at risk of loss of academic status or drop-out. By dealing with barriers to academic success (e.g., memory loss, anxiety, poor organizational skills, or simply community reintegration issues) a VITAL provider can improve academic performance and facilitate access to needed health and mental
Promoting Mental Health in the Transition from College to the Workplace

**PI:** Kathleen Biebel, Ph.D.  
**Funding:** The Jed Foundation  
**Budget:** $39,992  
**Time Frame:** 11/30/2016-12/31/2017

**Description:** The transition from college to the workplace can be a high-risk time fraught with emotional/developmental challenges and stressors that can lead or contribute to mental health problems such as depression. Graduating students who have a positive history of depression may be at particularly high risk of relapse. Moreover, individuals without a history of emotional challenges may experience a first episode of depression as they attempt to navigate this potentially stressful transition. This project aims to forward our knowledge as a field by developing a rich understanding of the emotional needs of students during the transition from college into the workforce, and provide recommendations, based on the literature and a survey of students and employers across the US, to campus leadership and employers about how to best support and sustain the emotional well-being of the young adult workforce.

Promoting Women’s Health in Clubhouses

**PI:** Colleen McKay, M.A., CAGS  
**Funding:** International Center for Clubhouse Development  
**Budget:** $24,585  
**Time Frame:** 7/1/2016-4/30/2017

**Description:** This project will review the existing literature to inform the content of a web based questionnaire for current female members participating in Clubhouses located in the United States. The Program for Clubhouse Research will gather this information and prepare a report for Clubhouse International to use to educate staff and members of 190 Clubhouses across the United States. This project will leverage the national Clubhouse presence and unique access to women living with mental illness to study and better understand the healthcare issues and concerns specific to this group. Additionally, the project will inform the development of training curricula and programs specifically designed to decrease the disproportionate rate of premature death and comorbid physical health issues for women living with mental illness.

Reducing Attrition from Drug Treatment Court by Focusing on Participants’ Quality of Life

**PI:** Ekaterina Pivovarova, Ph.D.  
**Funding:** National Institutes of Health  
**Budget:** $465,989  
**Time Frame:** 4/1/2017-3/31/2020

**Description:** The United States, and Massachusetts specifically, is in the midst of a devastating public health crisis – the opioid epidemic. Individuals in the criminal justice system are at increased risk for substance use disorders and overdoses, with more than 50% of all offenders meeting lifetime criteria for substance use disorders and former inmates being 12 times more likely than community members to die from drug overdoses. Accordingly, the criminal justice system presents a unique opportunity to engage individuals in substance use disorders treatment, specifically through Drug Treatment Court.
(DTCs) programs. DTC programs decrease rates of substance use disorders, reduce frequency of relapses, increase engagement in substance use disorders treatment, and decrease high-risk behaviors, including criminal activities. Despite successful outcomes, program attrition can be as high as 75%, with an average completion rate of only 49%. Given the high-risk nature of this population and the observed effectiveness of DTC, it is critical to determine what factors impact attrition and to develop interventions to improve retention. This study proposes an innovative approach by focusing on how psychosocial factors, such as health-related Quality of Life, presence of positive social support, and self-efficacy about abstaining from substance use impact DTC attrition. The specific aims of the proposed research are 1) to evaluate the applicability and feasibility of Quality of Life measures in DTC populations, 2) to assess whether DTCs produce improvements in Quality of Life, social support, and self-efficacy about drug and alcohol abstinence, and 3) to examine whether Quality of Life can predict attrition from DTCs. Findings from this study will produce pilot data to develop an intervention aimed at improving Quality of Life and thereby retention in DTCs.

**Training and Strategic Planning For Helping Youth on the Path to Employment (TAYLRD)**

**PI:** Marsha Ellison, Ph.D.  
**Funding:** NAMI Kentucky, Inc.  
**Budget:** $108,624  
**Time Frame:** 10/1/2016-3/20/2018

**Description:** This project provides training and technical assistance to the TAYLRD initiative for young adults with behavioral health conditions in Kentucky, specifically addressing the adaptation of supported employment services for this age group. Activities include a needs assessment; in-person strategic planning and orientation to the Helping Youths on the Path to Employment (HYPE) service model; training in supported education services; creation of a community of practice for HYPE services; and ongoing technical assistance.

**Trauma Symptoms and Addiction among Adolescents: A Neuroimaging Study**

**PI:** Gina Vincent, Ph.D.  
**Funding:** Systems and Psychosocial Advances Research Center (SPARC seed grant)  
**Budget:** $10,000  
**Time Frame:** 10/1/2016-6/30/2017

**Description:** This study involves a secondary data analysis of neuroimaging data from two adolescent samples that were generated from the Investigator’s NIDA K01 study, *Neuroimaging Youth with Callous-Unemotional CD and Co-morbid Substance Abuse*. The broad purpose of this project is to use these samples to examine the association between trauma-related symptoms and substance abuse among youth with and without histories of stimulant (cocaine or methamphetamine) abuse. The aims of this pilot project are to examine the variability in neurological response to drug craving that is explained by trauma-related symptoms as opposed to callous-unemotional conduct disorder (CU-CD). Specific aims are to use 25 regions of interest from the reward system to examine (1) the association between self-reported trauma-related symptoms and intensity of drug craving (self-reported and hemodynamic activity); (2) the variance in activity explained by trauma-related symptoms versus CU-CD, and (3) the association between trauma symptoms and the function of the default network while individuals are at rest. Findings will inform an R34 application to develop an adapted addictions treatment for adolescents that is trauma informed.
Treatment of Justice-Involved Emerging Adults with Substance Use Disorders

**PI:** Maryann Davis, Ph.D.

**Funding:** NIDA (sub - Oregon Social Learning Center, INC.)

**Budget:** $1,672,103

**Time Frame:** 10/1/2016-4/30/2021

**Description:** Prevalence of alcohol and other drug (AOD) abuse and criminal activity is highest during emerging adulthood compared to any other developmental period, and causes extraordinary costs to society. Emerging Adults (EAs; ages 17-21) with AOD abuse have greater incarceration rates than EAs without AOD abuse, and AOD-abusing offenders have significantly more recidivism, severe offending, and incarceration than other offenders. Such serious behavior interferes with successful transition into adulthood – school completion, employment, and housing. Surprisingly, there are no interventions with established efficacy to reduce criminal activity among EAs, with or without AOD abuse. The proposed study will evaluate the effectiveness of MST-EA (Multisystemic Therapy – Emerging Adults), an adaption of MST with a skills coaching component, for reducing justice involvement and AOD abuse. EAs (n = 240) with AOD abuse and justice involvement will be randomized to receive MST-EA or Treatment as Usual. Aims will be to evaluate the effect over time of MST-EA for reducing AOD abuse and criminal activity, as well as to evaluate the effect of MST-EA on the key proximal target of treatment (self-regulation) and intermediate outcomes of treatment (gainful activities). A final aim of the study will be to investigate if the direct effect of treatment on criminal activity is mediated by its effect on self-regulation, AOD abuse, and gainful activities. In this specific age group, there is a complete absence of AOD abuse and recidivism reduction treatments with demonstrated effectiveness. The ultimate effect of the proposed research would be decreased AOD abuse and justice involvement in a high-risk population, as well as improved outcomes that have significant societal impact (e.g., reduced homelessness and unemployment).

The University of Massachusetts Child Trauma Training Center

**PI:** Jessica L. Griffin, Psy.D.

**Funding:** Substance Abuse & Mental Health Services Administration (SAMHSA)

**Budget:** $2,000,000

**Time Frame:** 9/30/2016-9/29/2021

**Description:** This project allows the University of Massachusetts Medical School Department of Psychiatry to maintain, expand, and enhance the Child Trauma Training Center (CTTC) with the aim of improving identification of childhood trauma, increasing trauma responsiveness among youth-serving professionals, and expanding access to evidence-based practices (EBPs) (e.g., Trauma-Focused Cognitive-Behavioral Therapy). The CTTC’s population of focus will be children and adolescents who have been exposed to trauma, ages 0-21 years, throughout the Commonwealth. Our priority population is Court-Involved Youth and the project will focus its efforts on the most underserved and high risk groups within and across our population of focus: transition-age youth, youth with substance abusing parents, lesbian, gay, transsexual, bisexual, and questioning (LGBTQ) youth, commercially sexually exploited children, and youth in military families. The CTTC has three primary goals: (1) to provide trauma-informed care training to develop, enhance, and strengthen the capacity of 10,600 front-line youth-serving professionals (e.g., within pediatrics, courts and other local and state agencies) to identify, screen and/or assess for childhood trauma, to implement trauma-responsive practices, and to provide referrals to EBPs; (2) to strengthen and enhance an innovative and EBP neutral, statewide Centralized Referral System (LINK-KID) to improve access to care for traumatized youth by providing referrals, statewide, to EBPs for approximately 4,000 youth during the grant period; and, (3) to provide Trauma-Focused Cognitive-Behavioral Therapy to youth ages 3-21 by training clinicians statewide through intensive learning communities.
Appendix B

SPARC Dissemination Products

Written Products:

- A Call for Comprehensive Psychotherapy Training
- Central IRBs: Enhanced Protections for Research Participants
- Collecting Histories of Education and Employment during Recovery (CHEER) Project
- Enhancing the Social Networks of People with Mental Illnesses: A Qualitative Study on the Role of Peer-Operated Recovery Learning Communities
- Evidence Based Practices in Mental Health: Advantages, Disadvantages, and Research Considerations (revised for 2017)
- Into the Light: Using Technology to Develop a Mother/Family Centered Peer Support Network
- Outside-The-Box College Accommodations: Real Support for Real Students: Tools for School II
- Paternal Postpartum Depression
- Phase 1 – Community Forums Deaf ACCESS: Adapting Consent through Community Engagement and State-Of-The-Art Simulation
- PRogroms In Support of Moms (PRISM) Research Study
- Protecting Research Participants: How Can We Reduce “Therapeutic Misconception” in Clinical Research Trials
- Supported Education (SEd): State of the Practice
- The DREAMers Study: Undocumented College Students and Their Mental Health Needs
- Tips for Mental Health Providers Working with Southeast Asian Immigrants/Refugees
- What is a 504 Plan and How Can it Help My Teen?
- Workforce Innovation and Opportunity Act (WIOA) and its Application to Youth and Young Adults with Serious Mental Health Conditions

ES = Available en Español; V = Available in Vietnamese; ASL = Available in American Sign Language

