

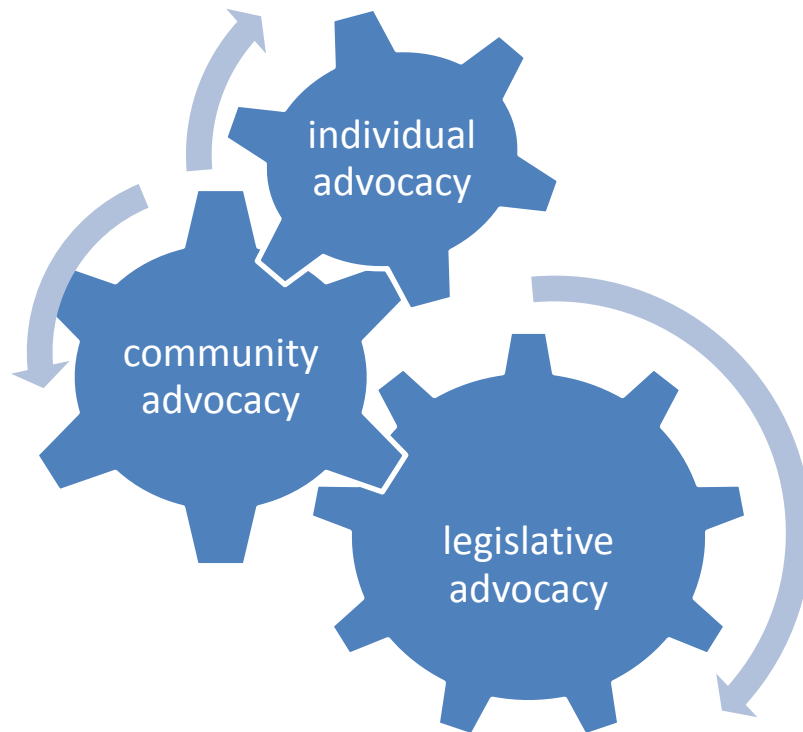


# Advocacy Toolkit

This toolkit is designed to demonstrate how advocacy consists of multiple layers, steps and levels. “Advocacy layers” can work together for the ultimate goal of better lives for people with disabilities and their families.

This toolkit is also designed to demonstrate the unique roles that siblings play within advocacy. From connecting with other siblings to make change to visiting with legislators, siblings offer perspectives that have not always been included in traditional forms or methods of advocacy.

The gears below illustrate the different levels of advocacy and how they are interconnected. People can be at different levels related to different situations. All levels are important to promote change.



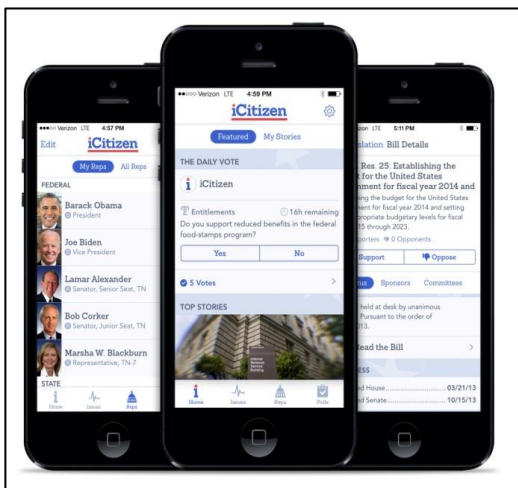
**This toolkit will help you advocate for what is important to you and your family.**



## TIPS FOR WRITING ADVOCACY LETTERS (OR EMAILS!)

- Email is the preferred option for sending written communication to Members of Congress. Email is just as effective as a First Class letter and it is received immediately by the Member. Communicating by fax is also effective.
- Try to stick to one typewritten page; two pages at most. If writing a regular letter, don't write on the back of a page. If writing longhand, take care to write legibly. In e-mail, always use proper net etiquette (avoid using all upper case letters as this connotes shouting, etc.).
- In a short paragraph, state your purpose. Stick with one subject or issue. Support your position with the rest of the letter.
- If the subject of your letter is a bill, cite it by name and number.
- Be factual and support your position with information about how legislation is likely to affect you and others. Avoid emotional, philosophical arguments.
- If you believe legislation is wrong and should be opposed, say so. Indicate the likely adverse effects, and suggest a different approach.
- Ask for the legislator's views and his/her support, but do not demand that support. Remember, Senators and Representatives respond to a variety of views, and even if they do not support your position on one issue or bill, they may support it the next time. So, ask for the legislator's views and express that you look forward to hearing from them on this issue soon.
- If writing a letter, make sure your name and address are legible. In email, make sure your name, full address, and e-mail address are included.

