

# Advisors to Self-Advocacy Groups



A REVIEW OF CURRENT LITERATURE

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# What is Self-Advocacy?

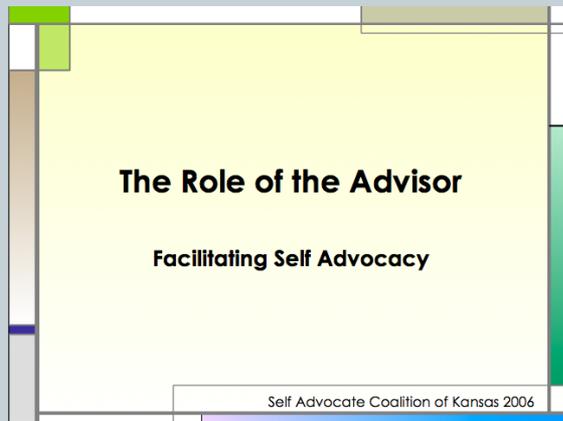


- According to Self-Advocates Becoming Empowered (SABE), self-advocacy...
  - “...is about independent groups of people with disabilities **working together for justice** by helping each other **take charge** of their lives and fight discrimination. It teaches us how to make **decisions** and **choices** 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><b>The Role of an Advisor</b> By Erick Yeary</p> <p>Advisor Michelle Aman from South Dakota, was asked about her role as an advisor.</p> <p><b>The Riot:</b> 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><b>The Riot:</b> 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><b>The Riot:</b> 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><b>What Do You Think About Your Advisor?</b> By Marian West</p> <p>Self-advocate Dennis Greenwood from New Hampshire, was recently asked how he felt about his advisor.</p> <p><b>The Riot:</b> What do you think about your advisor?</p> <p>Dennis: My advisor is very good and she helps me with different things.</p> <p><b>The Riot:</b> 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><b>The Riot:</b> 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.

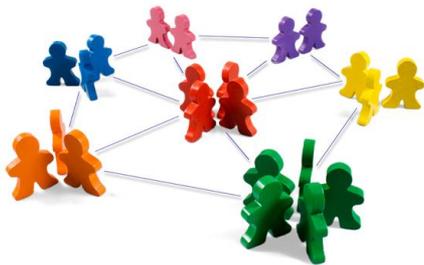
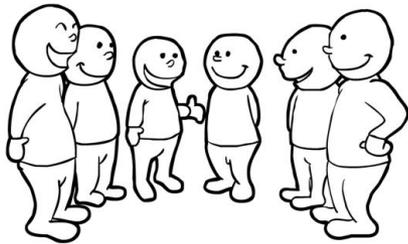
# Who is the advisor in a self-advocacy group?



- 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.





## **Current Literature Reveals 5 Major Themes:**

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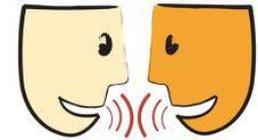
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- Differences in support needs between youth and adults
  - Youth may have different support needs than adults who have been involved in self-advocacy for a number of years.
    - ✦ Leadership development
    - ✦ Communication skills
    - ✦ Transition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