New ASL Translations of Existing SPARC Products:

- Childhood Bullying: Awareness, Interventions, and a Model for Change
- Institutional Review Boards: What Do They Do? How Do They Protect Subjects?
- Mindfulness and Health

SPARC and Transitions Research & Training Center Webinars:

- Accessing Evidence-Based Treatment for Traumatized Youth (Jessica L. Griffin)
- Deaf 101: How to Navigate Clinical Interactions with Deaf Sign Language Users (Melissa Anderson & Timothy Riker)
Employing Young Adult Peer Support Workers: A Toolkit for Providers (Jonathan Delman & Vanessa Klodnick)

Nothing about Us without Us: Growing Meaningful Young Adult Involvement in Your Organization (Amanda Costa & Tania Duperoy)

Part 1: Effective Clinical Supervision for Young Adult Therapeutic Peer Mentors (YA TPMs) (Vanessa Klodnick)

Part 2: Effective Clinical Supervision for Young Adult Therapeutic Peer Mentors (YA TPMs) (Vanessa Klodnick)

Promoting Maternal & Child Health Webinar (Nancy Byatt)

TAYLRD: Employment and Education Supports for Young Adults with Behavioral Health Issues (Marsha Ellison)

**Transitions Research & Training Center Comeback TV Videos:**

- Outside-the-Box Accommodations in College, Part 1 (featuring Laura DiGalbo)
- Outside-the-Box Accommodations in College, Part 2 (featuring Laura DiGalbo)
- Successful Adulting: My Must-Have Papers
- Unemployment: Is it Good or Bad for Young Adults? (featuring Joe Marrone)
- What Happens to my SSI When I Turn 18?
Perinatal depression occurs in 10 to 15% of all new mothers\textsuperscript{1, 2} and has been found to be as high as 23 to 52% in low-income populations.\textsuperscript{3, 4} Untreated depression during pregnancy and the postpartum period is associated with negative outcomes for mothers, infants and families. For instance, depression during pregnancy can influence maternal self-care and reduce the likelihood that women receive adequate pre-natal care.\textsuperscript{5} It is also associated with elevated risks of preterm birth, low birth weight, intrauterine growth restriction,\textsuperscript{6} pre-eclampsia,\textsuperscript{7, 8} illicit substance use\textsuperscript{9} and in severe cases suicidality and infanticide. Untreated depression during pregnancy is also one of the strongest predictors of postpartum depression (PPD), which is a well-known risk factor for negative cognitive and emotional developmental outcomes for children.\textsuperscript{6, 10}

Current Efforts to Address Perinatal Depression

With the increasing awareness of the frequency and impact of perinatal mental health issues, public health efforts have been made to promote screening\textsuperscript{11} and provide follow-up treatment.\textsuperscript{12} For instance, some states have initiated programs that provide perinatal psychiatric consultations to primary care and specialty practitioners who can prescribe for pregnant and postpartum women, and care coordination services to promote access to psychotherapy.\textsuperscript{13, 14} Recently, a federal bill, Bringing Postpartum Depression Out of the Shadows as part of the 21st Century Cures Act, was passed to support the development of similar programs in other states.

The Importance of A Family-Based Psychotherapy Approach

While these efforts promote detection and referral to psychotherapy, they do not ensure the availability of adequate psychotherapy options. It is particularly important to focus on psychotherapy for this patient population for a variety of reasons. First, many perinatal women will only seek psychotherapy as they prefer not to take medication while pregnant or breastfeeding.\textsuperscript{15-17} Indeed, a large cross-cultural study found that for those who seek professional help, “talk therapy” is seen as the preferred treatment.\textsuperscript{18} Secondly, psychotherapy is the only evidence-based treatment option during pregnancy and breastfeeding that is risk free for baby and mother and is therefore considered a first-line approach for mild-to-moderate depression.\textsuperscript{19} Thirdly, combined treatment approaches (medication plus psychotherapy) or psychotherapy alone tend to be more effective for co-morbid disorders, such as post-traumatic stress disorder, obsessive compulsive disorder, and substance abuse disorders.\textsuperscript{20-22} These are present in at least one half of women with PPD.\textsuperscript{23, 24} Lastly, but importantly, evidence suggests that treatments that target symptom reduction only, such as medication, are not sufficient to prevent the associated negative outcomes in children.\textsuperscript{25-27} Rather, it is thought that the association between maternal depression and negative child outcomes occur, at least in part, as a result of a complex set of interactions within the family system that do not completely resolve after a mother’s depression remits.\textsuperscript{28-30}
Certain types of psychotherapy interventions for perinatal women have shown positive outcomes for mothers, infants and families. For instance, psychotherapy interventions that address the infant-mother relationship seem to reduce the impact of PPD on children's cognitive and emotional development by improving maternal sensitivity, responsivity, affective involvement, reflective capacity, and attachment security. Similarly, psychotherapy interventions designed to include partners in treatment can positively impact maternal mood, improve the quality of the co-parenting relationships, and promote positive outcomes in children.

Translating Evidence-Based Therapies into Practice

Given the importance of psychotherapy that addresses the family system, there is a need to provide trainings for therapists in a family oriented approach to perinatal mental health issues. While several such evidence-based, manualized psychotherapies have proven effective, the use of these treatments remains limited due to the financial and logistical challenges of integrating new forms of psychotherapy into on-going clinical care settings. Indeed, several of these treatment models require a team approach of infant therapists, maternal group therapists and dyadic therapists working together, which further increases barriers to implementation. Moreover, evidence suggests that efforts to implement manualized psychotherapies in real-world settings face sustainability and fidelity challenge. Therapists tend to integrate what they find to be useful into their own style of practice and adapt therapies that have been validated in a pre-screened, narrowly defined patient populations to meet the specific needs of their patients’ more complex presentations.

Providing Psychotherapy Trainings Offers A Practical Solution

The perinatal period is a sufficiently distinct stage of life to warrant a minimum requirement for specialty training amongst therapists working with this patient population. Such practice is standard of care for therapists working with patients at other important life stages (childhood, older adults, etc). To this end, evidence-informed trainings on perinatal mental health issues could offer one realistic solution, improving therapists’ capacity to meet the specific needs of mothers and their families without requiring therapists to adopt an entirely new model of psychotherapy. Such trainings could cover essential topics of perinatal mental health (e.g., perinatal differential diagnosis, common risk factors, importance of social support and ways of connecting women to appropriate supports, common emotional issues, and strategies for addressing stigma and improving engagement), as well as evidence-based techniques for supporting the mother’s relationship with her infant and partner. Given the relative ease and affordability of such trainings, this common sense approach deserves to be more rigorously tested and compared to other evidence-based practices.

Research has provided us with a tremendously rich understanding of the perinatal period and the kind of psychotherapeutic techniques that can effectively address issues that arise during this time. It is now time to more fully integrate and disseminate this knowledge to providers who are working with the perinatal population so it can be widely used in thoughtful and nuanced ways. As we increase the detection of perinatal mental health concerns and increase pathways to access psychotherapy, let us not miss out on this opportunity to ensure that new mothers and families get what they need from psychotherapy, so they are given their best chance to move forward.
Institutional Review Boards (IRBs) play a critical role in research, and assure safety and fairness to participants enrolled in research studies. The IRB, made up of researchers, administrative staff, and community members, must make decisions about the safety and fairness of research procedures consistent with:

- Federal regulations;
- State regulations;
- Ethical guidelines; and
- Rules specific to each institution where the research will take place.

As such, the IRB research review can be complicated and lengthy. When the same research study is conducted at multiple sites, the IRB review process is often increasingly complex, costly, and may excessively delay the start of the research study. Multisite studies are often reviewed by multiple IRBs (an IRB review at each site participating in the study), which can slow down study approval, result in duplication of effort, and occasionally produce contradictory decisions by different IRBs. To address these problems, the federal government has promoted the use of single IRBs (referred to as Central IRBs or CIRBs), where a single IRB is responsible for the review of all sites where the research study is conducted. For instance, if a research study will involve the enrollment of participants at all five campus locations in the University of Massachusetts system, only the IRB at the University of Massachusetts Medical School (UMMS) will review the study on behalf of all the locations.

This CIRB process is new and requires careful study to understand its pitfalls and benefits. As such, UMMS and Columbia University received a National Institutes of Health (NIH) grant to study how different institutions conduct reviews of research involving multiple sites. We’ve completed over 100 interviews with IRB administrators, department chairs, research reviewers, and staff about their experiences using a Central IRB. Additionally, we have attended IRB meetings around the country where a CIRB method was used. We are now in the process of reviewing, organizing, and coding data from these interviews and site visits.

Our study comes at a critical point, as NIH has recently announced that beginning in 2017 all research conducted at multiple sites must be reviewed by a CIRB. We believe our work will:

- Inform the current NIH mandate of CIRB review;
- Document what works and what doesn’t with existing CIRB procedures;
- Highlight potential obstacles faced by IRBs as they transition towards centralized review; and
- Offer solutions to help institutions develop methods to use a CIRB approach.

The ethics of research is of vital importance to all research participants, but even more so for at-risk and disenfranchised individuals who may require additional protections and safety procedures for enrollment in research. We hope our work will result in the development of more efficient, ethical, and safe procedures for reviewing the ethics of clinical research.

This study is conducted by researchers in the Systems and Psychosocial Advances Research Center (SPARC) in the Department of Psychiatry at the University of Massachusetts Medical School (UMMS) and Columbia University. The team at SPARC is led by Charles Lidz, Ph.D., Professor Emeritus, and includes Ekaterina Pivovarova, Ph.D., Assistant Professor, and Research Coordinators’ Alexandra Murray, M.P.A. and Debbie Truong, M.A. Our collaborators at Columbia University include Paul Appelbaum, M.D., Dorrall Professor of Psychiatry; Medicine, and Law; Robert Klitzman, M.D., Professor of Clinical Psychiatry; and, Deborah Stiles, J.D., Vice President for Research Operations.

This is a product of Psychiatry Information in Brief. An electronic copy of this issue with full references can be found at http://escholarship.umassmed.edu/pib/vol13/iss10/1
Why is this study important?

Work and school experiences in early adulthood predict later career success. However, YA living with SMHCs have low employment and educational attainment rates. Lack of educational attainment and career exploration in YA with SMHCs can lead to little or no economic progress later in life.

In addition, YA with SMHCs are more likely to become first-time parents at an earlier age than their peers without SMHCs. Research suggests that YA who become parents when they are under the age of 27 are likely to be unemployed or under-employed in short-term, part-time, low-paying jobs.

