Diaper Information Sheet
For Children, Youth and Adults with Disabilities

Some children and youth with special needs may require diapers for a much longer time than what is considered to be typical. Others may need diapers throughout their lives. This document offers information that families may find helpful in coping with this expense.

Terminology
When seeking funding, remember that the official term is “disposable incontinent supplies”. In other words, do not ask the doctor/provider for a prescription for “diapers”.

Getting Started
Individuals insured by Medicaid/AllKids in Illinois - Person must be 4 years old or older. The upper age limit is 99.

Illinois Medicaid also has regulations on quantity allowed per month:
https://www.illinois.gov/hfs/MedicalProviders/notices/Pages/prn120615b.aspx

Private insurance companies - if they cover this service, may have different age limits). Diapers are rarely covered by private insurance.

Need from your doctor
1. Individual needs a letter of medical necessity from physician/doctor (e.g. - “John Doe is my patient. His diagnosis is ____________. Due to this diagnosis, he is not able to be toilet trained and requires disposable incontinent briefs in the amount of ____# per day)

2. Individual needs a prescription from physician/doctor in addition to letter.

Determine the third-party payor
This is the insurance provider that covers the incontinence supplies. It can be:
- Private insurance through an employer, Affordable Care Act, Union
- Medicaid/All Kids
- DSCC
- Other

Please Note: The Arc of IL Family to Family Health Information Center does not provide diapers.
Some combination of a-d above

Find a company/vendor
This is the company that sells the incontinent supplies and is willing to bill your insurance/third-party payor. Ask friends, classmates, and providers for names of companies/vendors in your area.

If you are enrolled in a Medicaid Managed Care (MCO) Plan, you can only obtain diapers from a vendor who is contracted with your MCO. You will need to first contact your Care Coordinator at your health plan. (If you need a Care Coordinator, please call the toll-free customer service number printed on your insurance card).

You cannot go into a retail store and pay for incontinent supplies with a Medicaid card or an insurance card. a medical supply store may accept a third-party payor but you will need to ask about this specifically.

Here is the link to the list of Medicaid Managed Care Plans in Illinois in 2020:
https://www.illinois.gov/hfs/MedicalClients/ManagedCare/Pages/default.aspx
You can also look online for vendors who will ship directly to you, and possibly bill your third-party payor. You need to find this out before you place an order.

Follow the rules established by your third-party payor:

- If you have Medicaid and private insurance - you can only use vendors who accept both forms of coverage. NOTE: Medicare does not cover adult diapers or incontinent supplies:
- You must get a denial letter from private coverage first before Medicaid will pay the claim if you have both forms of coverage (same rules apply if you have a Medicaid waiver as with “regular” Medicaid).
- You can only obtain supplies per the frequency and amount prescribed by your physician/doctor.
- If you have private insurance only, coverage may not be an included benefit - but submit a claim and appeal anyhow.
- You may be able to deduct “incontinent supplies” as a qualified medical expense from income taxes, if you qualify. See IRS Publication 502 Medical and Dental Expenses for more information:

What about a Diaper Service
You cannot include in medical expenses the amount you pay for diapers or diaper services, unless they are needed to relieve the effects of a particular disease.
If your child receives services from the Division of Specialized Care for Children (DSCC), contact your DSCC consultant for more information:  
http://dscc.uic.edu/find-an-office/contact-us/

**If you have no coverage**
Consider one or more of the following options to set aside money to cover the cost of incontinent supplies:

Health Savings Account (HSA):

ABLE Account (State of IL):
- [https://savewithable.com/il/home.html](https://savewithable.com/il/home.html)
- [www.kiplinger.com/article/insurance/T065-C001-S003-opening-an-able-account.html](www.kiplinger.com/article/insurance/T065-C001-S003-opening-an-able-account.html)

Contact the National Diaper Bank Network to locate a diaper bank in your area:
- [http://nationaldiaperbanknetwork.org/](http://nationaldiaperbanknetwork.org/)

Food banks sometimes have diapers available, or can refer to programs in your area that may be able to help. To find a food bank near you, see:

Ask friends and family to save coupons for you and watch for sales on incontinent supplies (a/k/a diapers).
- How to Find Diaper Coupons Online: [https://pocketsense.com/diaper-coupons-5177975.html](https://pocketsense.com/diaper-coupons-5177975.html)

**Additional Tips**
You will need to provide the diapers and other needed supplies at school and at other places/programs in which your child participates. Arranging for adequate supplies in all of your child’s environments is important.

It is essential to disclose or to share information about your child’s toileting needs up front with any caregivers and/or school staff.
Remember that in order to protect your child/family member, disposable gloves must be worn by caregivers and other staff during toileting and diaper changing.

- The family is usually responsible for providing the gloves (except for in medical facilities, school settings, group homes and other residential facilities).
- Disposable gloves are not typically covered by third party payors. They can, however, be included as a deductible income tax expense.
- Remember that you do not necessarily need to purchase “medical” gloves. Disposable gloves can often be found at lower prices at big-box home improvement stores, beauty supply stores, dollar stores and other discount outlets.

If your family member is allergic to latex, you will need to make sure that only latex-free gloves are used. It’s a good idea to get a doctor’s order documenting the need for latex-free precautions and make sure that this information is shared with anyone providing personal care for your child/family member. For more information on latex allergies see: http://www.aafa.org/page/latex-allergy.aspx

Children and adults who use incontinent supplies may have related skin conditions which require topical medications (barrier creams, diaper rash ointments, for example) and/or specialized cleaning products (wipes). These items may also be covered by a third party payor if prescribed by a doctor for the treatment of a specific condition. More information about diaper rash is available at: https://www.uwhealth.org/health/topic/symptom/diaper-rash/diras.html

Another helpful resource: https://www.rush.edu/services-treatments/psychiatry/autism-resource-center/elementary-school: click on “Incontinence Supplies”

Please feel free to contact The Arc of Illinois Family to Family Health Information Center with questions!
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Email: mary@thearcofil.org
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