The role of the family advocacy team in sustaining supported employment

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Abstract

BACKGROUND: The Individual Placement and Support (IPS) Learning Community was established in 2002 to increase access to Individual Placement and Support (IPS) supported employment. In 2008, learning community leaders launched the Family Advocacy Project to advance the role of families in providing education and advocacy for IPS.

OBJECTIVE: This paper describes the perspective of the Family Advocacy Project leaders in understanding the sustainment of IPS services.

METHODS: Representatives from ten family teams were interviewed by phone using a structured protocol.

RESULTS: Most of the state family advocacy teams were part of the National Alliance on Mental Illness and included people other than family members. Education and advocacy were reported as the main goals of the teams. Facilitators and barriers to advocacy were described.

CONCLUSION: The state family advocacy teams though small in numbers place a clear focus on advocacy and education activities that may impact the sustainment of IPS.

Keywords: Supported employment, role of families, individualized placement and support

1. Introduction

IPS is an evidence-based practice for helping people with severe mental disorders gain and retain competitive employment (Bond & Drake, 2014; Luciano et al., 2014). Numerous reviews have concluded IPS participants have higher rates of competitive employment, fewer days to the first competitive job, more hours and weeks worked, and higher wages (Druss, 2014; Marshall et al., 2014). There is also a growing literature exploring the cost-effectiveness of IPS compared with traditional vocational services, which has favored IPS (Marino & Dixon, 2014).

In 2001, Dartmouth Psychiatric Research Center partnered with Johnson & Johnson Office of Corporate Contributions to help state leaders develop the state and local infrastructures to increase access to IPS (Becker, Drake & Bond, 2014). Starting with three states, the program evolved into a large network known as the IPS Learning Community. In the United States, the IPS Learning Community is administered in each participating state or jurisdiction through the collaboration between the state mental health authority and the state vocational rehabilitation administration. Currently, the IPS Learning Community includes 22 states or jurisdictions (i.e., 20 states, the District of Columbia, and Alameda County, California). In addition, three European countries (Italy, Netherlands and Spain) have joined. The IPS Employment Center oversees the program and provides ongoing technical assistance and consultation on IPS.

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Through a two-tiered approach the IPS Employment Center connects with the state mental health authority and state vocational rehabilitation leaders to plan, implement, and monitor IPS in a sustainable way, and expand the number of sites within states and regions. The IPS Employment Center convenes an annual meeting of state leaders to form relationships, exchange information, and strengthen partnerships. During the year through frequent teleconferences, the leaders discuss current challenges, new ideas, and strategies for IPS implementation and dissemination. As part of the IPS learning community, state leaders collect simple outcome data from all participating local sites in their state. The IPS Employment Center summarizes and shares the outcomes with the state leaders to make comparisons with other states, set outcome goals, and determine training and technical assistance needs. In addition, states and sites in the learning community volunteer to participate in research projects to further knowledge regarding employment and education as part of recovery from behavioral health disorders. For example, state leaders and site IPS supervisors completed interviews in a three-year study to investigate the sustainability of programs in the IPS learning community.

Recognizing families as an important stakeholder group for IPS, the learning community leaders established state family advocacy teams to work with other stakeholders, focusing on education and advocacy (Cohen & Becker, 2014). The state family advocacy teams are viewed as having an important role in changing public policy by increasing access to evidence-based supported employment services and promoting high quality services at the local level through partnership with state mental health and vocational rehabilitation agencies (Cohen & Becker, 2014).

This paper presents the findings obtained from telephone surveys of family advocacy team leaders in the US, aimed at understanding the barriers and facilitators of the sustainment of IPS programs in states participating in the learning collaborative, as seen from the perspective of family advocates.

2. Method

Interviews with family team leaders were a part of a larger study that examined the sustainability of IPS over a two-year period with programs in the IPS Learning Community in the U.S. (Bond et al., 2016). In the parent study, the research team interviewed 129 IPS program leaders in 13 states, and found that over a 2-year period 96% of the IPS teams were sustained (Bond et al., 2016). The most commonly reported barriers to sustainment were agency prioritization, local community factors, and workforce issues, while most commonly reported facilitators were funding, agency prioritization, and leadership (Noel et al., 2017). The current report aims at gaining the perspective of an additional important stakeholder group.

