

Healthcare Guide

Northwestern Illinois Center for Independent Living

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How to Use this Guide

Centers for Independent Living (CIL's) were started in the late 1970s, to establish a non-residential center to support people with disabilities, live their independent lives. It took a while for this grassroots effort, known as the Independent Living Movement to find its way into all 50 states and the US Commonwealth; but we are here, and we are a strong service!

Illinois was one of the earliest adaptors of the Independent Living Movement, in the early 1980's. Northwestern Illinois Center for Independent Living (NICIL) is one of the original five (5) CIL's in Illinois.

Fast forward 35-plus years and today, NICIL, as well as 21 other CIL's, continue to work hard every day to develop programming and services that support our consumers, in the five (5) county-NICIL territory which includes: Carroll, Jo Daviess, Lee, Ogle, and Whiteside Counties. Our time is dedicated to serving all people with disabilities to live their independent lives, as they see fit. It is an honor and a privilege to serve!

Our services are tailored to each individual with whom we work. There are some common barriers which keep individuals from living independently. These barriers (or topics) are referred to in the industry as issue areas. There are nine (9) issue areas:

- Assistive Technology
- Attitudinal Barriers
- Communication
- Education
- Employment
- Healthcare Services
- Housing
- Physical Barriers
- Transportation

All NICIL staff are trained to be subject matter experts in these issue areas. Our team has developed issue-area guides to be available to our consumers, which are user friendly. These guides are designed to provide a basic understanding of the issue area, as well as to give information for self-direction. However, we want to be part of the process of independent living, so please, contact our team for one-on-one (individual) services.

Please use this guide to give you a helping hand in understanding the Healthcare issue area and use the resources provided as a starting point. When you are ready, know that we are here to support your independent living path. Remember, while NICIL staff are experts in healthcare, we do not have any medically trained personnel on staff.

Check out our website, www.nicil.org for access to all of our issue area guides. Contact the office at 815-625-7860 or via email at frontdesk@nicil.org to request for a copy to be emailed to you. Enjoy!

Introduction

Healthcare is one of the most important aspects of life. It is vital for every person to have access to good healthcare and do our best to take care of our bodies. We only get one! Healthcare, in general, has been difficult to navigate, and the paperwork/insurance can be overwhelming. The stress of understanding the healthcare system, in combination with the financial expense, can make a process which should protect us and make us feel at ease, suddenly daunting.

The purpose of this guide is twofold. First, we want you to feel empowered to take care of your own health, as best you can, on your own. This means using practical knowledge found in a variety of areas of life to guide you. Second, this guide will walk you through the more formal process of healthcare, which involves other entities and how they relate to you. In general, this guide aims to help you navigate the world of healthcare and make you aware of accommodations, and help you can receive, in order to live the most independent life possible for you.

This guide has several sections. We want you to keep this, as a reference guide for now and the future. We hope this guide serves as a helpful tool, which will help you fully immerse yourself into the world of healthcare.

Please note that this book is not a replacement for professional advice given by qualified experts. Do not be afraid to ask for help from the resources listed. Medical Professionals are here to make sure you receive the best healthcare possible and are given the accommodations you need. Whether you are a person with a disability yourself, a family member, or simply an individual interested in learning about the resources that exist in our area, we are hopeful that this guide, in the context of disability, will be of help to you in both understanding and navigating our healthcare system.

How to get started? First things first! Understand that it will take time and effort to find the right medical expert for you. Read this guide, understand your own healthcare needs, then call us for an appointment to become a healthier you in 2020!

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Getting Started to a Healthier You!

There are many jokes circulating about getting old. Some are funny; some are disrespectful, and some are factual. As we age, our bodies and health do decline. This is a fact of the aging process and life.

We can help slow down some of the aging process through our mind, body, and spirit. The NICIL team has spent many years working with our consumers and seeing some of the positive, healthy choices that are made. We are passing them onto you!

- Reduce stress, every day with everything.
- Get plenty of sleep.
- Drink plenty of water.
- Enjoy some sunshine and fresh air. Wear sunscreen!
- Walk, or some other form of exercise, at least 30 minutes per day.
- Make a healthy eating plan and stick to it!
- Focus on positive things.
- Find your passion.
- Find hobbies that make you happy.
- Find fulfillment.
- Find your spirituality in whatever form speaks to your heart.
- Help others every chance you get.
- Find time to relax or meditate.
- Turn off electronics, including the TV.
- Volunteer. Many organizations need you!
- Find ways to teach your expertise.
- Be kind to everyone every day.
- Be prepared to eliminate negative people in your live, then do it!
- You are not obligated to make someone happy; this is their choice.
- Choose to be happy.

