



I AM A LEADER



This page is dedicated around the HOW.

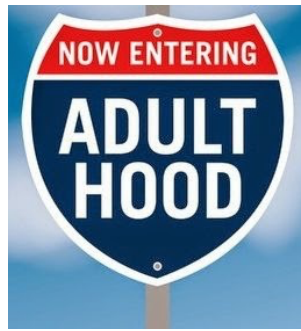
I'm a **youth/young adult**, **how** can I get involved? I am a **Parent/caregiver**, **how** can I help my youth/young adult to become a self-advocate or youth leader? We are a **community based organization** (CBO's) such as: Family to Family, Parent to Parent, Family Voices or a **state agency** **how** can we include Youth with Special Health Care Needs (YSHCN) voices into our programs?

For Youth with Special Health Care Needs

CT Kids as Self Advocates (CT KASA) suggests the following steps in their Youth Leadership, Train the Trainer Guide.

The first step to getting involved is by beginning with you:

1. Become a self-advocate, learn about your disability, become comfortable talking about it and educating people about it.
2. Learn how to speak up and express your needs
3. Make goals, start out small, make them personal and give yourself a timeline to aim for.
4. Tell others about your goal to get others to support you and keep you motivated.
5. Being an expert on your disability you know yourself the best.



The next step is the transition from self-advocacy to youth Leadership:

- Ability to lead a project or meeting
- Organization- being able to keep things organized, so that running a meeting is smooth.
- Effective Communication- Be calm, kind and a good listener. With these skills more respect will follow.
- Effectiveness working with group- Always work as a team player. Listen to what everyone is saying, don't be afraid to voice your ideas and concerns.
- Ability to set goals and follow through- Reach out to your local Parent to Parent and Family Voices Programs, they can assist you in learning about LifeCourse and other Person Center Planning. This will help you to set your goals and show you how to reach them.
- Professionalism- (DOES NOT MEAN TO CONCEAL DISABILITY)- There is no need to hide your disability. You have as much import and agency as the next person. You may find that sometimes people have no patience, but just hang in there and state your point. They will see how powerful you can be.
- Communication is key to success. Listen and allow others to take their turn to voice their point of view.
- Accountability- Everyone should be accountable for their own actions.
- Receiving and giving constructive feedback- As you transition into a leadership role you will learn how to give and receive constructive criticism. It is very important not to put people down for their ideas

For more information on CT KASA's train the trainer guide, please visit

www.pathct.org



For Families: How you can help your child/youth become a self-advocate

1. Encourage them to learn about the impact of their diagnosis/disability and how they can self-identify. It is important for them to understand how their disability impacts their lives but it is also just as important for them to be able to speak about it to avoid be labeled or “othered”
2. The Pacer Center suggests: Individualized Education Program (IEP) meetings as a great place to begin practicing self advocacy. As early as they are able encourage them them ask questions during their IEP meeting.
3. Practice goal setting. LifeCourse framework and core belief suggests that everyone has the right to live, love, work, play and pursue their own life aspirations and so should your child/youth. No matter what their disability. Encourage them to dream and help them to meet their goals.
4. Develop the skills to speak up for themselves. Everyone has the right to have their voice heard.. If speech is limited due to disability, help them to unlock their voice by seeking tools that will assist them such as: Augmentive and Alternative Communication (AAC) devices. These can range from picture boards or pictograms to computerized devices that synthesize speech from text and others that are even more advanced.
5. Encourage them to learn about their strength and needs and how to advovate or ask for and accept help when needed.

For CBO's /State agencies

The Association of University Centers on Disabilities suggests the following ways to get self-advocates involved in programming:

1. First, believe that self-advocates can and should be LEND trainees or any other program.
2. Value the viewpoint of the self-advocate, giving them the opportunity to present in class about disability issues and self-advocacy. They will give the other trainees the point of view of a person with a disability.
3. Have supports in place, depending on the self-advocate's needs.
4. Most importantly, ask the self-advocate what supports they would need and work with the self-advocate to develop them. For example, a mentor for the Family/Self-Advocacy discipline would be available to provide support to the self-advocate.
5. Work with the self-advocate to develop a schedule for (LEND) that fits in well with the schedule for the other parts of their life.
6. Check-in with the person regularly to make sure things are going well.
7. It may be helpful to adapt the materials (e.g. large print text or materials with pictures or in audio form) according to the self-advocate's preferences.
8. The self-advocate may need to go over the readings for class with someone
9. Have someone available to accompany the self-advocate when they are doing observations for the class.
10. The bottom line: Always ask the self-advocate what works best for them.