Family & Individual Empowerment: The Midwest Advocacy Project

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Disclosure

Relevant Financial Relationship(s)
None

Off Label Usage
None
Objective

• Describe the Midwest Advocacy Project (MAP), related research findings, and implications for advocacy organizations and those they serve.
Mayo Clinic’s TBI Model System Center
Continuous NIDRR-funded research center since 1998
Midwest Advocacy Project (MAP)

- Test whether a curriculum-based approach to advocacy training improves advocacy behavior when compared to a matched group engaged in self-directed advocacy activities.
- Arose from Mayo TBI Regional Advisory Council with BIA and other community members and people affected by TBI.
- “Get out of the hospital and into the real world”
- “Community-based research with results we can apply sooner vs. later”
MAP Hypotheses

Programmed advocacy training will:

1. Demonstrate better advocacy skills
2. Lead to greater advocacy activity, behavior, perceived self-control
3. Increase media attention, policy, regulation, legislative activity
MAP Study Design

- **Design:** Community-based randomized practical behavioral trial
- **Partners:** BIA’s in MN, IA, WI
- **Participants:** Individuals with TBI, family who met inclusion criteria
- **Randomize:** Curriculum *versus* self-directed
- **Frequency:** One day/month x 4 months
Midwest Advocacy Project

MIDWEST ADVOCACY PROJECT: Randomized Practical Behavioral Trial, 2007-12
Curriculum Group

• Facilitated by BIA staff in each state, consistent format/materials, some state specific information

• Based on BIA-MN pilot work
  - Pre-2005: “Realize Your Power”

• Guest speakers, homework

• 6 hour sessions with breaks, structured
Curriculum Group

• Assist participants to:
  • Gain necessary skills to access services, funding, other supports
  • Gain skills needed to increase self and community awareness about TBI
  • Initiate and track service and policy changes that influence their lives
  • Improve ability to obtain full access to community life and successful living
## Curriculum Content

<table>
<thead>
<tr>
<th>Sess.</th>
<th>Curriculum elements</th>
</tr>
</thead>
</table>
| #1    | • Introduction to BIA, Mayo Clinic  
          TBIMS  
          Insights from past trainees  
          History of advocacy disability  
          Brain Injury Basics  
          Process of systems advocacy  
          Setting advocacy goals  
          Homework - visit a service provider |

| #2    | • Homework review  
          Long term supports  
          Fighting for your rights  
          Appeals and conciliation process  
          Community Organizing 101  
          Organizing strategies and tactics  
          Advocacy within medical systems  
          Advocacy within insurance systems  
          Homework – attend local meeting |
## Curriculum Content

<table>
<thead>
<tr>
<th>#3</th>
<th>#4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homework review</td>
<td>Homework review</td>
</tr>
<tr>
<td>State budget process overview</td>
<td>Advocacy skill tracking system</td>
</tr>
<tr>
<td>How a bill becomes a law</td>
<td>(post cards)</td>
</tr>
<tr>
<td>Small groups - prepare mock hearing testimonies</td>
<td>TBI legislative issues (healthcare, special education)</td>
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<tr>
<td>Candidate forum discussions</td>
<td>Tour of Capitol and state office building</td>
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<tr>
<td>Elections, voter registration</td>
<td>Policy maker panel</td>
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<tr>
<td>Generating media interest</td>
<td>Mock hearings with state legislators and feedback</td>
</tr>
<tr>
<td>IEP plans, County services, coalitions/collaborations</td>
<td>Graduation ceremony and evaluations</td>
</tr>
<tr>
<td>Homework - host a legislative forum</td>
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Self-directed Group

• “Usual” condition = **support group** (commonly offered by BIAs and other advocacy organizations)

• Met same number of hours/days in same locale

• Provided with an overview of study, internet service, basic resources

• Goal to “become better advocates”

• Mayo study staff helped group elect a leader, thereafter only reiterated study goal
Subjects in both Groups

• Recruitment approach consistent across states
• Randomized after recruited
• Person with brain injury/family randomized together
• Research remuneration provided to each subject
• Travel expenses reimbursed if lived 60+ miles from training locale
MAP Study Design

- **Primary outcome measure:** Pre-post letter and video rated via the *Advocacy Behavior Rating Scale (ABRS)*

- **Secondary outcome measures:**
  - Advocacy Activities Scale (AAS), Perceived Control Scale–Brain Injury (PCS-BI), CHIEF, SF-12, Satisfaction With Life Scale
Data Collection

• Collected before 1\textsuperscript{st} session, end of 4\textsuperscript{th} session

• 2 behavioral assessments
  • \textbf{Write} a letter to a provider, policy maker, other authority regarding an issue of personal concern for which they wanted to advocate for change
  • \textbf{Speak} for up to 5 minutes (video-recorded) about the same issue to a mock authority
Data Collection