Sounds easy? No, not really. This takes effort! You do not have to do all of these in one day, but start somewhere. That is truly the first step! You are worth the effort!

If you are interested in learning more on a specific aspect of being healthy, please let us know. We offer one-on-one training in many areas, such as healthy eating, managing stress, medication management, and many more!

The next step is to understand the process of healthcare, so that it does not stress you out. We will discuss this in the following sections. If you need help, we have the experience to support you! Call us at NICIL.

Definitions

There are oftentimes when people use language (slang or abbreviations) that may not make any sense to those who are not familiar with a specific. In this section, we want to take the time to identify some common terms that will come up in your exploration of the healthcare system.

Insurance terms:

- **Deductible:** The amount you owe for covered healthcare services before your health insurance or plan begins to pay
- **Copayment:** The amount you pay out of pocket for the cost of a medical service or item, such as a doctor's visit, after your deductible is met. Copayment are usually calculated as a percentage of the total service cost.
- **Premium:** The amount you pay for your health insurance or plan each month
- **Network:** The doctors, hospitals, and suppliers your health insurer has contracted with to deliver healthcare services to their members
- **HIPAA:** Health Insurance Portability and Accountability Act. This is a large act (law) that covers healthcare rights and privacy rights. You should be familiar with all your rights, in particular, what your insurance company has a right to know.

Insurance Billing terms:

Explanation of Benefits (EOB): A written statement from your insurance company that explains what you as an individual are required to pay and what services your insurance company covers for health care services. Insurance providers is required by law to provide this for you. You can check the pages of the EOB for additional information.

Medicare terms:

Medicare is a type of insurance that is provided for qualified individuals receiving Social Security. Medicare provides different types of coverage, which are referred to as Parts. These parts are as follows:

- Part A provides inpatient/hospital coverage.
- Part B provides outpatient/medical coverage.
- Part C offers an alternate way to receive your Medicare benefits.
- Part D provides prescription drug coverage.

Medicare Supplement Policy: Also called a Medigap policy, Medicare Supplement Policies can be purchased to help cover some of the out of pocket expenses not covered by Medicare.

Medicare can be difficult to understand and navigate. There are State Health Insurance Program (SHIP) sites, throughout Illinois to assist individuals in understanding and selecting the best plan for them. NICIL is a certified SHIP site with three (3) certified staff on hand. Call us for an appointment!

Other Public Benefit terms:

Public benefit is the official term for needs-based programs. Individuals who meet the criteria for the benefit program receive the benefit as long as the need still exists. This criterion has an application process designed to be accessible and fair to all people who wish to apply.

- SNAP: Supplemental Nutrient Assistance Program is the federal name of the food subsidized program through the US Department of Agriculture
- LINK: Name of the Illinois SNAP program
- TANF: Temporary Aid for Needy Families
- Medicaid: Medical benefits assistance
- All Kids, CHIPRA: Specific children's healthcare insurance
- Low Income Home Energy Assistance Program (LIHEAP)
- School Breakfast and Lunch Programs
- Special Milk Program
- Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)
- Summer Food Service
- Unemployment Insurance
- Weatherization Assistance Program

The examples listed above are State of Illinois programs, which may also be federally subsidized. These programs require annual reapplication to continue receiving benefits and is not an automatic renewal. There is no formal notification of renewal any longer, so it is now each person's personal responsibility to meet renewal deadlines.

It is important to note that Illinois and federal laws require the agencies in charge of distributing benefits to have language alternatives available, as well as make any reasonable accommodation needed to receive help in completing their application process.

Social Security terms:

The Social Security Administration (SSA) has two (2) main benefits programs for individuals not eligible for retirement benefits which include:

- Social Security Disability Insurance (SSDI) is an insurance program to provide monthly insurance payments, based on the individual's contributions into the program during years of employment. This is a wage-based, earned program. The amount that each person is awarded is based on their past income contribution.
- Supplement Security Income (SSI) is a needs-based program and is a specific amount each year. This is not intended to be a lifetime financial support. It is designed to be a temporary support, while new skills are learned or while there is recovery from a disability or long-term illness.

Both programs require a lengthy application process and only 6% of the applicants receive the award on their first application.

Overwhelmed or confused? It can be that way! NICIL team members are trained to assist in application processes for all benefits programs. Call us for an appointment.