Who is involved in this study?

CHEER aims to recruit 60 YA with SMHCs. Forty participants will be YA who are not parents, between the ages of 25-30. Twenty participants will be young parents between the ages 22-30, who have been parenting for one year or more. All participants must meet the following criteria:

- Have been diagnosed with a SMHC (e.g., Major Depression Disorder, Anxiety Disorder, Schizophrenia, etc.) before the age of 22
- Have some post high school employment and/or education experience
- Have a history of one or more of the following:
  - Overnight hospitalization
  - Partial hospitalization
  - Being a client of/receiving services from the Massachusetts Department of Mental Health
  - Receiving special education services
  - Needing to take a formal leave of absence from school and/or employment due to their mental health condition

What does the study involve?

Participants will take part in a 90 minute one-time, in-person interview that focuses on past and current education, training, and work experiences – both successes and challenges. The interview also includes questions about how other parts of the participant’s life influences work and education experiences, such as:

- General and family background
- Mental health and physical health
- Major life events
Parenting and child rearing (if applicable)

All participants will receive a $30 gift card for their participation.

What are the anticipated outcomes?
After data analysis is complete, we will be able to:

- Provide a descriptive picture of the typical education, employment, and job training goals and experiences of YA with SMHCs
- Identify key targets for future services and interventions for YA with SMHCs that contribute to school and work success and alleviate challenges they face
- Assist service providers in developing improved support systems for young parents with SMHCs and their families

We will use study findings to inform the development and delivery of services that support the school and work experiences of young adults, including young parents, with SMHCs.

References


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Social connectedness and affiliations have powerful effects on the health of people with severe mental illnesses (SMI), resulting in reduced psychological distress, fewer psychiatric hospitalizations, and improved self-confidence. Yet, people with SMI often have difficulty building and maintaining social connections, and there is no established best practice for helping individuals with SMI socially integrate. In fact, the social networks of people with SMI, in comparison to those of people without disabilities, are smaller, less satisfactory, and more likely to be made up mostly of relatives and other mental health consumers.

“Social integration” involves a process through which an individual establishes and maintains meaningful interpersonal relationships characterized by mutual exchange with community members in nonclinical settings. The research on how people with SMI (re)integrate socially is sparse and lacking a conceptual framework. Peer-operated programs, which are administratively and financially controlled and staffed by people with lived experience of mental illness, have shown some promise in helping people with SMI build or rebuild their social networks.

Massachusetts-based Recovery Learning Communities (RLCs) are peer-run programs that offer safe and supportive environments for individuals with SMI to develop, practice, and solidify social relationships. Some of the opportunities that RLCs offer are: peer support groups, wellness classes, education, employment supports, computer lab and library access, as well as community meetings. Engagement in peer support activities allows participants to create relationships and practice a new identity (rather than that of a “mental patient”), leading to improved coping skills, social functioning, and quality of life.

In 2014, researchers from the UMass Systems and Psychosocial Advances Research Center (SPARC) partnered with the Central Massachusetts RLC to complete a pilot study exploring the relationship between RLC participation and experiences of social integration. Utilizing participatory action research (PAR) principles, investigators from both SPARC and the RLC worked collaboratively to design an exploratory qualitative study, analyze data, and present findings.

A qualitative interview guide, grounded in a conceptual framework examined the impact of various aspects of the RLC on the psychosocial life of participants. Investigators interviewed ten RLC participants for this pilot study. Participants RLC attendance varied from 1 to 4 times a week for anywhere from 4 months to as long as 4 years.

In addition, investigators held a focus group with RLC staff members, who are also persons with lived mental health experience. A modified grounded theory approach was used to code and analyze the data. Two investigators engaged in comparative analysis to identify key themes.

Twelve themes regarding RLC impact on social integration emerged. The identified themes fall into one of two domains: 1) RLC Attributes and 2) Psychosocial Outcomes. Each domain was organized into two categories. The RLC Attributes categories are Atmosphere and Opportunities, while the Psychosocial Outcomes categories are Intrapersonal and Interpersonal.
RLC Attributes: What is it about the RLCs that help participants become more socially active?

Atmosphere:
- **Judgment-free:** Having been diagnosed and otherwise “judged” in other treatment and social settings, RLC participants were pleased that staff and peers at the RLC saw them as people first, and not as cases or illnesses;
- **Flexible:** RLC participation is completely voluntary and participants can choose whatever meetings and activities they wish to engage in; and
- **Relaxed/open:** RLC peers and staff share concerns, emotional support, and coping strategies that promote personal and social well-being.

Opportunities:
- **Leadership:** RLC participants are provided opportunities to facilitate peer groups and trainings and to organize social and advocacy activities;
- **Meeting peers:** Many new RLC participants are isolated and have a poor self-image. RLCs offer new opportunities to meet peers and people in the larger community; and
- **Trainings and workshops:** RLC participants can choose to attend appealing groups, classes and trainings that assist in personal recovery and/or encourage social interaction.

Psychosocial Outcomes: How do the social lives of RLC participants’ change with RLC participation?

Intrapersonal Outcomes:
- **Positive identity transformation:** Participants begin to see themselves as capable of working and socializing;
- **Increased self-esteem:** Many participants observe for the first time that recovery is possible and they become more optimistic and hopeful;
- **Increased sense of responsibility:** Participants begin to pursue jobs and (re)build family relationships; and
- **Improved coping skills:** Participants develop wellness management plans and reduce stress; many use hospitals and emergency rooms less frequently.

Interpersonal Outcomes:
- **Enhanced social networks and activities:** Participants often make numerous friends through RLC activities or other outside social events. As a participant’s social skills increase and their social anxiety lessens, they begin to build relationships outside of the RLC community; and
- **Holding jobs and other positions of responsibility:** Participants develop new skills, gain the confidence to seek employment, and become more resilient, allowing for longer periods of employment.

Our small convenience sample, all of whom participated in the activities of a single RLC, suggests caution in making inferences to other populations. The framework for social integration of people with SMI should be further developed through additional qualitative studies with a larger and more representative group of RLCs and people with SMI. These and other data could be used to develop structure, process and outcome measures of social integration through further study, perhaps using a participatory action research approach. When measures are developed or adapted, longitudinal studies could assess relative effectiveness of RLCs.

The atmosphere at the RLCs allows for the creation of opportunities that permit individuals with mental illnesses to develop an improved sense of self, make friends, and build stronger social networks. As part of their quality improvement strategy, RLCs should regularly assess the continuing presence of their key attributes that support this atmosphere and opportunities. Additionally, these key attributes should be seriously considered by other programs wanting to promote social integration for people with SMI.

To learn more about RLCs please visit the MA DMH website: http://www.mass.gov/eohhs/consumer/behavioral-health/mental-health/recovery-learning-communities.html

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One widely accepted definition of Evidence Based Practices (EBPs) is that they are interventions for which scientific evidence consistently shows that the practice improves client outcomes. EBPs rely on the classifications of research studies and findings according to a variety of evidence. In general, the highest standard requires evidence from several Randomized Clinical Trials (RCTs) by multiple teams of investigators comparing the practice to alternative practices or to no intervention. EBPs provide evidence of effective treatments or services based on rigorous research approaches that include randomization, control groups, studies with matched participants, blinding of service providers (so they are unaware of study participants or the treatment each individual receives), statistical analysis (often meta-analysis), and drawing accurate conclusions from study results.

A panel convened by the Robert Wood Johnson Foundation in 1998 identified six program models providing services to adults with serious mental illness (SMI) as EBPs. The six models are illness management and recovery, medication management, assertive community treatment, family psycho-education, supported employment, and integrated dual diagnosis treatment. Today, a wide range of models serving persons diagnosed with SMI that produce beneficial outcomes have accrued varying levels of evidentiary support from RCTs, quasi-experimental research designs, and other systematic research evaluation methods. These models are listed on a variety of EBP registries and databases on the internet including The Campbell Collaboration, The Cochrane Collaboration, and the Substance Abuse and Mental Health Services Administration's (SAMHSA's) National Registry of Evidence-based Programs and Practices (NREPP). Other practices have not been reviewed or summarized with the intensity and rigor or examined using research designs sufficient to label them EBPs despite the increase in internet EBP registries.

Evidence Based Practices in Mental Health: Advantages, Disadvantages, and Research Considerations

Colleen E. McKay, MA, CAGS

Advantages of Evidence Based Practices

There are several advantages to identifying services as EBPs:

- EBPs identify effective interventions based on reviews of multiple rigorous studies rather than on subjective interpretations of the reviewer, clinician, or stakeholder(s);
- EBP services receive support from a broader research base that includes psychological and biological research, and sociological evidence from multiple studies;
- Identification of EBPs may allow funders to direct limited resources to programs and areas where they will have the greatest impact;
- Many EBPs have corresponding manuals and guidelines to assist with service implementation and fidelity to a particular model; and
- Some EBPs have support from systematic assessments of existing research studies (meta-analysis) which allow readers to draw conclusions from a body of research. Meta-analysis offers a consolidated quantitative review to evaluate the results from multiple studies.

While identifying services as EBPs has advantages, over reliance on EBPs also has some distinct disadvantages:

- Limiting services to only EBPs may fail to incorporate models supported by consumer advocates or persons with lived experience. These models may not be identified as EBPs or offered within a system of care because of a lack of empirical research, not because they lack effectiveness;
• Restricting EBP research to RCTs may limit participation to individuals with specific diagnostic criteria in order to enhance effect sizes. While serving the immediate research needs, addressing the effectiveness for the broader population is beyond the scope of most RCTs;¹

• Most EPBs have not been developed and tested for specific cultural groups. Systematic methods for implementing EBPs to address culture-specific issues are vital;

• Many existing services or programs have yet to be included in research, making it impossible to know which have the best outcomes. We have no scientific way of knowing how these programs compare to EBPs unless we include these programs in our research;

• Evidence that examines the long-term effects of some EBPs does not exist. A service proven effective at one point in time does not mean that particular service will provide long-term lasting benefits; and

• Issues of adequate funding and fidelity to a particular model may affect the generalizability of study findings. Funding for services is often inadequate making full implementation of EBPs difficult, which could compromise fidelity to a particular EBP model.