*(Source: Disability Policy Seminar)*



### **iCitizen**

The **iCitizen** app can help you easily find information on your mobile device. **iCitizen** is a FREE app that lets you look up your federal and state representatives, look at their voting records, rate them, look at their campaign contributors, and look up their sponsored bills. The app also lets you look up legislative progress by issue as well as take polls on different issues.



The Honorable \_\_\_\_\_  
House of Representatives  
Washington, DC  
Date

Dear Representative \_\_\_\_\_:

I am writing to request two important changes to the Older Americans Act: 1) Include aging caregiver of people with disabilities in the National Family Caregiver Support Program, and 2) Include future planning services for people with disabilities to be provided by Aging and Disability Resource Centers. I have a sibling with disabilities and these changes will positively impact my entire family and the millions of siblings and their families across the state and country.

The National Family Caregiver Support Program (NFCSP) was created by the Older Americans Act and was the first federal program to recognize the needs of the nation's family caregivers who provide the vast majority of long-term services and supports. Including aging caregivers of people with disabilities in the provisions for the Aging and Disability Resource Centers (ADRCs) is very important to brothers and sisters of people with disabilities because as parents age, many siblings become increasingly involved in caring for their siblings.

Also, include future planning as one of the priorities within the ADRCs is of crucial importance to siblings as our families need to make informed plans for our siblings' future needs. As our parents age, our siblings' futures can become increasingly unclear. Unclear expectations and lack of resources about future planning often contribute to increased emergency situations at the time of the caregiver's passing. Including future planning as part of the ADRCs' role will help ensure smooth transitions of care for our families. A previous Senate version of the OAA Reauthorization (S. 1028) includes the addition of future planning services provided by ADRCs. We urge you to incorporate this addition in the House OAA reauthorization.

Thank you for your work assisting American families through the reauthorization of the Older Americans Act. Including the roles that aging caregivers for people with disabilities will broaden the support to families who need it. Also, adding "future long-term care needs" as a priority for the ADRCs will benefit families and help them plan for the future in a way that will strengthen families and communities.

Sincerely,



# What Will You Say? Sharing Your Story Effectively for Change

Your stories and experiences are among the most powerful tools for change. Sharing them effectively with professionals, legislators and other advocates can make a big impact. Use the space below to fill in your own information to this approach.

## Use the “Hook, Line and Sinker” approach:

**Hook:** Details about you, your sibling or family (including your district)



**Line:** Your main concern (and a specific story that shows the problem)



**Sinker:** What you want changed and how you want it changed





## **Talking Points On Siblings of People with Disabilities**

### **Why are sibs important?**

- Siblings often have the longest-lasting familial relationships.
- Many of the estimated 3.5 million individuals with developmental disabilities (I/DD) in the United States have brothers and sisters.

### **Family caregivers:**

- Family caregivers are the largest source of long term care services in the U.S; from 2000 to 2015, the number of family caregivers is estimated to increase by 80%.
- In the US, 72% of people with I/DD live with their families and, in 25% of these homes, the caregivers are older than 60 years of age.

### **Sibling roles:**

- Siblings often become the next generation of caregivers when parents are unable to provide care. Frequently, the oldest female sibling becomes the caregiver.
- Most siblings anticipate fulfilling greater supportive and caregiving roles.
- The peer nature of the relationship makes siblings uniquely positioned to support their brothers and sisters with disabilities to lead self-determined lives. This support can include many areas such as employment, voting, transportation, relationships and sexuality, healthcare, housing supports, and more.
- Even though siblings have unique roles and are likely future caregivers, the needs and perspectives of siblings are often overlooked. By addressing the needs of siblings, their brothers and sisters with disabilities will have better outcomes.
- Siblings often juggle the caregiving of their aging parents, their own children, as well as their brothers and sisters with disabilities.

### **Sibling Needs:**

- While support programs and services have been developed for individuals with I/DD and their parents, supports for siblings have been limited.
- There is a specific need for information on future planning. Future planning is critical because it helps start an important dialogue among families and helps break up the planning process into manageable steps. Future planning programs should include both the siblings with and without disabilities in the entire process.