When to Involve Professionals

Depending on your family, you may have grown up in a time when seeing the doctor was only when you were sick, or annually for a school exam. Today our expectations of the medical field have changed, and the medical field has welcomed these changes! Medical professionals would like their patients to have a healthcare action plan. This is a plan that is put together by both the patient and the medical professional to provide support in keeping healthy. This may include, but is not limited to:

- Periodic visits
- Periodic lab tests
- Healthy eating plans
- Exercise plans
- Medication management
- Pain management plans

These are only a few of the different types of plans that are available through working with your healthcare providers, but you have to be part of the plan for your health! Communication is an important aspect. Talk with your medical providers and invite them into the planning process! Chances are they are waiting for their invitation!

Doctor Visits:

Ease the stress when it is time to make an appointment by being prepared, starting with your call into the office for an appointment. Here are some suggestions:

- Have your calendar in front of you to ensure you are free.
- Offer alternative dates and times if you are not able to take an appointment at the date/time offered.
- Be cooperative! They are not trying to prevent you from seeing a member of your medical team, but you are not the only patient they have! They also have other obligations, with the medical facility that may take them out of the office.
- Be prepared to give a list of what you need to see the medical professional for. This should not be kept a secret, so that your professional can be prepared for your visit. They are professional; they have seen and heard it all!
- Mind your manners, they are trying to assist you, not offend you.
- Be clear on your needs

Going to the doctor does not have to be a negative experience. It may involve waiting and talking to people about things that make you uncomfortable or even embarrassed! It's no surprise that going can cause some amount of stress. This is one reason why it is important to prepare for your appointments ahead of time! Below are some ideas about what to bring and do when you visit your doctor. (Wyant, 2018):

- A list of your current symptoms
- A list of your past symptoms, and the dates you experienced them
- A list of your current medication (even better, bring it with you in the original bottle)
- A list of your past medication, any adverse reactions, and why you stopped taking them

- Allergies
- Diagnoses
- Past procedures/surgeries, including dates
- Results from lab work, imaging, medical tests, etc.
- Names, phone numbers, fax numbers and addresses of all your doctors
- Names, phone numbers and relationships of emergency contacts
- The name, phone number, fax number and address of your pharmacy
- Something to take notes with or a voice recorder
- Something to pass the time while waiting
- A prioritized list of what you want to talk about
- Your insurance cards
- A calendar/planner
- Ask lots of questions, this is your health!
- Consider bringing someone with you
- Ask for an interpreter if you need one, ahead of time
- Ask for reasonable accommodation(s) to communicate effectively with your healthcare provider if needed, ahead of time
- Listen carefully to the doctor's advice

For more information on how to be prepared for a doctor's appointments, see:
<https://www.nia.nih.gov/health/how-prepare-doctors-appointment>

Did you know that your medical professional can provide discharge papers to you, at every visit? These are documents that tell you what you discussed with the medical professional, any medications or other supplements, follow up care notes, and any specific instructions. You can ask for this each time you visit a medical professional. This could help you follow your healthcare plan!

Disability Check Appointments

If you are a person with a disability, or several disabilities, you will want to schedule an annual disability check with your medical professional. You will need to have this separate from any other medical check or illness.

What is a Disability Check appointment and why is this important? During this appointment, you are focused on your disability and any medical issues with this disability. Whether you have one or more disabilities the approach to each disability is the same. Here are some items to prepare, followed by questions to ask, so that you and your medical provider are prepared for the future.

How to prepare for this appointment:

- Keep track of the following by using a log with dates and times:
 - All symptoms regularly experienced
 - Any unusual situations or symptoms that are occasional or rare
- Keep track of any side effects from the medication or anything else

- Note any major life stresses
- Note any weight changes
- Report any issues with medications
- Note any changes to mental health conditions
- Note energy levels
- Note any changes to skin conditions
- Note any changes in eating habits
- Note any changes in your bowel program
- Note any new symptoms (such as incontinence, no appetite, sleep loss, etc.)

Preparing for the future:

Social Security, as well as other programs, require medical-based evidence for determining eligibility and/or ensuring that someone meets the criteria for the program. What this means is that the requester (Social Security, Department of Rehabilitation Services, Medicaid, etc.) requests medical records from your medical providers. These records are reviewed for proof of the disability or medical condition. For example, if you applied for SSDI and Medicaid due to your decline with diabetes, you must have medical records showing:

- The medical condition has been diagnosed.
- The treatment plan or care plan has been developed to minimize risk (advancement).
- Medication is being taken as prescribed.
- Treatment plan is being followed.
- Continuing care is ongoing (regular medical appointments)

If this information is not in the medical records, then there is no medical-based evidence to support this need, and the application for the requested services or benefits will be rejected.