Recommendations for Policy Makers, Researchers, & Service Providers

1. Consider a range of evidence as an alternative means of classifying and assessing EBPs. The extent to which there is evidence from quasi-experimental designs, qualitative studies, case studies, or testimony from program participants may be useful in evaluating services. Consider designing studies that examine a wider variety of programs and services located in prevalent systems of care to build the evidence base for programs and services that need to be scrutinized using rigorous research methods.

2. Devote resources to examine services that have not undergone rigorous scrutiny to determine their effectiveness. In order to make viable comparisons between different program models we must provide tests that allow us to draw fair conclusions.² Comprehensive research examining a wider variety of existing and innovative services, particularly those with fidelity to their respective models, will increase the quantity and quality of the evidence base; and

3. Consider the needs of the “consumer voice” or voices of persons with lived experience. There is considerable support for a variety of services from consumer advocates and the recovery movement.³, ⁴ Studies or reviews of the effectiveness of mental health services readily adopted by consumers and stakeholders and EBPs may be beneficial.

An Example of an EBP Review Conducted Within SPARC

The Program for Clubhouse Research at UMass Medical School’s SPARC led a systematic review of the evidence for the Clubhouse Model of Psychosocial Rehabilitation. The Clubhouse Model was reviewed and included in the list of programs on SAMHSA’s NREPP in 2010. Clubhouses strive to help members (adults and young adults living with SMI) participate in mainstream employment, educational opportunities, community-based housing, and health promotion activities, in order to reduce hospitalizations or involvement with the criminal justice system, and improve satisfaction, social relationships, and quality of life.

The review conducted within SPARC targeted research on outcomes in a variety of domains associated with the Clubhouse Model including employment, education, social relationships, quality of life, health promotion activities, and hospitalizations.⁵ This review indicated higher levels of evidence for the Clubhouse Model including at least one RCT in the domains of hospitalization, quality of life, or employment.

Evidence for other domains appeared promising, as there was evidence from multiple observational studies that suggested the Clubhouse Model had a positive impact. However, there is a need for additional studies using rigorous methods including RCTs, studies with matched participants, or observational studies to evaluate programs with fidelity to the Clubhouse Model. Studies that examine the Clubhouse Model and other established EBPs would be useful. Efforts such as these are important steps in examining services that would benefit from additional research and/or designated as an EBP.
Perinatal mood and anxiety disorders (PMADs) are estimated to occur in up to 20% of women who are either pregnant or have recently given birth and can include postpartum depression, anxiety, obsessive compulsive disorder, mania and psychosis. Of women diagnosed with a PMAD only a small number will receive treatment. For some women the stigma and shame associated with mental illness prevent their help seeking, and access to care may be limited by time and resource constraints. The prevalence and limited treatment of these illnesses make PMADs a significant public health issue. Left untreated, these illnesses can dramatically impact a woman's ability to care for herself and her child, and in severe cases may result in maternal and/or infant mortality. Peer support has been demonstrated as an effective treatment intervention when delivered in-person and over the phone. However with the increasing popularity of online patient communities and social media in health care delivery, further exploration of peer support delivered through online and mobile technology is needed. The use of technology has the potential to dramatically improve access to peer support and ultimately to treatment for women from underserved communities and those in rural locations.

**Into the Light** is a Tier 1 Patient Centered Research Outcomes Institute (PCORI) Pipeline to Proposal project. Postpartum Progress Inc. (PPI), the lead organization, is a national non-profit dedicated to raising awareness and reducing stigma related to maternal mental illness. The project team, comprised of five patients with lived experience, a project lead and a research lead, will identify key stakeholders, and build collaborative relationships with the academic community to develop comparative effectiveness research based questions regarding women with perinatal mental health conditions. Central to the project is the development of patient engagement and recruitment strategies, and a dissemination plan that translates outcomes into accessible, easy to understand information to assist patients in making health related decisions.

PPI is an innovative leader in the development of online peer support networks and has successfully built an online community of women across the US and around the world via online communication tools and social media. (Visit [www.postpartumprogress.org](http://www.postpartumprogress.org).) The PPI blog, founded in 2004, is the most widely read blog in the world on perinatal mental illnesses (over 3 million page views to date in 2016). The PPI Facebook page has over 32,000 followers. PPI provides a monitored, private web-based peer support forum (involving over 6,000 mothers); a closed Facebook group (with over 125 participants); international distribution of free patient-focused education tools; the world's largest annual event raising awareness of maternal mental illness; and an annual patient-focused conference. Over the next months, the Into the Light team will: (1) develop better ways to understand the efficacy of peer support; (2) explore peer support models enabled by health technology, to augment clinical treatment (medication and/or psychotherapy) and to explore additional options for women and their families; and (3) specify engagement, recruitment and dissemination strategies for women with perinatal mental health conditions to facilitate their participation in future research. The ultimate goal is to generate patient-informed research questions with real-world relevance and impact.
Students who have a mental health condition may need additional support to help them do the best they can in school and work. The “American with Disabilities Act” (ADA) entitles students with disabilities, like mental health conditions, to get academic help with academic accommodations and other legal rights.

Most schools are used to providing typical accommodations such as: note taker, extra time for assignments, and assistive technology for students of many different disabilities. Yet, the challenges of having a mental health condition are unique.

This tip sheet will help you to think “outside-the-box” to get the educational accommodations that help you with your unique struggles.

**What Are Academic Accommodations Anyway?**

Academic accommodations are like any other helping tool, like an audio book or a calculator. They are changes in how you participate in your courses. When considering the accommodation, you need think about things like:

- Where you take your test or where you sit in class
- How information is given to you (recorded audio, written notes, visual presentations, etc)
- How you work with students or how you respond to being called upon
- Extended or broken-up time for in-class work, tests, projects, and/or homework

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**Important to Note**

Academic Accommodations are not the same as modifications. This means that they are not a change in the curriculum of the class or how you are graded. They are more of a change in how you do the same work so that you have the same opportunity that everyone else has regardless of your mental health condition or other disability.

**Learn about the basics of accommodations and how to get them, see our “Tools for School” tipsheet:**

[http://escholarship.umassmed.edu/cgi/viewcontent.cgi?article=1066&context=pib](http://escholarship.umassmed.edu/cgi/viewcontent.cgi?article=1066&context=pib)

**Outside-The-Box Educational Accommodations**

The following table contains some examples of educational accommodations that may be helpful to the unique challenges of having a mental health condition:
| **Advance Warning or “Pre-Processing”** | If classes make you nervous, it may help if the professor lays out what is going to happen at the start of class. This allows for “pre-processing” so that you can prepare mentally for what’s to come, easing any anxiety about not being prepared for class. |
| **Broken Time** | If you struggle with having to focus for a long period of time, a “broken time” accommodation may help. “Broken time” is different from “extended time.” Having “extended time” involves having 150% of the time originally given to take an exam, or some call it, “time and a half.” In “broken time,” you work for a period of time on classwork, an in-class essay or exam, during which you are allowed to take short breaks. You spend the same amount of time on the activity as everyone else, but the time is just broken up. Taking a break can refresh and reorient your mind, allowing you to better focus on the activity. This way whatever time you spend feeling anxious or distracted will not count towards your total time given. |
| **Professors Limiting or Changing the Way Demand Responses are Requested** | Being called upon in class or “demand responses”, can cause a lot of anxiety. Limiting being called upon in class unless your hand is raised can be requested as an accommodation. If the professor has established a need for in-class participation that counts towards your grade, the accommodation can be that the professor prepares the student before calling on them in class so that the student has time to ready themselves. |
| **Reframing Participation Questions or In-Class Feedback** | Professors can “reframe” questions in order to help you give a clearer, more correct, or specific answer while participating in class. If a discussion in class needs to be cut short because of time, but you still need further explanation, you can request that the professor meets with you after class. |
| **Reducing Distraction** | Finding classes with a small number of students can help if you struggle with concentration. If the school can’t provide a smaller class, you may be accommodated by having a reserved seat at the very front of the class. |
So How Do I Figure Out Which Accommodations Work Best for Me?

Your campus disability services office (or accessibility office) is where you go to ask for accommodations and they can sometimes help you think about the different ones you’d like to try. The person who knows you and your challenges best is you. What are your strengths and struggles? Also, it is very important to have a group of people that know you and support you so that they can help you figure out what support(s) you might need to achieve your goals.

The following are some tips to keep in mind while requesting accommodations:

- Work with your support network to talk about your needs and how your challenges affect you in the classroom, on campus, during examinations, and while you are working.

- Your support people cannot request an accommodation for you at your school’s Disability Services Office, but they can go with you if you need an advocate or a companion as you request the accommodations you need.

- Talk to your doctor about your strengths but also your challenges in school. They will need to write a letter that describes the specific ways your condition affects your ability to learn in college.

- Contact the disability services within your school, remember these services are there to make sure they provide you with the best solutions. On the first day of classes, professors usually provide information about how to contact them in the course syllabus.

- Work with your professors and your school to understand their requirements from you as a student.

Don’t miss our Comeback TV episode Outside-the-Box Accommodations in College, Part 1

In this episode, Gus has a special guest, Laura DiGalbo, to talk about college accommodations and some advice on how to get them in a way that will really support college students with mental health lived experience.  
https://www.youtube.com/watch?v=0VivSnSNXXE
Resources


More information available at:

- [http://escholarship.umassmed.edu/cgi/viewcontent.cgi?article=1066&context=pib](http://escholarship.umassmed.edu/cgi/viewcontent.cgi?article=1066&context=pib)

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We'd like to give a special thanks to Laura DiGalbo for her expertise and the information she shared with us during her recent webinar, “Tools for School-College Accommodations for Students with Psychiatric Disabilities,” which also informed this tip sheet. Laura DiGalbo has worked in the fields of Rehabilitation & Education for over 30 years in Connecticut. Laura is currently an adjunct faculty at Central Connecticut State University and has particular interest in the retention of college students, including those with psychiatric disabilities, who may need help coping with the rigor of college coursework.

If you’d like to contact Ms. DiGalbo at her practice, please e-mail her at ldgalbo@aol.com. For more information about her work, please visit [http://www2.ccsu.edu/faculty/DiGalbol](http://www2.ccsu.edu/faculty/DiGalbol).
While postpartum depression (PPD) has historically been associated primarily with mothers, recently there has been increased awareness of the experience of fathers and strategies to address postpartum depression in men. For fathers willing to seek help, the lack of recognition of paternal PPD results in limited supports and treatments. Given the potential implications of paternal PPD, it is essential for new fathers and their healthcare providers to recognize the prevalence of paternal PPD, the symptoms, and the challenges surrounding this issue for men.

