Health Access for Independent Living (HAIL)

Empowering Consumers to Manage Their Health

Community Living Summit
Sept. 19-21, 2016
Alexandria, Virginia
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Why We Need HAIL

• One major reason that people with physical disabilities have significant health disparities is due to barriers to health care.

• People with physical disabilities may have secondary conditions that limit their health.
HAIL Goals

For Consumers:
• Learn to recognize and address secondary health conditions
• Develop skills to learn to be empowered health care consumers
• Set and achieve short-term health-related goals

For CIL staff:
• Assist consumers to be healthier by addressing secondary conditions
• Empower consumers to understand and exercise their rights to access health care facilities and services
• Help consumers to gain knowledge and take action to address their health care needs
Partnership with CILs

• Independent Living philosophy supports building consumer self-direction in managing health.

• Consumers tend to trust CIL staff members to help them remain independent in the community.
What Secondary Conditions?

• We conducted a needs assessment of CILs nationwide to identify:
  • frequently reported secondary conditions
  • barriers to accessing health care and improving health

Results: top Secondary Conditions were chronic pain, depression, and fatigue
What Knowledge and Skills do Consumers Need?

• Why and how to access screenings and preventive care

• Rights and strategies to access health care facilities and services

• Information and tools to help self-manage health
What Are the Steps to Implementing HAIL?

• The CIL Staff member supports the consumer to:
  – Identify Health Needs
  – Find Resources
  – Pursue Short-Term Goals

“HAIL Steps are succinct and simple”
  --Sheila (consumer)
1. Identify Health Needs

• What secondary conditions?
• What consumer skills?

“You pretty much look for what you’re needing and the website gives you an opportunity to define that.”

Saundra (consumer)
2. Find Resources

Use the HAIL Searchable website:

www.hail.ku.edu

“You have enough information on the website to pursue options. You don’t feel like you have to search all over the place.”

Jack (consumer)
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 opportunities to live in and to be part of the community. Just like others, many people with disabilities want to:

• Work or volunteer in the community
• Enjoy activities with friends and family, like going to sports events or caring for children
• Do things they love but have become difficult, like gardening or arts and crafts.

Or, some people may simply want to stay out of the hospital and remain in their own home. But, we need to find ways to give people with disabilities information and support that can help them to be healthy.

Please check out this site to learn how YOU, as a CIL staff member or a consumer, can use this program.

If you have feedback to share about this page or any part of HAIL, please use the Suggestion Box to send it to us. We want to know how to improve the program to meet the needs of CIL consumers and staff.

The contents of this website were developed under a grant from the Department of Health and Human Services (DHHS), National Institute on Disability and Independent Living Research grant number NIH074800. However, those contents do not necessarily represent the policy of DHHS, and you should not assume endorsement by the Federal Government.

Contact Health Access for Independent Living (HAIL)

rtcil@ku.edu

The goal of HAIL is to give useful health information to consumers with physical disabilities who want to improve their health.

That information will come from a trusted source: an Independent Living Specialist (ILS) or other center for independent living (CIL) staff member.
Navigating the HAIL Website

Finding Resources Page

You can use the HAIL database to find health information that interests you. Just check your topics in the three lists, then hit the SUBMIT button. The program will return a list of resources on the topics you chose.

You must select at least one option from each section. (The red asterisk means you must make a selection.) Check N/A (not applicable) if none of the items in a list interest you.

If you would like to learn about one condition at a time, choose the one that you are most concerned about. You can always go back and get information on the others later.

For each of the following lists, choose one or more items that interest you. (The red asterisk * means you must check at least one box.) Choose N/A (not applicable) if you don't want information about any of the listed items.

**Physical Disability?**
- N/A
- Amputation
- Arthritis
- Cerebral Palsy
- Joint Replacement
- Multiple Sclerosis
- Muscular Dystrophy
- Parkinson's Disease
- Post-Polio Syndrome
- Spina Bifida
- Spinal Cord Injury
- Spinal Muscular Atrophy

**Secondary Health Conditions?**
- N/A
- Depression
- Fatigue
- Pain

**Health Resources?**
- N/A
- Medical:
  - Medication and Medical Intervention
- Non-Medical:
  - Social Intervention such as Support Groups and Stress Management
  - Psychological Intervention such as Relaxation Psychotherapy
  - Physical Intervention such as Nutrition/Exercise/Over/Rest
  - Living Well with Disability (LWD)

[Submit]
Navigating the HAIL Website

Consumer Skills Page

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About  Finding Resources  Consumer Skills  Secondary Conditions  FAQ  Suggestion Box

Working with Care Providers  Preventive Care  Health Coverage  Managing Medications  Assistive Technology  Health Records

Consumer Skills

We all need certain skills to maintain our health. The fact sheets in this section focus on things you can learn to do to stay involved, informed and in charge of your own health and health care needs.

To see the fact sheet, click on the topic in the menu above or at the left.

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Navigating the HAIL Website

Secondary Conditions Page

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Secondary Conditions

The HAIL database has information on common health problems called secondary conditions that are experienced by people with physical disabilities. Click the name on the top or left menu to see the fact sheets we have created on:

- Depression
- Fatigue
- Pain

These are called secondary conditions because they often occur as the result of a primary disability, and can be more serious and limiting than the primary disability. They can be very serious if a person experiences multiple conditions, such as pain and depression resulting from an amputation.

We chose to focus on these three conditions because research shows that they affect people with physical disabilities at a much higher rate than non-disabled people.

These conditions are not inevitable, nor do people have to “just live with it.” There are solutions they can try. We have collected a range of resources for those who want to tackle one or more of these secondary conditions.

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3. Pursue Short-Term Goals

• Short term goals help assure success
• Tracking goals – perhaps the hardest part

“HAIL gave me the motivation. Now if I feel I’ve hit a plateau I have the confidence to quickly go back and find new ideas.”

Saundra (consumer)
Example Goals

• **Outcome Goals:**
  - Address pain, reduce pain medication
  - Lose weight
  - Increase Mobility

• **Process Goals:**
  - Exercise
  - Cut back on sodas
  - Use a walker
Next Steps for HAIL

• Revise based on trial results and feedback.
• Keep adding more resources and tools.
• Test with another CIL.
• Repeat . . .