



# FACT SHEET

## Health Access for Independent Living (HAIL): Empowering Consumers to Manage Their Health

### Why It Matters

People with disabilities have significant health disparities compared to people without disabilities. That means they are less healthy in general and more likely to have a chronic condition, like diabetes or heart disease. One reason for these differences is that people with disabilities often encounter barriers to health care and health promotion activities.

In addition, many people with disabilities (also called consumers) have secondary health conditions, like pressure ulcers or depression. Secondary conditions result from a person's primary disability, such as spinal cord injury, and they can be even more serious to a person's health. For people with disabilities, these health problems can pose a major threat to living and participating in the community.

One solution to this problem is to teach consumers with physical disabilities how to manage their own health and health care. This can be a complex task, but with support and guidance, taking charge of your health is easier.

The Health Access for Independent Living (HAIL) program is designed to provide just that. In HAIL, consumers work with a trained Center for Independent Living (CIL) staff member at their local CIL. Together, they identify health-related goals and make plans to achieve them. With improved health, consumers can be more involved in their community.

### What Is HAIL?

HAIL provides consumers with the knowledge and skills to manage their own health and health care. For this research project, we partnered with CILs to deliver that knowledge and skills.

For years, CILs have helped consumers learn the skills they need for independent living. With the HAIL program, CILs and their staff can give consumers another tool for remaining independent and active. Our researchers train CIL staff how to use the HAIL process and its website ([www.hail.ku.edu](http://www.hail.ku.edu)) to help consumers take charge of their own health.

*"HAIL steps are succinct  
and really simple."  
- HAIL Consumer*



This trial of HAIL focused on people with mobility-related disabilities.  
Photo courtesy CDC/Amanda Mills.

Working with their CIL staff member as a trusted advisor, HAIL participants:

- Learn to recognize and address secondary health conditions.
- Develop skills for healthier living, such as managing their medications and working with their health care providers.
- Set and achieve short-term health-related goals.

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*“So much information on just this website. Topics covered in the website were awesome.”*  
- CIL Specialist

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### How HAIL Works

The consumer and CIL staff member work together on three steps for improving health.

**Step 1: Identify Health Needs.** The CIL staff member and consumer use a checklist that helps consumers decide which health needs matter most to them. Some people may want to focus on a secondary condition, like combatting their fatigue. Or a consumer may want to improve a health-related skill, such as learning when to get preventive health screenings.

**Step 2: Find Resources.** After they identify their needs, consumers use the HAIL website’s “Finding Resources” database for ideas on how to address their specific needs. They can search for both medical and non-medical resources. Non-medical approaches include social, psychological and physical methods, such as support groups, relaxation psychotherapy, and nutrition or exercise.

Searching the Internet can often be a frustrating experience. HAIL’s website streamlines the search for useful health information. It gives information from reliable health websites, along with some information that is specific to living with a disability.

[hail.ku.edu](http://hail.ku.edu)

The HAIL website (pictured below) provides resources for CIL specialists to use in assisting consumers.

**Health Access for Independent Living (HAIL)**

Home About Finding Resources Consumer Skills Secondary Conditions FAQ Suggestion Box IL Specialist Toolkit

## Welcome to HAIL - Health Access for Independent Living!

**Did you know that people with disabilities can be healthy?**

HAIL was created to support [center for independent living \(CIL\)](#) staff to assist their consumers with physical disabilities who want to be healthier. The program helps CIL staff members and consumers work together to set and reach some health goals that are chosen by the consumer.

Not long ago, people with disabilities were thought of as sick, and not able to improve their health. Sometimes they did not get information or services, like flu shots, that would help them to be healthier. Also, people with disabilities might not have the skills to use health care services well, like working with their doctor or managing their medications.

Now it is well known that people with disabilities can be healthy, and can do things that will help them to feel better and more able to do what they want in life. Since the passage of the Americans with Disabilities Act (ADA), there have been more

**What Is HAIL?**

Watch our video for an overview.

Health Access for Independ...  
with providers  
- Managing your medications  
- Other Skills

Click on the video above, or visit YouTube:  
[Health Access for Independent Living](#)

The website contains resources about three secondary conditions that we know are common among consumers: pain, fatigue and depression. It also offers tips on building these skills to understand and improve your health care:

- Working with Health Care Providers
- Accessing Preventive Care
- Understanding Health Coverage
- Managing Your Medications
- Using Assistive Technology
- Organizing Your Health Records

**Step 3: Pursue Short-term Goals.** Consumers use the resources they have found to complete short-term goals – ones they can accomplish in about three months. They give themselves tasks that are realistic and “doable,” and set a time frame to complete them. For example, a consumer may decide to take a yoga class as a way to address her fatigue. She and the CIL specialist make a plan for finding and attending a class that is right for her.

When you have a goal, it’s important to have some way to track progress – otherwise, how can you know if you’ve achieved the goal? Tracking progress can be as simple as putting hash marks on a calendar or as complicated as downloading an application to a smartphone. In HAIL, the key is finding a tracking strategy that is most comfortable for the consumer. Tracking progress is also useful for reviewing what worked and what could be improved. Then, the cycle continues as consumers set new health-related goals.

### Testing HAIL: Putting Theory into Practice

For this research, we teamed up with one CIL in Kansas to test the HAIL process with a small group of people who have mobility-related physical disabilities. The group consisted of four consumers who worked with two CIL staff members over a three-month period.

We trained the CIL staff members how to use the HAIL process and website. These CIL specialists provided individualized support to consumers through home visits. We wanted to know if the HAIL process could fit into their regular work with their consumers.

### Getting Results

The consumers set both short-term goals, like exercising regularly and eating better, and long-term goals, such as reducing their pain or getting off pain medication. In this brief three-month trial, participants achieved many of their short-term goals as milestones to their longer-term goals.

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*“You guys are on the verge of something amazing! This is going to go well with people [with disabilities] who will want to stay home [instead of entering an institution].”*  
- CIL Specialist

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The HAIL process helps consumers work with CIL staff specialists to identify their health-related needs, then find resources to pursue their goals.

One consumer said, “Before I started this program, I could not walk around the block. Now, I can enjoy community activities. I can walk back and forth to the library. I can walk back and forth to the art in the park. I’ve tried so many other programs and [couldn’t get] running with it. This program has been a fantastic opportunity.”

### **Lessons Learned**

The CIL staff and consumers who took part in HAIL stressed the importance of such a health-related program, now more than ever. As partners in our pilot study, they made suggestions that will help us adjust HAIL for the next round of testing.

We plan to add more resources to the HAIL website as we get feedback from our consumers about topics that would be useful to them. New resources may include:

- Additional secondary conditions.
- More topics related to aging and disability.
- Information to educate the consumer’s support systems (family and friends).
- A choice of ways to track goal-related progress that suit different needs and situations.

### **Next Steps**

For the next tests of HAIL, we will incorporate our lessons learned, then repeat the study at two other CILs with more CIL staff and consumers.

Our ultimate goal is to empower consumers to use the HAIL program independently, to take charge of their health and to be more informed health consumers. For example, if a health care provider does not recommend a flu shot, the informed consumer might request one.

With this empowerment, consumers may also have fewer secondary health conditions, be able to avoid institutionalization, and enjoy increased community participation. However, this process starts with recognizing the role of CIL staff working as trusted advisors with their consumers.



Organizing your health care records is one of the skills that HAIL consumers can learn.

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- HAIL Consumer

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