Prevalence of Paternal Postpartum Depression

For both men and women, PPD is defined as moderate to severe depression diagnosed in the postpartum period, which is shortly after or up to one year following delivery. Studies suggest anywhere from 4 to 25 percent of fathers experience paternal PPD, rates that are not dissimilar to mothers. Fathers are most likely to experience a first onset of paternal PPD in the first 3 to 6 months of the postpartum period. Much of what is known about paternal PPD comes from studies of mothers and PPD. Research suggests that depression in one partner is significantly correlated with depression in the other. One study found 24 to 50 percent of men with paternal PPD also had partners with PPD. This suggests a high likelihood that infants may be in family situations where multiple caregivers are depressed, which can lead to more severe disruptions in infant development. Maternal PPD is the primary risk factor for predicting paternal PPD. While the relationship between maternal and paternal PPD is still being researched, studies report that male partners of depressed women generally feel less supported, and experience more fear, confusion, frustration, anger, and uncertainty.

Becoming a father is associated with little sleep, new and increasing demands, and new responsibilities that may trigger stress, fear, and anxiety, all of which can lead to depression. Men with previous histories of depression as well as those who are young fathers are at increased risk of developing paternal PPD. Men are likely to underreport their symptoms of depression due to the stigma associated with depression, along with concerns about not aligning with cultural concepts of masculinity.

Symptoms of Paternal Postpartum Depression

Postpartum depression includes depressive episodes that last for longer than two-weeks during the postpartum period. Symptoms associated with both paternal and maternal PPD include:

- Loss of interest in activities
- Significant weight loss or gain
- Fatigue or loss of energy
- Insomnia or hypersomnia
- Feelings of worthlessness or guilt
- Severe anxiety
- Inability to concentrate
- Thoughts of self-harm or suicide
While many PPD symptoms are similar for fathers and mothers, some symptoms are unique to men. These symptoms include:

- Irritability
- Indecision
- Impulsivity
- Violent behavior
- Avoidance behavior
- Substance abuse

**Impact of Paternal Postpartum Depression on Child Development**

In contrast to a large body of literature on maternal care and child development, the relationship between quality of paternal care, that is fathers caring for children, and child development has been less well documented. An increasing number of studies, however, suggest that many fathers with depression exhibit the capabilities to interact with their infants just as well as mothers with depression, and that the role of fathers and paternal care is important for children's social, cognitive and emotional development.

Infants establish both basic biological and behavioral regulatory patterns as well as secure attachments through interactions with primary caregivers in the first year of life. However, most attachment research focuses on mothers and infants. For example, mothers with PPD are more likely to exhibit helplessness and negative emotions, and exhibit more irritability, hostility and apathy towards their infants. Unaffectionate parenting from both mothers and fathers may lead to the development of insecure attachment with infants. It is reasonable to suggest that limitations and deficits revealed for mothers with PPD and their infants regarding attachment are potentially concerns for fathers with PPD and their infants; this is an area that merits further investigation.

The impact on children of paternal PPD may be long term. One study of children of fathers with paternal PPD found an increased number of emotional and behavioral issues including conduct problems and hyperactivity. Major depression in fathers is associated with lower psychological functioning and increased suicidal ideation among sons, and increased rates of depression among daughters during young adulthood.

**Future Directions**

Becoming a parent is a significant life transition that comes with a range of experiences and emotions that can be both gratifying and rewarding, as well as challenging and stressful. While much of the attention to this transition has focused on the experiences of mothers, the experiences of fathers must also be recognized. Health care providers do not routinely talk with men about the transition to fatherhood or screen them for depression. Increased awareness of and knowledge about paternal PPD may facilitate identification and promote treatment for fathers.

Future research should focus on understanding the unique characteristics and experiences of men living with paternal PPD. Researchers should examine more heterogeneous groups of fathers and explore risk factors for developing paternal PPD. Studies of the changes that occur during fatherhood, as well as the co-occurrence of depression in couples, could bring an increased understanding of paternal PPD, leading to better screening and treatment options.

Earlier intervention of paternal PPD can lead to improved outcomes for fathers, mothers and children, which can lead to improved well-being for families.
Phase 1 – Community Forums Deaf ACCESS: Adapting Consent Through Community Engagement and State-of-The-Art Simulation

Melissa L. Anderson, Timothy Riker, Kurt Gagne, Stephanie Hakulin, Todd Higgins, Liz Stout, and Kelsey Cappetta

The U.S. Deaf community is a sociolinguistic minority group of 500,000 Americans who communicate using American Sign Language (ASL). This population is one of the most understudied populations in biomedical research. At this time, most research procedures are not designed to provide access to Deaf people and informed consent procedures for research are not provided in an accessible language for Deaf participants. Furthermore, because of a long history of mistreatment of Deaf people in the research world, there is a feeling of mistrust toward researchers and strong resistance to enrolling in research studies.1-3 It is vital that researchers find a way to improve access and build trust with the Deaf community to include this underserved and at-risk population in biomedical research.

In 2016, the University of Massachusetts Medical School (UMMS), in partnership with Brown University, was awarded a 2-year grant from the National Institute on Deafness and Other Communication Disorders (NIDCD) to improve Deaf people’s trust and involvement in biomedical research. The Deaf ACCESS: Adapting Consent through Community Engagement and State-of-the-art Simulation research team is led by Melissa Anderson from UMMS and Co-Investigator Timothy Riker from Brown University. The study team also includes four Deaf Community Advisors. Because the research team includes five Deaf members, American Sign Language is the primary language used while working together.

The Goals of Deaf ACCESS Are To:

- Gather feedback from the Deaf community through community forums and focus groups regarding their experiences with health research and identify how researchers can better include Deaf people in research studies.
- Develop a training program for researchers related to recruiting and enrolling Deaf people in research studies, specifically the informed consent process.
- Test and evaluate this training program with researchers and research assistants who have not previously worked with Deaf individuals.

Deaf Community Forums

During the first phase of Deaf ACCESS, the research team hosted three Deaf community forums in October and November 2016. These forums assisted the research team in identifying the barriers and facilitators to the full engagement of the Deaf community in biomedical research. The community forums were held at locations well-known and trusted by the Deaf community – Deaf schools and a Deaf independent living center.

To recruit Deaf individuals to these forums, they developed and disseminated a one-page recruitment advertisement. This ad was also converted into a brief video conducted entirely in ASL. Both the ad and video were shared in a variety of ways to reach as much of the New England Deaf community as possible.

During each forum, attendees were invited to share their experiences in the research world, and to make recommendations about how researchers can better
include Deaf people in their studies. Hearing researchers from UMMS and other institutions were also invited to all three community forums, where they could engage in an open conversation with attendees about the historic mistreatment of Deaf and hard of hearing individuals in the research process, participate in a formal apology on behalf of the hearing research community, and collaboratively explore steps needed to move forward – an approach known as the “Truth and Reconciliation Model”.3

At each community forum, seating was arranged in a semi-circle format to provide full visual access to attendees. Three ASL interpreters were hired to facilitate communication between signing and non-signing attendees. Five Certified Deaf Interpreters, who are Deaf, native signers, were also present to provide specialized support to participants with various language backgrounds and communication needs. The interpreters worked together to ensure that all participants received the same information and opportunity to participate in the discussion equally. Forum discussion (in both spoken English and ASL) was recorded via five video cameras surrounding the room, simultaneously recording each sector of the semi-circle.

Preliminary Results

At the end of each community forum, attendees were asked to complete brief evaluations. Evaluation results showed that 73% of participants reported feeling positive about sharing their research experiences. 86% of participants reported that they enjoyed the opportunity to advise researchers about how to improve their work. One participant described the forum as “excellent,” and indicated that they were “glad it happened.” Another participant stated that there was “good information” shared, while another wrote that they were “very interested” in what was discussed.

To identify common themes discussed at the forums, the research team conducted qualitative analyses of the video footage. The most frequently reported barriers to engaging in research were the following:

- “Research in the general public is not for me”/communication access will not be provided;
- General mistrust of hearing people due to history of negative/oppressive experiences;
- Failure of researchers to communicate study results back to the Deaf community; and
- Tendency of researchers to benefit from data provided by Deaf research participants, without any efforts to return to the Deaf community to help set-up programs or other interventions based on research findings.

Next Steps

The data collected during the Deaf community forums is being used to inform the next stages of the Deaf ACCESS project, which are:

1. Hosting four focus groups about how to adapt the informed consent process for Deaf research participants, each in ASL, with six Deaf community members.
2. Developing a prototype training intervention about how to deliver culturally appropriate informed consent using an ASL interpreter.
3. Conducting simulation-based training sessions to test the prototype’s feasibility and acceptance.
4. Producing a set of guidelines for the enrollment of Deaf people in biomedical research.

References


IN ASL: Deaf ACCESS Research Brief 1
https://youtu.be/qmrdslpGbeQ

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Upwards of 1 in 7 women suffer from perinatal depression, which is defined as depression during pregnancy or in the year after delivery. Maternal perinatal depression can have profound negative effects on the mother, fetus, child and family.1-11 Despite these recognized negative effects, perinatal depression remains under-diagnosed and undertreated.12-16 Women who are pregnant or who have just had a baby have regular contact with obstetric providers. Helping front-line obstetric providers serving pregnant and postpartum women to address depression may provide a solution to this critical public health issue. Massachusetts is fortunate to have MCPAP for Moms17,18, a first in the nation statewide program that helps obstetric care providers address depression through training, consultation, and care coordination.

The University of Massachusetts Medical School was awarded a 5 year grant from the Centers for Disease Control and Prevention (CDC) to study how to reach this underserved population. Building on the work of MCPAP for Moms, investigators will test an innovative new approach as a potential model to address perinatal depression. This new approach, the PRogram In Support of Moms (PRISM), is a more proactive approach than MCPAP for Moms that will empower Ob/Gyn practitioners to develop processes to treat their patients’ psychiatric needs in their own practices, ensuring that their patients do not fall through cracks in the depression care pathway.

An ongoing pilot study of PRISM suggests that while both MCPAP for Moms and PRISM improve depression symptoms, there is a greater decrease in depression severity with the additional intervention components included in PRISM. Over the next 5 years, investigators will run a randomized control trial that compares a set of 6 Massachusetts practices using MCPAP for Moms to a set of 6 practices using MCPAP for Moms plus PRISM.

