

Advisors to Self-Advocacy Groups



A REVIEW OF CURRENT LITERATURE

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What is Self-Advocacy?

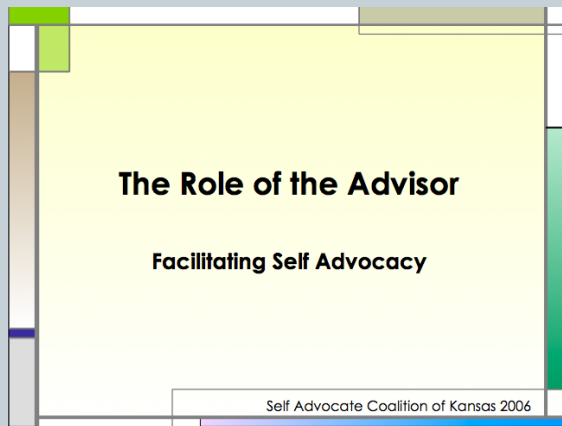


- According to Self-Advocates Becoming Empowered (SABE), self-advocacy...
 - “...is about independent groups of people with disabilities **working together for justice** by helping each other **take charge** of their lives and fight discrimination. It teaches us how to make **decisions** and **choices** that affect our lives so we can be more **independent**. It teaches us about our **rights**, but along with learning about our rights, we learn **responsibilities**. The way we learn about advocating for ourselves is by **supporting each other** and helping each other to gain **confidence** to **speak out** for what we believe in.” (Dybwad, 1996, p. 2)

Self-Advocacy and Advisors



- Many self-advocacy groups have developed tools for training their advisors:



Riot! Report **Page 3**

<p>The Role of an Advisor By Erick Yeary</p> <p>Advisor Michelle Aman from South Dakota, was asked about her role as an advisor.</p> <p>The Riot: What is the role of an advisor?</p> <p>Michelle: To support people when they ask for your help and to offer assistance when needed. The self-advocate should always be in the lead.</p> <p>The Riot: How do you make sure everyone in the group is involved in meetings?</p> <p>Michelle: Talk before the meeting, set-up a game plan and discuss it afterwards. If someone didn't speak during the meeting, figure out why so they will want to talk next time.</p> <p>The Riot: How do you share your opinions with the group without influencing their decisions?</p> <p>Michelle: We go around the room and ask for everyone's opinions - including the advisor - that way everyone is heard.</p>	<p>What Do You Think About Your Advisor? By Marian West</p> <p>Self-advocate Dennis Greenwood from New Hampshire, was recently asked how he felt about his advisor.</p> <p>The Riot: What do you think about your advisor?</p> <p>Dennis: My advisor is very good and she helps me with different things.</p> <p>The Riot: How does your advisor help you take part in meetings?</p> <p>Dennis: She gives everyone a chance to talk. She listens and talks with you about the program. I think a lot about my three advisors.</p> <p>The Riot: Do you respect your advisor's opinion? If so, why?</p> <p>Dennis: She is a good person and she listens to me and everyone in the group. She talks to me when I am wrong and get out of hand at meetings.</p>
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- However, relatively few researchers have built upon this knowledge.

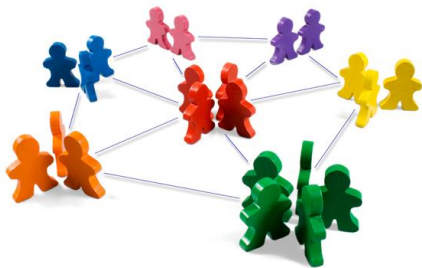
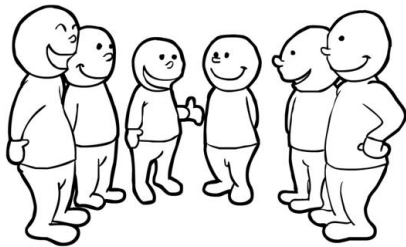
Who is the advisor in a self-advocacy group?



- An advisor is a person with or without a disability who is not a voting member of the self-advocacy group, but who is available to support the group in various ways.
- Responsibilities may include:
 - Assisting with group meetings
 - Providing information on community resources
 - Supporting self-advocates in speaking up for themselves
- Advisors can have a significant influence on self-advocacy groups.



Types of Self-Advocacy Groups



- **Autonomous**
 - Run by self-advocates with support from advisors (ex. SABE)
- **Divisional**
 - Part of a parent or professional organization that supports self-advocacy (ex. The Arc)
- **Coalitional**
 - Part of a larger disability civil rights organization (ex. CIL)
- **Service Systems**
 - Part of an agency that provides services to individuals with disabilities (ex. a residential service provider or DD community agency)

Current Literature Reveals 5 Major Themes:

Advisor Functions

Empower vs. Control

Advisors' Training Needs

Advisor Turnover

Youth Self-Advocates

- Advisor Functions
 - Leadership development
 - Group facilitation, including conflict resolution, leading discussion, and counseling
 - Planning, organizing, and managing logistics, including transportation and long-term planning
 - Identifying potential resources including grant-writing and connecting with community resources
- Evolve over time as the group's needs change





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- Empower vs. Control
 - Core values of advisors
 - Medical vs. Social Model
 - ✦ Instead of emphasizing deficit, advisors must focus on competence and strengthening what self-advocates can do.
 - Linguistic dynamics





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- Training Needs
 - Distinct lack of formal training
- Training needed in the following areas:
 - History of the self-advocacy movement (in the US and internationally)
 - Philosophy and mission of the self-advocacy movement
 - Duties and expectations of advisors
- Needs change over time as needs of group evolve.





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- **Advisor Turnover**
 - Groups report high levels of advisor turnover.
 - This can disrupt the strength and cohesion of self-advocacy groups and distract them from their advocacy work while they seek out and train new advisors.
 - Volunteer vs. paid advisors



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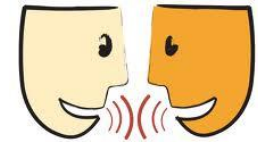
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- Differences in support needs between youth and adults
 - Youth may have different support needs than adults who have been involved in self-advocacy for a number of years.
 - ✦ Leadership development
 - ✦ Communication skills
 - ✦ Transition
 - ✦ “Second wave of self-advocacy”:
Different agenda than older self-advocates



Implications for Future Research



- Changing advisor roles and functions as the self-advocacy movement continues to evolve
- Factors that influence individuals to become advisors
- Training needs of advisors compared to the training and preparation they receive
- Quality of advisors and what makes an effective advisor
- Reasons contributing to high turnover rates for advisors
- Youth self-advocates and their support needs
- Self-advocates who become advisors



Including the Perspective of Self-Advocates



- Self-advocates as consultants, researchers, and participants



Quality of Advisors



Research Questions:

- We know there are effective advisors as well as advisors that are not as helpful, but what does that mean?
- What makes a good advisor?

Methodology:

- Qualitative interviews with advisors, youth self-advocates, and adult self-advocates.

Interview Questions:

- What do you think makes a good advisor or support person?
- Can you give some examples of types of good support?
- Examples of support that was not as helpful?
- Can you tell me about a time when a support didn't work out?



What to do with this information?



- Help establish recommendations and guidelines for advisors
- Share with SABE, NYLN, and AUUCD