Involvement with your medical professional is needed! It is proof that your disability or illness exists. Should there be a decline in your condition or side effects caused by the condition, continuing medical care will show this in the medical records.

Final note: Medical Professionals and your insurance do not want you to suffer or not go to the doctor. They want you to do so! Not for the money, but to be part of a healthy you!

Medication Management

New state and federal laws have been put into place to help with drug interactions and allergies. This is great news for anyone who takes medication!

Medication management is a term used in understanding the correct use of medication; taking it at the right time, with the right conditions, for the right reason. This is important! We suggest that during your Disability Check Appointment, you also discuss

your medications with your medical provider. Be prepared with questions to ensure that this appointment is productive for you. Examples of questions to ask:

- Is this medication the most effective one for my use?
- Are there any changes that I might experience as I continue to use this medication?
- Is the dosage still correct for me given...? (List any changes, such as weight loss or gain, advancement in disability, advancement in age, etc.)

You may have other questions as you prepare your list. Remember, the medical professional works for you. Your discussion/questions are an important contribution to your overall care plan!

One Pharmacy – One Expert:

There is always concern when there is more than one pharmacy involved in fulfilling a prescription(s) for an individual. The reason is drug interaction. If an individual has medication(s) at multiple pharmacies, drug interaction may come into play. Insurance companies have improved software to alert them, but the risk of potential drug interactions and overuse is a serious matter.

We encourage you to use one pharmacy to help manage your medication. Just like meeting annually with your medical professional, meet with your pharmacist. They are experts in their field. They can answer questions about your medication(s), talk with you about the timing for taking your medication(s), food intake instructions, and provide other valuable information.

One last note, you know all that paperwork that comes with your medication(s)? These information gems are valuable! Read the material! These are from the manufacturer and drug distributor, which list updates to side effects, effective ways to take the medication (as the manufacturer intended,) drug interactions, and much more. Be informed about what is going into your body!

Advocating for Medical Care

There are times with your medical professionals when you will have to advocate for yourself. This is when doing your homework and keeping record logs will especially be beneficial. If you feel the need to, then advocate for your health. Here are some tips for advocating for yourself, if you have never thought about this before:

- Make sure you know what you want to accomplish and have an expected outcome. Write down what you expect and wish for an outcome, so you can use this to stay focused on your effort in advocating. Ask for the outcome you desire.
- Be confident!
- Be professional. Advocacy is not a loud, in-your-face confrontation. Advocacy is calmly making your point.
- Be polite, there is no room for being rude. Be firm if needed, but polite.

- The medical professional works for you, and you have options if you're not being heard or your medical needs are not being met. The choice is yours to seek a new professional!
- Bring your log of symptoms. This helps in making your point.
- You are entitled to your medical records, so bring (or get) a copy, if needed.
- Prepare your conversation. Practice, Practice, Practice! Take the emotion out of it. When it comes to you and your advocacy, emotion can sometimes cloud the conversation. Relax, this is a conversation.

Once you have advocated, then allow the process to work. For example, if you advocated for a specialized test, next, the insurance company needs to approve it. This may take some time. It is ok to check back within a reasonable amount of time.

In our training on Healthcare, our NICIL Executive Director tells a story about advocating for herself:

“I felt awful and could not seem to get better. I went to doctors, specialists, even moving to another community for their improved health services. This went on for more than 15 years. I was misdiagnosed multiple times. At one point, even told I needed mental health expertise for “making up stories”. I had finally had enough. I went to my primary doctor, told my story again, but this time I said, I am not leaving, until we have an answer to what is making me sick. Whatever it takes, but today this (illness) gets answered. The doctor was not happy, but agreed to run new labs and explore the ones I suggested.”

“After two (2) weeks of labs, the results were back. I had Hashimoto Disease (an autoimmune disease). I finally had an answer, and I was finally relieved! By this point, I had the disease for more the 25 years! If I had not advocated for myself that day, mostly likely I would not be alive today.”

You have rights in the healthcare field, as you do everywhere! If you do not feel that you are getting the services that you expect, you may exercise those rights through advocacy. Some of these are:

- Right to second opinions.
- Right to obtain new medical care.
- Right to see and obtain a copy of your medical records.

Know your rights and how to properly exercise them. Call NICIL if you need to explore this further. Advocacy is one of our core competencies.

What if you feel that you were not given the appropriate accommodations or service during the time of your medical appointment? It depends on what it was that was not provided for you. Using accommodations as an example:

You are deaf and your preferred method of communication is an interpreter. Does your medical professional have to provide this? YES! At the time of the appointment, you

request the accommodation. The medical provider must provide a certified interpreter. The cost is paid for by insurance and/or the medical professional, never the patient.