Practices using PRISM will receive:
- Provider access to immediate resources, referrals, and psychiatric telephone consultation for patients through MCPAP for Moms;
- Clinic-specific implementation of stepped care depression treatment, that is care that is delivered and/or adjusted in stages or steps, including training support and toolkits; and
- Assistance with implementation of proactive treatment engagement, monitoring, and stepped treatment response to depression screening and assessment for patients.

This study will provide data to further determine whether one approach is more effective than the other. The goal is to share study findings and materials in order to address this critical issue on a national level.

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Prior research has demonstrated that clinical research trial participants are often unable to differentiate between experimental and conventional care. TM research shows that some research participants consent to participating in a clinical research trial without fully understanding the research process. To protect the rights of participants in clinical research trials, researchers should ensure that participants fully understand what it means to be in a clinical research trial so they can make informed decisions about whether or not to participate.

**History/Background**

“Therapeutic misconception” (TM) describes when a clinical research trial participant fails to understand the difference between participating in a clinical trial versus receiving conventional treatment, i.e., treatment as usual. Individuals experiencing TM mistakenly assume that by enrolling in a clinical research trial they will receive the latest experimental treatment, without understanding the differences including that they will be randomly assigned to either an experimental or a conventional control group. Patients in conventional treatment receive personalized treatment plans, which allow for treatment changes that are best for a particular patient. Conversely, patients in clinical trials receive treatment controlled by a strict clinical research protocol.

Methodology/Design

Study participants were randomly divided into two groups: an experimental group and a control group. Members of each group watched a narrated educational Power Point presentation about the hypothetical clinical research trial they were being asked to pretend to consent to. Members of the experimental group watched an additional presentation explaining exactly what a clinical research trial is, and how participating in a clinical research trial may be different than receiving conventional care.

After viewing the presentation(s), all study participants completed a survey that included background information, a measure of TM, and the participant’s decision about whether they would agree to participate in the hypothetical clinical research trial they learned about during the presentation(s).

Preliminary Outcomes/Future Impact

Preliminary analyses show no significant differences between the groups regarding their decision about whether or not to participate in the hypothetical clinical research trial. However, results indicate a statistically significant difference in TM scale scores, suggesting experimental group participants were less likely to experience TM. This suggests that including a brief educational presentation about the purpose, nature, and design of clinical research trials during the informed consent process does not negatively impact recruitment, and can help reduce TM.
Supported Education (SEd): State of the Practice
Shums Alikhan, Deirdre Logan, Marsha Ellison, Kathleen Biebel

Findings

Core Components of SEd Programs
There are several different approaches to SEd, each designed to help individuals with a serious mental health condition (SMHC) succeed in the post-secondary education environment. These approaches vary according to their setting, location, array of available services, and integration with the mainstream post-secondary education environment. Past researchers have identified ten common core features of SEd programs. Based on our research, all SEd programs involve some combination of these components.

We concluded that SEd is better thought of as a set of services, supports and infrastructures that support the education goals of individuals with SMHCs.

Funding Difficulties
Finding sustained funding is a common theme across our literature review, environmental scan, and site visits. Although multiple funding streams do exist, there does not seem to be a single funding strategy to fund SEd services. Due to the lack of a core funding strategy, programs draw from different funding sources that vary in terms of stability and sustainability. For example, some SEd programs reported that they often partner with colleges or universities for funding, while other respondents mentioned that their programs bill Medicaid to support services wherever possible. We have found that the most feasible funding model for SEd programs is to braid funding from a variety of sources (municipal, federal, state, collegiate, and/or private corporations). Published case studies that demonstrate successful braided funding strategies in support of SEd services could serve as examples that will help program administrators circumvent funding challenges.

Evaluation and Research
Other gaps in the SEd knowledge base include:

- Agreed-upon definitions of SEd programs and goals;
- Knowledge of how to implement SEd; and

Common Components of SEd Programs

1. Specialized staff with a dedicated effort to SEd
2. Counseling for careers and educational goals
3. Facilitating financial aid
4. Skill building for educational success
5. Facilitating educational enrollment and retention including acquiring educational accommodations
6. Information about rights and resources
7. Mental health support
8. Coordination with post-secondary education institutions
9. Accessing supplemental educational supports
10. And providing general supports regarding other non-education specific barriers and life stressors

Investigators at the Transitions Research and Training Center at the University of Massachusetts Medical School partnered with RTI International to conduct the “Feasibility Study for Demonstration of Supported Education to Promote Educational Attainment and Employment among Individuals with Serious Mental Illness”. The study was funded by the Assistant Secretary for Planning and Evaluation (ASPE). This project:

- Examined the state of the science of current SEd programs in the US;
- Identified key considerations that can be used to design studies to validate SEd as evidence-based practice;
- Compiled evidence on SEd programs;
- Identified gaps in the knowledge base about SEd; and
- Looked at possible approaches for addressing unanswered questions about SEd. A final report is available on the Transitions Research and Training Center’s website.
Unanswered research questions related to program outcomes.

Our research demonstrates that while sites collect some data, they need to collect additional data and agree on key outcomes for SEd research projects. Current SEd research and program evaluations lack sufficient rigor or adequate sample sizes.

In order to fully understand educational attainment and employment outcomes, it is essential to conduct SEd studies with data collection time frames of 3 or more years from baseline. Longer follow-up will allow studies to adequately capture longer-term educational degree attainment and ultimately job sustainability outcomes. Few studies on supported education use randomized control-designs, which are essential to understanding the impact of SEd on core outcomes of interest. More rigorous research is needed in order to demonstrate that SEd is an evidence-based practice. A project with an experimental design, including random assignment and a control group, can best position SEd programs for consideration as evidence-based practice.

A Feasibility Study

Data suggest that a demonstration trial showing the efficacy as well as the benefits of SEd is both necessary and feasible. Our study found that SEd programs are well poised to conduct systematic data collection on SEd processes and outcomes. We recommend the use of a two-stage demonstration study:

Stage 1 to prepare fidelity and implementation guides; and

Stage 2 to conduct a multisite randomized control trial with long-term follow-up.

Such a study would assist in generating the potential evidence needed to move SEd from a promising practice to an evidence-based practice, thus encouraging future funding and widespread adoption.

Background

Individuals with SMHC find challenges in educational attainment and employment. More than 50% of students aged 14 or older with a mental health condition drop out of high school, which is the highest dropout rate of any disability group. Students with SMHC also experience low grade point averages (GPAs), poor attendance, and highest course failure and expulsion/suspension rates among all students with disabilities. Individuals with SMHC have a post-high school employment rate of only 50%. Since educational attainment is strongly correlated with employment outcomes, such as unemployment and wage earnings, it is imperative that these students get the support needed for educational success.

To meet the need of students with SMHC, SEd programs have been developed throughout the country. SEd programs aim to help individuals with SMHC succeed in career, educational, and inter-personal development. Each SEd program is unique and little is known about the success of these programs.

Methodology

Three components associated with our project included:

1. A literature review;
2. An environmental scan of SEd researchers, program managers, and other key informants; and
3. Site visits to three programs implementing SEd service delivery models.

Three sites were selected based on geographic location, service setting, and target population in order to demonstrate the difference between SEd programs across the United States. We visited:

- Early Assessment and Support Alliance (EASA). A statewide initiative in Oregon focusing on meeting the needs of young adults experiencing a first episode of schizophrenia-related conditions.
- University of Minnesota. A campus-wide initiative to support the mental health needs of all students.

At each site, discussions were held with department leaders, providers, community partners, and individuals who had participated in SEd programs. Discussions focused on program history, financing, staffing, services, evaluation efforts, successes, and challenges.


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Undocumented college students face several barriers that may place them at high risk of poor mental health. Despite growing up and receiving primary and secondary (K-12) education in the U.S., many undocumented young adults cannot legally work, vote or drive in most states. Their illegal status interferes with their ability to accumulate relevant/practical work experience leading to the inability to develop the necessary job skills before graduating high school, which can limit their employment opportunities.

Several studies indicate undocumented college students experience several psychosocial stressors related to their illegal status. Undocumented students experience high rates of depression, anxiety, loneliness and fear of deportation/detainment.4-5 While twenty U.S. states offer in-state tuition to undocumented college students, restrictive conditions may limit where and when an undocumented student can attend college.6 Navigating the system to receive in-state tuition can also be a major stressor. Undocumented college students often have limited pathways to legal citizenship, which may cause undocumented college students to “fear discovery” and feel separation from their peers.5

The goals of our study are twofold:
- To examine how not having legal citizenship status impacts the mental well-being of undocumented college students; and
- To identify what social supports are in place for college students to alleviate psychological stressors associated with not having legal citizenship status.

The study team is in the process of conducting 25 semi-structured interviews with “1.5 generation” undocumented Hispanic college students who have been in the U.S. since before the age of 15. Starting in the fall of 2016 they began recruiting study participants from colleges in New Jersey and Massachusetts. Recruitment and interviews are conducted in person or via phone.

Having a better understanding of the mental well-being and potential supports for undocumented college student has implications for improving counseling and mental health services on campus for undocumented college students, as well as creating structural supports (e.g., peer networks).
Racial and ethnic minorities, immigrants and refugees are less likely to receive adequate mental health care than native citizens. Considerable research has documented the historical, cultural, and contextual challenges that are unique to immigrant and refugee populations, which create barriers to finding and accessing mental health services. In addition, many immigrants and refugees struggle with the effects of trauma experienced prior to leaving their home country. Findings from a recent study of Worcester, Massachusetts’ providers indicate that immigrants and refugees from Southeast Asian countries, specifically Vietnam, Cambodia, and Laos, often do not recognize symptoms of stress as psychological in origin. This tip sheet is a collaborative effort between the Systems and Psychosocial Advances Research Center at UMass Medical School and the Southeast Asian Coalition of Central Massachusetts, Inc. (SEAC). SEAC was founded in 1999 to address the lack of culturally and linguistically appropriate support services for Southeast Asian Immigrants in Central Massachusetts, which includes Laotians, Cambodians, and Vietnamese. SEAC provides training to mental health providers who work with immigrants and refugees from these countries. SEAC employs Cultural Brokers, who are tasked with linking persons served with mental health professionals as well as facilitating community connections to meet other identified needs. For individuals starting therapy, Cultural Brokers attend initial sessions to support clients and mental health providers to help build trust and educate and address any cultural issues as necessary.

### Be Culturally Sensitive
- Limit physical contact. People from Southeast Asia are often not comfortable with physical contact. Handshaking with a male client may be acceptable, but it may be better to ask before offering a handshake. A small respectful bow is acceptable to all genders. Touching the head is particularly offensive to this population.