• 5 questionnaires
  • Baseline advocacy behavior, perceived control/efficacy related to advocacy, perception of environmental barriers, quality of life, satisfaction with life

• Post card follow-up
  • Mailed quarterly for duration of the grant to subjects in both groups to track participation in advocacy activities
Advocacy Behavior Rating Scale (ABRS)

1. **Clarity** (Communication is easy to understand and relevant to the primary message)
2. **Cogency** (Facts and logic are used to support opinion)
3. Passion (Personal stories, anecdotes and feelings are offered to support opinion)
4. **Appropriateness** (Feelings and opinions are expressed without being offensive and without personal attacks)
5. **Potential Effectiveness** (Likelihood that the presentation would make an impression and be remembered by the person receiving the communication)

0 - Absent/poor, 1 – Fair, 2- Good, 3 - Very Good, 4 – Excellent

Total Score 0 to 20
<table>
<thead>
<tr>
<th>Variable</th>
<th>Curriculum (N=129)</th>
<th>Self-Directed (N=128)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>48.3 (21.2, 77.5)</td>
<td>47.2 (19.9, 86.4)</td>
</tr>
<tr>
<td>Male</td>
<td>51 (40%)</td>
<td>46 (36%)</td>
</tr>
<tr>
<td>Female</td>
<td>78 (60%)</td>
<td>82 (64%)</td>
</tr>
<tr>
<td>Minnesota</td>
<td>47 (36%)</td>
<td>46 (36%)</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>41 (32%)</td>
<td>41 (32%)</td>
</tr>
<tr>
<td>Iowa</td>
<td>41 (32%)</td>
<td>41 (32%)</td>
</tr>
<tr>
<td>Patient</td>
<td>69 (53%)</td>
<td>75 (59%)</td>
</tr>
<tr>
<td>Family member</td>
<td>60 (47%)</td>
<td>53 (41%)</td>
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# Comparison of Treatment Groups

**Persons + family** p-value (two sample t-test)
- Letter: 0.4447
- Video: 0.9357

**Persons with brain injury only**
- Letter: 0.9838
- Video: 0.8259

**Family members only**
- Letter: 0.1290
- Video: 0.9874

**Persons with brain injury, regardless of treatment group**
- Letter: 0.0713
- Video: 0.3673
% Participants improving by 3+ points on ABRS from pre- to post-

Letters

Survivors - curriculum
Survivors - self directed
Family - curriculum
Family - self directed

MIDWEST ADVOCACY PROJECT: Randomized Practical Behavioral Trial, 2007-12
% Participants improving by 3+ points on ABRS from pre- to post-

Videos

- Survivors - curriculum
- Survivors - self directed
- Family - curriculum
- Family - self directed

Percentage

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Post cards
(130 of 215 responded)

- Arranged for a helmet fair, bike rodeo or other safety event
- Involved in other injury prevention activities
Post cards

- Wrote a letter to the editor of a newsletter: 20%
- Gave an interview to the media: 10%
- Wrote an article for a paper or journal: 10%
Post cards

- Attended a public meeting or rally: 50%
- Spoke at a public forum: 30%
- Arranged/hosted a legislative home visit: 10%
Personally visited an elected official or public employee
Summary of Findings

• “No difference between treatment conditions in advocacy behavior.” AKA *curriculum no better than self-directed*

• “Clear improvement in ratings of advocacy behavior for family members regardless of treatment condition.” AKA *families improved more than individuals with TBI*

• Any kind of intervention improved letter writing
Summary of Findings

• High levels of some advocacy activities on follow-up assessment (e.g. contacting public officials)

• Limitations – motivated group, self selected, those with brain injury not clinically evaluated, anxiety related to behavioral measures, ABRS may lack sensitivity to change
MAP Conclusions

• Which curriculum is taught in advocacy training may not be important

• Having people with advocacy interests come together with intent to improve related skills can result in such

• In other words…. *bringing together motivated individuals most important*
MAP Conclusions

- Consider alternative methods for improving advocacy skills among individuals with TBI
- Likely need to make adjustments/accommodations during training based on level of cognitive functioning

- MIDWEST ADVOCACY PROJECT: Randomized Practical Behavioral Trial, 2007-12
MAP Dissemination


- In preparation: Second manuscript focused on secondary outcome measures
Applications?

- *Brain Injury Alliance of Iowa has deployed Advocacy training for many years (as have many other advocacy organizations).*
Applications?

- If bringing together motivated individuals most important...

- Then LESS curriculum and MORE focus on creation of a comfortable space for natural leadership to emerge (in Iowa this includes coffee and rolls).
Applications?

- Challenge is still to come together at the PLOC (political level of concern) to bring a prioritized message.
- Seems to be a place for a facilitator to navigate local, regional, and interdisciplinary differences to get to:
  - “One Voice”