2.1. Sample

In 2013, 12 of the 13 states that had joined the IPS learning community in 2012 or earlier had established state family advocacy teams. We contacted the leaders of each of the state family advocacy teams and invited them to participate in the study. Ten (87%) of the 12 leaders agreed to participate. Both of the nonparticipating teams consisted of a single family member.

2.2. Survey methodology

An experienced-and-trained interviewer conducted telephone interviews based on a survey developed for this project. The survey included both open- and closed-ended questions. Closed-ended questions using Likert type scales included questions on the subject of team makeup (e.g., size and composition), and others concerning the quality of the team relationships with other partners in the learning community. Open-ended questions focused on factors critical to sustaining IPS (facilitators), factors working against sustaining IPS (barriers), and team goals.

2.3. Data analysis

Quantitative data were summarized using descriptive statistics. For the open-ended questions, we used thematic analysis (Clarke & Braun, 2006), following the recommended stages, which include familiarization with data, coding, searching for themes, reviewing themes, and defining and naming themes (Clarke & Braun, 2016). The verbatim responses for each of the open-ended questions were reviewed separately. After repeated review of the data, 15 codes were developed, based on patterns noted in the responses. A codebook was developed, with categorization rules for all 15 codes that were identified and then grouped into seven cohesive and discrete themes.
3. Results

3.1. Family advocacy team composition and structure

The state family advocacy teams had been in existence for an average of four years, although respondents indicated that they had been advocating for IPS and/or had been part of the IPS learning community for an average of 5.5 years (SD = 3.3), because many respondents had previously been in advocacy roles, workgroups or both before the teams were started. Team leaders reported an average of 4.8 family members on the team (SD = 2.8) at the time of the interview. Seven of the ten teams indicated that people other than family members were part of the team, including mental health service recipients, an IPS trainer, or State Mental Health Authority (SMHA) staff. Nine of ten respondents indicated that the teams were part of the National Alliance on Mental Illness (NAMI).

Three of the ten teams (33%) met as a group at least monthly, and reported having monthly contact with the mental health authority, vocational rehabilitation liaison, and IPS trainer. Two teams reported weekly contact with the IPS trainer (20%).

All ten respondents identified education and advocacy as the two main goals for their family advocacy teams. Respondents indicated that family teams offered trainings and presentations on the value of IPS, and the value of work on recovery, through an already existing program, such as NAMI’s Family-to-Family course. Other educational efforts included educating families and consumers (other stakeholders) about supported employment and its recovery benefits. The educational tools included newsletters and IPS presentations during family meetings.

All family teams reported that advocacy for IPS funding was a central goal. Strategies to accomplish this goal included educating legislators on key funding committees about IPS and directly advocating to the legislature for either continued funding or expanded funding for IPS services. In describing advocacy efforts, respondents often referred to “marketing strategies” (e.g., writing about IPS in newsletters, publicizing success stories in newsletters, and sharing information about IPS at health fairs).

Perceived facilitators and barriers to sustaining IPS are reported in Table 1, which depicts the frequency of responses by category and code. Respondents indicated that buy-in through the state mental health authority is an important facilitator to sustain IPS, along with stakeholder education. Workforce training and technical assistance were also viewed as important facilitators. A committed strong state IPS trainer was essential; and mentioned as important was the availability of training and technical support to prepare a qualified IPS workforce.

Perceived barriers to sustaining IPS included funding, specifically payment mechanisms and prioritizing IPS. Some respondents indicated that state funding structures and processes were barriers. For example, no reimbursement for job development was sometimes mentioned as a barrier. Many indicated limited funding, recent funding restrictions, as well as uncertainty related to continued funding as additional barriers.

4. Discussion

Respondents stated that the main activities of the state family advocacy teams were advocacy and education for IPS services. State family advocacy teams can play an important role by lobbying their state legislators for increased IPS funding (Cohen & Becker 2014). For example, a state family team arranged a legislative hearing that included testimony about the importance of work for people with serious mental illness that resulted in increased funding for IPS (Minnesota). Other state family teams have addressed issues of educating family members about the benefits of IPS and employment by revising a chapter of the NAMI education curriculum (Illinois), developing mass media strategies with public service announcements (Oregon), and educating families about the impact of working on entitlements through a training curriculum (Maryland) (Cohen & Becker 2014). Family advocacy team leaders indicated that a strong committed state trainer is an important factor in sustaining the IPS workforce, making the funding for this resource an important focus of education and advocacy efforts.