### Common mental health conditions experienced by Southeast Asian immigrants/refugees are:
- Depression
- Anxiety
- Post Traumatic Stress Disorder
- Adjustment Disorders

Mental health conditions among individuals from Southeast Asia often present as physical ailments including:
- Headaches
- Sleep Disorders
- Backaches
- Stomach aches
- Digestive disorders

Southeast Asian immigrants/refugees do not talk about mental health conditions easily, as stigma and superstition about mental health and illness are pervasive. Due to cultural beliefs about mental health conditions, fears of stigma, and repercussions to one's family, Southeast Asian immigrants and refugees do not often seek professional help, often resulting in increased symptom severity and decreased functioning. Developing trusting and respectful relationships is critical to best addressing the mental health needs of Southeast Asians. Below are some culturally-informed strategies mental health providers can use to build strong therapeutic alliances with their Southeast Asian clients.

### Be Culturally Sensitive
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• Minimize eye contact. Maintaining consistent eye contact, while valued in American culture, is often considered inappropriate and disrespectful by many Southeast Asian cultures.

• Be mindful of nonverbal communication, such as winking, the “OK” symbol, putting one or both of your hands in your pockets or on your hips while talking. A variety of common gestures that are fine in American culture can be seen as offensive or misinterpreted in Asian cultures and vice versa. For example: the “OK” symbol many Americans make with their fingers is offensive to individuals from Southeast Asian countries. Winking is considered indecent; and putting your hand in your pockets or on your hips shows arrogance and disrespect. In Vietnamese culture smiling shows respect and can convey an apology for a small offense (e.g., being late) or show embarrassment.12

• Acknowledge the importance of family. Traditionally, family is the primary social unit in Southeast Asian culture.7 Each family member has a specific role and position within their family unit,7 and family is usually the first place a person goes for help.13 Due to the importance of family, offering extended family counseling is a way to engage your client in treatment.7

• Recognize that mental health symptoms may be described as physical ailments. Be aware that Southeast Asian clients may have a different way of describing their mental health condition. Unlike Americans who may describe depression as feeling “sad” or “down,” a Southeast Asian client may report somatic issues.

• Use reliable and culturally validated screening and assessment tools (e.g., Hopkins Symptom Checklist and Harvard Trauma Questionnaire).7

Build Trust

• Take your time. This may be the first time your patient has seen a mental health care professional, so don't be in a hurry. You may need to use a long-term supportive treatment approach instead of a time-limited psychotherapy approach.14

• Focus on education. Educate your client about the process of mental health treatment, so they are informed and know what to expect.7

• Be aware of any potential language barriers. A Cultural Broker may accompany your client to the first few sessions and may act as an interpreter. However, there needs to be care with using interpreters, especially family members, as they may have biases about mental health treatment, which can lead to misinterpretation and miscommunication. A professional interpreter, familiar with mental health care is best.

• Be mindful of the impact of authority figures. Health care professionals are often seen as authority figures and many Southeast Asian immigrants/refugees do not want to question or contradict what you are saying, even if they don't understand what you are saying. One strategy to address this, is to ask your clients to repeat back what you have said to them in their own words to confirm that they understand what you’ve said.

• Acknowledge fears about seeking mental health treatment. Explore and acknowledge your client’s feelings about seeking professional help, especially his or her fears and anxieties related to seeking mental health help and treatment.13 This may help reduce your client's discomfort and increase their level of trust in getting treatment.13

• Understand your client’s history. You need to gather information on pre-migration stressors, trauma, refugee
Understanding your client's environment. Find out if your client's basic needs (e.g., housing, food, employment) are being met. If not, work with your client and the Cultural Broker to find assistance.

Treat each client as an individual. Do not assume that all Southeast Asian clients will have the same symptoms and react the same. You should tailor your treatment to each client's unique needs.

Acknowledging the importance of family, culture, traditional medical approaches, and religious beliefs is key to building a trusting relationship with clients. Understanding the cultural context can help you provide more effective treatment.

Medication education may be needed because medication noncompliance is frequent among Asian clients. The reasons for stopping early can be side-effect intolerance; feeling better and thinking they can stop the medication; the medication not working fast enough.

If you want to work with this population, take the time to educate yourself about the Southeast Asian immigrant/refugee subgroup populations. Practicing culturally competent care will encourage your clients to seek out and participate in mental health treatment. Partnering with Cultural Brokers, culturally competent social workers, patient advocates, and organizations like the Southeast Asian Coalition of Central Massachusetts, Inc., can assist you in building a trusting relationship with your new client.
As a parent of a teenager with a disability, you may have heard the term 504 plan or Section 504 before, but not really understood what it means and how it can help your son or daughter. Section 504 is a civil rights federal law that public school districts are required to follow. In this tip sheet, we offer parents and guardians some information on 504 plans.

A 504 plan is...

- Based on Section 504 of the Rehabilitation Act of 1973. This federal Act prohibits the discrimination of students with disabilities in public school systems and ensures these students receive the educational supports they need to succeed in school.

- An education plan which:
  1. Identifies the modifications and/or accommodations needed to remove learning barriers for a student within mainstream education.
  2. Outlines the responsibilities of all stakeholders (e.g. parents, student and school) in removing these learning barriers.

- Not just for academic purposes and can be used for extracurricular activities and athletics.

To qualify for a 504 plan, a student must...

- Generally be between the ages of 3 and 22 (which can vary by program and state/federal laws).

- Have an enduring, documented health-related, learning or behavioral disability which has been evaluated as substantially limiting one or more major life activities (e.g. reading, concentrating, thinking, communicating, etc.).

What are the benefits of a 504 plan?

- Legally requires public schools to provide accommodations and modifications to qualified students with disabilities (including mental health conditions or learning disabilities).

  Examples: Counseling, preferential seating, adjusted class schedules, assistive technology like “smart pens”, voice recorders or computers for taking notes, extended time for assignments, quiet space for test taking, etc.

  Can be helpful throughout your student’s lifetime as evidence of having a disability in order to qualify for some disability services (e.g. housing, transportation, vocational rehabilitation, Social Security determination).

What is the difference between a 504 Plan and an Individualized Education Plan (IEP)?

<table>
<thead>
<tr>
<th>504 Plan</th>
<th>IEP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Students who do not qualify for special education services under IDEA, but who have an ongoing, documented disability that have been evaluated as requiring accommodations to succeed in school, as provided by the Rehab. Act of 1973.</td>
<td>Students with one or more disabilities outlined within the Individuals with Disabilities Education Act (IDEA) who have been evaluated as needing special education services.</td>
</tr>
<tr>
<td>A 504 plan does not have to be a written document and is less comprehensive than an IEP. No due process is outlined in Section 504 legislation – schools districts are left to define this for themselves.</td>
<td>An IEP must be a formal, written document. It must meet many due process requirements by law (i.e. detailed plans and timelines for the evaluation, specialized instruction, and educational services of a student, etc.). An IEP has many procedural safeguards and rights.</td>
</tr>
<tr>
<td>Students with 504 plans receive accommodations and/or modifications to curricula in a mainstream classroom.</td>
<td>Students with IEPS may receive specialized instruction and other educational services in a mainstream classroom or special education classroom depending on their needs.</td>
</tr>
</tbody>
</table>
Should my student ever get a 504 plan instead of an IEP plan, or get both?

- If a student’s disability does not impair them enough to need specialized education services then a 504 may be obtained (if the student is qualified) instead of an IEP.
- In most cases it is not necessary to have both an IEP and a 504 plan while in school. Get a 504 plan if your teen doesn’t qualify for, or doesn’t want, special education services.
- Because some students may perceive special education services as stigmatizing, getting a 504 plan is an alternate way to acquire necessary accommodations.

How can my teen get a 504 plan in high school (or earlier)?

- A 504 plan evaluation process may be started by a parent/guardian or the school. If you believe your teen is qualified, you should ask your teen’s school to provide a 504 plan.
- To get a 504 plan, your teen must be evaluated to see if he or she is deemed to have a qualified disability. This evaluation process includes:
  - Documentation of the disability (such as a doctor’s diagnosis),
  - Evaluation results (if the student was recently evaluated for an IEP),
  - Observations by the student’s parents and teachers,
  - Academic record, and
  - Any independent evaluations (if available).
- If your teen has a qualified disability, a 504 plan can be created and implemented by a 504 committee. This committee may include the teen, their parents, teachers, and school administrators.
- Parents and students should check in with the school about the 504 plan as updates are not required by law.

Can my teen use their 504 plan in college?

- Neither a 504 plan nor a high school IEP apply directly to college; but either can be helpful.
- To get accommodations in college, students must apply to student disability services. The accommodations described in a high school 504 plan can help a student advocate for their needs with student disability services in college.
- It is important to note that colleges are not required to provide accommodations just because a student had a high school 504 plan or an IEP.
- A student can still apply for and receive accommodations in college even if they didn’t have an IEP or 504 Plan in high school. Colleges are required to provide accommodations to students with a disability who qualify for them under the Americans with Disabilities Act.

References


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This publication can be made available in alternative formats upon request.
OVERVIEW

The Workforce Innovation and Opportunity Act (WIOA) became law on 7/22/2014, the final regulations governing it published on August 19, 2016. The majority of the relevant areas covered in this brief will focus on the issues related to disability, for which generally state agencies of vocational rehabilitation (VR) have specific responsibilities. Nevertheless, the workforce system as a whole has a mandate under this law to be accessible to all people with disabilities, including those with mental health challenges.

The U.S. Department of Labor (DOL) envisions WIOA as a governmental commitment to providing high quality, continuous, and seamlessly delivered services for youth and young adults beginning with career exploration and guidance, continued support for educational attainment, opportunities for skills training in in-demand industries and occupations, and culminating with a good job along a career pathway or enrollment in post-secondary education. DOL’s vision, endorsed by the Rehabilitation Services Administration, is that WIOA is quality-focused, employer-driven, customer-centered, and tailored to meet the needs of regional economies. It is designed to increase access to and opportunities for the employment, education, training, and support services that individuals need to succeed in the labor market, particularly those with barriers to employment.

WIOA implements the Department of Labor’s model for the entire workforce system and VR for adults and youth. Many sections are specific to students and to youth with disabilities. Though none pertain specifically to youth with significant psychiatric disabilities there are many areas that providers, advocates, family, members, and youth themselves should be aware of as avenues for possible employment related services and interventions. This brief will highlight some of the key topics to consider. A listing of resources for those seeking more information can be found at the end of this report.