Another example: You have a power chair, and the doors are not wide enough for power-chair accessibility. What happens next? The medical provider should have doors that are wide enough, which is part of ADA compliance. That being said, the provider must have an alternative location for examination that is equal to, if not better than a traditional examination room. In other words, the employee lounge or the waiting room may not be used to conduct the examination!

These examples are rare, but that doesn't change the reality: Accommodations must be made. NICIL can assist you in understanding when advocacy may be needed. Give us a call.

Confidentiality and HIPAA

Confidentiality is a big deal! No one has a right to give any medical information to another party, without your written and expressed consent. What does that really mean? First, read and know what you are signing anywhere! Your medical providers will offer you paperwork that releases them from liability and also gives permission for them (the medical provider) to share information with certain parties, when needed, which may include insurance, or providers who may contract them with a hospital or clinic. Once you sign these, you have given your medical provider your express consent to have your records released to these parties.

You may revoke this consent anytime you want and part of your paperwork also gives you the process on how. You are entitled to a copy of all the papers you sign, at any medical appointment. Usually, this is not verbally shared, but it is in the signed papers. A word of caution in refusing to sign the paperwork: you do not have to sign, but realize that if you do not sign, you may not be seen by your provider or you may be asked to pay in-full for the service upfront.

HIPAA, which is the Health Insurance Portability and Accountability Act prohibits the sharing of confidential information with anyone particularly, without expressed written consent.

For clarity, it needs to be understood that this is not meant for emergency situations. Emergency situations must be immediately resolved and information shared, as needed, without written permission. Here's an example: Someone seeing a medical provider, who is threatening to harm themselves or another. The medical provider is a mandated reporter, by law and will take the necessary steps to secure the health and well-being of his patient. Mandated reporting is another topic, all-together!

Beyond Medical – Other Providers

Other Providers have the same responsibilities as Medical Providers. All rights and obligations remain. Examples of other providers would be:

- Mental health counselors and doctors.
- Chiropractors.
- Specialties.

Special note: It is your responsibility to understand and cooperate with your providers with co-insurance, co-payment, or any other financial obligation requested by your provider. To ensure that your insurance will pay for a provider of any type, contact your Insurance Provider's Members (Customers) Helpline or use your insurance provider's website. Providers rights and responsibilities does not mean insurance approval.

Also, you should ask the provider if they accept your insurance, when you are booking your appointment. All insurances are not accepted by all providers. This may be something for you to consider during open enrollment periods, with your insurance carrier. Not knowing, not checking, not authorizing does not mean you are not responsible for the bill!

Tips and Suggestions

Tips and suggestions for healthcare, is that possible? Yes, it is! Here are a few which we have not mentioned previously:

- Consult your insurance provider's hotline phone number or go online and visit their website. Most keep a current list of their approved medical providers by zip code or county. Find out which providers, and services, are provided or not.
- What if my provider is not covered by my insurance? Call the Members hotline number and talk with them about the provider and your needs. They may be able to get the provider covered.
- I have to go to the doctor in another town, who will provide my transportation? This is a bit complex, but start with your insurance company because many offer to assist in transportation arrangements or cost reimbursement. Your local transportation agency may also help. Contact them for assistance. Also, NICIL can offer you other potential options, based on your situation.
- I read the materials in this booklet and still don't want to see the medical professional or participate in a healthcare plan or treatment plan. Do I have to? No, you don't! As long as you are making an informed decision about the choice you are making. It is your choice, your responsibility, and your health. You are free to make this decision as you see fit, but you are not free to blame anyone else for your decision making. First and foremost, be informed!

NICIL has more than 35 year of experience in supporting the independent living movement. We assist in helping people with disabilities live the life of their choosing. Call us if you have question or concerns about any aspect of your life.

Conclusion

We hope that this guide has not only given insight into what to speak with your medical provider about, but also on how to plan a healthy lifestyle. We at NICIL believe that we can all live passionately and enjoy all areas of our lives every day!

The NICIL team is ready to help you with choosing your independent life, in any way we can. Our services for one-on-one sessions are free. Workshops, classes, and developing resumes do have a fee, and we would be happy to share our pricing schedule. Being independent is just that; your way, your choice! We want to be a part of this process! Call us for your appointment; we will be waiting!

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Resources

<https://www.nia.nih.gov/health/how-prepare-doctors-appointment>

<https://medicare.gov>

<https://www.illinois.gov/hfs/MedicalClients/Pages/default.aspx>

<https://www.ssa.gov/>