The state family advocacy teams provide education to family members through NAMI programs, including the NAMI Family-to-Family education program, as well as other venues potentially important avenues for increasing the degree to which family members are united in promoting IPS. Awareness of IPS is an important precursor to its use and advocacy. A pilot evaluation might examine what information is provided, what questions or concerns are raised by
### Table 1
Factors characterizing efforts to launch IPS using family advocacy

<table>
<thead>
<tr>
<th>Factors</th>
<th>Dimensions</th>
<th>Concepts</th>
<th>Facilitators</th>
<th>Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency Relationship</td>
<td>Multiple Agencies</td>
<td>Quality of relationships between multiple state offices or other institutions or both.</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Buy-in</td>
<td>Department of Mental Health</td>
<td>State’s Department of Mental Health employee attitude toward IPS program.</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Provider</td>
<td>Provider employee attitude toward IPS program.</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Vocational Rehabilitation</td>
<td>VocRehab employee attitude toward IPS program.</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Family/Stakeholder</td>
<td>Involvement</td>
<td>Family and stakeholder groups are or are not actively involved in IPS initiative.</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>Marketing or education is or is not used to promote IPS initiative (includes outreach).</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Funding</td>
<td>Family Advocacy</td>
<td>Funding mechanisms for family-advocacy programs.</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Payment Mechanism</td>
<td>Navigating funding or billing systems involved with reimbursement.</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Reinforcement</td>
<td>Outcome Monitoring</td>
<td>Data and progress monitoring</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Supported Employment</td>
<td>Job Availability</td>
<td>Job market is thought to effect the success of Supported Employment</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>State Policies</td>
<td>State policies are mentioned more generally (e.g. not being structurally adequate) in reference to Supported Employment.</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Prioritization</td>
<td>Determining the order of dealing with tasks related to IPS</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Understanding</td>
<td>Clients’ understanding of the functions of the Supported Employment program.</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Work Force</td>
<td>Staffing AdequaScy</td>
<td>Staff quality or availability.</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Training/TA Provision</td>
<td>Trainer and Teaching Assistant (TA) quality or availability.</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

family members, and what they learn from the training sessions. Such a project could lead to standardized education tools to benefit family members and service users alike.

Vocational rehabilitation (VR) has the potential not only to support access to IPS but to add revenue for IPS services. Because VR counselors receive training on the subject of disabilities, are aware of different types of jobs, for themselves and the disabled, and often have information on how many employers in their area, they bring expertise to the IPS team. VR participation in IPS delivery is sufficiently important that is incorporated in a written standardized instruction and is assessed during program-level IPS fidelity evaluations. The relationship between VR and IPS providers varies by state, based on the interviews conducted, although it is likely that relationships vary by locality as well. Family advocacy teams could ask to participate in training VR counselors about IPS, in order to share their stories and explain how proper collaboration helps their family members.

The family advocacy teams are small and seem slow to develop, suggesting a possible need for additional support to strengthen their efforts and partnerships. Team members are volunteers with full time jobs or other responsibilities, so they represent a limited resource. Some teams indicated a need to foster and develop their relationships with IPS providers and VR, which would enable them to combine forces effectively in sustainability efforts. Strengthening stakeholder partnerships is key. Participating in local and state steering committees is one mechanism to build partnerships. Presenting success stories at annual meetings and legislative hearings is an additional possibility.

The state family advocacy teams could organize their efforts to educate and advocate for IPS funding (and IPS trainer funding) embedded in the federal-state block grant process for funding mental health services. Although the family team leader perceptions were not corroborated through interviews with other stakeholders, nor through gathering concrete evidence of changes effected, they did indicate their belief that families can and do play an important role in increasing access to IPS. Since many family members are affiliated with NAMI, some of these activities could be built into the work of local NAMI chapters and NAMI National.
5. Conclusions

The key goals of state family advocacy teams are education and advocacy related to sustaining IPS and addressing barriers to funding and access to IPS. The teams see themselves as playing an important role in local and national advocacy efforts to secure funding for IPS programs.

Future research should document system and funding changes resulting from the leadership from the state family advocacy teams in regards to their goals of systems advocacy, educating families, and marketing of IPS to key stakeholders and the general behavioral health community. Support may be needed for state family advocacy teams to identify, share, and use tools to build local networks and implement strategies to expand access and funding for IPS.

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Conflict of interest

The authors have no conflict of interest to report.

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