REQUIREMENTS IN THE LAW

Title IV of the Act gives specific definitions of both student and youth with a disability in a secondary, postsecondary, or other recognized education program who meets the age requirement for the provision of transition services in the state, is eligible for, or receiving, special education related services under IDEA or is a student who is an individual with a disability for purposes of Section 504 of the Rehabilitation Act of 1973. The term “student with a disability” in the law refers to an individual with a disability who meets the age requirement for the provision of transition services in the state, is receiving special education services under an IEP or is a Section 504 eligible student who may not be under a school based IEP. The term “youth with a disability” refers to anyone with a disability aged 14 to 24, regardless of whether they are in school. There are areas of the law where “significant disability” or “most significant disability” come into play. These are technical terms referring to both the number of functional life areas a person’s disability interferes with and the potential need for vocational rehabilitation services. Specifics of who is covered by them vary slightly from state to state.

Within Title I of WIOA, there are further technical distinctions related to “in school” and “out of school”
youth. Out of school youth dovetails with the definition of “youth with a disability” except the minimum age set is 16 due to school drop-out laws. The simple formulation to keep in mind is that all students with disabilities are “youth”, but not all youth with disabilities are “students” under these definitions.

Workforce systems are required to spend at least 75% of their youth funding for services for out of school youth. Out of school youth, whether meeting the definition of disability or not, are exempt from the financial necessity requirements that other youth participants must meet if they are in one or more of “high-risk” categories including:

- school dropouts;
- individuals who are within the age of compulsory attendance but have not attended school for at least one calendar quarter of the most recent complete school year;
- individuals subject to the juvenile or adult justice systems;
- homeless individuals;
- runaways;
- current and former foster care or out-of-home placement youth;
- youth in poverty areas; and
- individuals who are pregnant or parenting.

**Key Areas for Youth and Young Adults to Explore**

Some key areas for youth and young adults to explore with their local VR agency and/or One Stop Career Center (called American Job Centers):

- The law expects the VR system to help with transition related activities for students with disabilities (called Pre-Employment Transition Services or PETS in the law) who are already VR eligible or potentially eligible (which could cover almost any student with a serious mental health disability).
- WIOA specifies the need for multi-agency coordination to plan for and deliver employment services among various systems including workforce, VR, the public educational system, education providers, and disability systems such as mental health.
- There are specific requirements within the law for VR agencies to commit certain minimum proportions of federal funding that they receive to PETS or Supported Employment services for youth with the most significant disabilities.
- With funds targeted for Supported Employment with youth with the most significant disabilities, states may provide extended services, for a period up to four years. Prior to the enactment of WIOA, these extended services were not permitted under either the VR program or the Supported Employment program.

**Specific Issues Relevant to Youth and Young Adults with SMHC**

PETS must include at a minimum the following, with other related yet optional services as possibilities:

1. Job exploration counseling
2. Work-based learning experiences, which may include in-school or after school opportunities, or experience outside the traditional school setting (including internships)
3. Counseling on opportunities for enrollment in comprehensive transition services or post-secondary education programs
4. Workplace readiness training to develop social skills and independent living
5. Instruction in self-advocacy, which may include peer mentoring.

- There is an expectation within WIOA that both PETS and any other employment services for youth and students with disabilities must focus on integrated competitive employment situations or one in which the person is working on a short-term basis toward competitive integrated employment. The law strongly discourages and in most cases prohibits focus on segregated or sheltered settings and/or ones in which subminimum wages are paid.
• There are many areas of the new law that specify services for youth and young adults with and without disabilities. It is important for youth and their advocates to contact both their VR and Workforce systems (One Stop Career Centers/ American Job Centers) to ask how they will use these to support employment related services for youth and young adults with SMHC. Often youth with mental illness are not readily acknowledged as being part of this group in comparison to youth with disabilities that tend to elicit more overt public sympathy such as those with intellectual/developmental disabilities or serious physical impairments. Therefore, advocacy for service access may need to be a significant priority for consumers, families, and advocates seeking assistance under WIOA authority.

• WIOA emphasizes the need for a variety of real life work experiences (“work based learning”) for students in school as part of transition planning and programming. This focus should include youth with mental health needs still in school under an IEP or a 504 plan.

• Section 511 of WIOA puts significant restrictions on the use of subminimum wage unless certain specified activities take place first, generally including referral to VR. VR must apply stringent criteria before supporting the use of subminimum wages when these youth are employed. As a practical matter, youth, young adults, and their advocates should assume that any employment will be at minimum or local prevailing wage for the position and strenuously oppose any attempt to apply the sub minimum wage exemption to their situation.

• The regular workforce system (represented in the structure of One Stop Career Centers or American Job Centers) has an obligation to ensure “programmatic” as well as physical accessibility for all its services including those targeted for youth. Thus, youth with SMHC and their advocates should work with their local centers to identify the accommodations needed to ensure these programs meet the needs of youth with serious mental health barriers.

• Many youth services specified under WIOA require falling below a threshold of low income eligibility. However, many youth and young adults with mental health problems who may not have been formally identified as being a youth with a “disability” would be exempt from this requirement because they may often meet one of the “high risk” categories definitions.

• There are several minimum percentage of funding requirements for workforce system general youth services and VR transition services for students with disabilities including those with SMHC. These requirements relate to making sure such services are work based and employment enhancing (e.g., internships, work shadowing, summer work experience).

• VR agencies are encouraged to work with the local educational agencies and state educational agencies to develop a process so that individuals expressing interest in VR services are able to access the program and apply for services through a referral process that is simple and engaging, not burdened by overly complex and time consuming procedures.

• The “teeth” of this and most laws are in the implementing regulations which the Department of Labor issued on August 19, 2016. So youth and their advocates should make sure they are informed about these regulations and become familiar with these regulatory procedures. Most of these VR regulations are already in effect and some for the workforce system as a whole may not be operative until January 1, 2017.

Measures of Accountability & Success

WIOA includes common measures of accountability across the entire workforce system, including VR agencies. There are 6 common measures that must be adhered to, specific to educational issues that affect youth. These common measures in the law are:

1. The percentage of participants, who are in unsubsidized employment during the second quarter after exit from the program;
2. The percentage of participants, who are in unsubsidized employment during the fourth quarter after exit from the program;
3. Median earnings of participants, who are in unsubsidized employment during the second quarter after exit from the program;
4. The percentage of participants who obtained a recognized post-secondary credential or a secondary school diploma, or its recognized equivalent during participation in or within one year after exit from the program. A participant who has obtained a secondary school diploma or its recognized equivalent is only included in this measure if the participant is also employed or is enrolled in an education or training program leading to a recognized post-secondary credential within one year from program exit;

5. The percentage of participants who during a program year, are in an education or training program that leads to a recognized post-secondary credential or employment and who are achieving measurable skill gains, defined as documented academic, technical, occupational or other forms of progress, towards such a credential or employment; and

6. Effectiveness in serving employers. (AUTHOR’S NOTE: These include data regarding factors like "repeat business" or penetration rate of interactions into the total number of employers within a region or types of employer related service delivered).

RESOURCE MATERIALS:


8. Notices and information about the final regulations can be found at: https://www.gpo.gov/fdsys/pkg/FR-2016-08-19/pdf/2016-15980.pdf


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New SPARC Publications


evidence for the clubhouse model of psychosocial rehabilitation. *Administration and Policy in Mental Health and Mental Health Services Research*. Advance online publication. doi:10.1007/s10488-016-0760-3


Appendix D

New SPARC Faculty and Staff

New SPARC Faculty

**Sheldon Benjamin, M.D.** is Professor of Psychiatry and Neurology at the University of Massachusetts Medical School (UMMS), where he has served as Director of Neuropsychiatry since joining the faculty in 1986. He is currently the Interim Chair of Psychiatry, and is the Director of the Combined Neurology/Psychiatry Residency Program. Dr. Benjamin is board certified in both psychiatry and neurology by the American Board of Psychiatry and Neurology (ABPN) and is certified in Behavioral Neurology/Neuropsychiatry by the United Council on Neurological Subspecialties.

He served as President of the American Association of Directors of Psychiatry Residency Training (AAD-PRT) in 2010-2011, and President of the American Neuropsychiatric Association from 2013-2015. He is a Distinguished Life Fellow of the American Psychiatric Association, a Fellow of the American Academy of Neurology and a Fellow of the American Neuropsychiatric Association.

A specialist in the evaluation of behavioral problems at the interface of psychiatry and neurology, his interests include neuropsychiatric problems in movement disorders, seizure disorders, dementia, traumatic brain injury, developmental disability, as well as neurobehavioral issues in general psychiatric disorders and bedside neurocognitive assessment. He teaches clinical neuroscience and neuropsychiatry and; has published and presented widely on neuropsychiatry, clinical neuroscience training of psychiatrists; educational technology; and residency training issues. He is co-author of *The Brain Card®,* a guide to comprehensive bedside neuropsychiatric examination, and is one of the authors of the ACGME-ABPN Psychiatry Milestones.

New SPARC Staff

**Teresa Conrado, C.B.C.S.** is an Administrative Assistant for SPARC and the Transitions ACR. Teresa assists in all areas within SPARC with various administrative duties.

**Shelley Grover, M.B.A.** is a Social Media Specialist for SPARC. Shelley focuses on knowledge translation and dissemination activities, and developing and overseeing all social media efforts.

**Marcela Hayes, B.A., B.S.** is a Research Project Director who leads various research projects focused on adapting and testing supported employment and education models to improve the mental and behavioral health of individuals across their lifespan. Marcela oversees the translations of Transitions ACR tip sheets into Spanish and is working to develop a Family Advisory Board at SPARC.
Raphael Mizrahi, B.S. is a Research Coordinator who works on the Triangle study, and the Let’s Talk about Parenting study. He also provides technical assistance to the Delaware Youth Council organization and co-facilitates the Youth Advisory Board.

Emma Pici-D’Ottavio, B.A. is a Research Coordinator who works on several research projects including the Sequences of Education and Employment (SEED) Research Study and the Deaf ACCESS Research project. Emma’s research interests include community-based research, therapeutic interventions, and peer support approaches for youth and young adults.

Wiktor Wisniewski, B.A. is a Research Project Director who is currently working with Maryann Davis on her randomized control trial *Effectiveness Trial of Treatment to Reduce Serious Antisocial Behavior in Emerging Adults with Mental Illness.*