Visit 7: Independent Living

Objective: At this visit you will have the opportunity to explore the skills needed for independent living and dealing with insurance, re-visit the Independence Capability checklist and discuss independent living.

In this section:

- Insurance Primer
- Health Insurance Terms
- Rate Your Independence Capability
- Resources – www.kaisernetwork.org/, www.kff.org/consumerguide

At this visit:

- Nutrition assessment- bring your 3 day food record to clinic
- Physical assessment- a brief visit with PKU doctor
- Re-visit Rate Your Independence Capability
- Discuss strategies for independent living
- Review Insurance Primer
- Confirm next visit

Who is involved:

- **You**
- Your support team:
  - Your parents
  - PKU clinic physician
  - PKU clinic social worker
  - PKU clinic nutritionist

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Health Care Insurance Primer

Adapted from: Spokane County Parent Coalition website,
http://www.spokaneparentcoalition.org/health_insurance_acronyms.htm

How long am I able to stay on my parents' insurance policy?

Be sure and read the Insurance Coverage Booklet that is provided to your parents by their employer or check the insurance company's website for coverage information. An adolescent is generally covered by parents insurance until age 18 unless he/she is a full time student then coverage is extended until age 23. Most plans require an annual documentation of student status after age 18.

What are my insurance options if I am a full-time college student and over 23 years of age?

Again, this requires some detective work on your part. The health insurance plan offered by your college or university may provide adequate coverage for general health maintenance and emergency care. It is unlikely this type of policy will cover medical food/formula for treatment of PKU. Another option is a COBRA (See **Health Insurance Terms and Acronyms**) which will enable you to stay on your parents' policy with the payment of an additional premium.

How do I know what the insurance terms mean, for example, PPO, self-referral, managed care?

Check the **Health Insurance Terms and Acronyms** list. Once you have a general idea about the meaning of a term, you will be more able to interpret the coverage of your policy.

What if I am offered a job but insurance coverage is not part of the employment package?

If you are working and living in Washington State, the Washington State Basic Health Plan (see below) may be the best option. If you are in another state, a similar program may be available.

What is the Washington Basic Health Plan and what are the criteria for enrollment?

The Washington State Basic Health Plan provides insurance to a person who is employed but is not offered insurance through his/her employer. The rules, guidelines, application process, and premiums change frequently. For the most up-to-date information check the website at **http://www.basichealth.hca.wa.gov/.** After you have checked the website, make a list of your questions, and call the PKU Clinic to ask for

help in clarification, if you need it. Remember, in order to keep insurance in effect you must pay the premium on time.

What questions should I ask my Human Resources Department about coverage?

Be sure that you know what your insurance options are. Once you know the basic choices, ask for detailed information. This information may be in a booklet format or on a website. For example, if Group Health is an option for you, check the Group Health website at http://ghc.org; then click on 'need coverage?' and the various coverage packages will be displayed. If you have questions, talk with your company's Human Resources Representative.

If I am having problems with my insurance, how do I approach solving the problem?

If you are covered by your parents' insurance policy:
1) Talk with your parents and be sure that they understand the problem in the same way that you do.
2) With your parents, work out a strategy to approach the problem/question by first reading the insurance booklet or the on-line information about coverage from the insurance company, then talking with your insurance representative.
3) If you are still having problems either understanding the problem or working out a solution, call Jan Garretson, MSW (206-543-2499).

If you are covered by your own insurance policy,
1) Work out a strategy to approach the problem/question by first reading the insurance booklet or the on-line information about coverage from the insurance company, then talking with your insurance representative.
2) If you are still having problems either understanding the problem or working out a solution, call Jan Garretson, MSW.

When do I need to obtain a new physician referral?

You will need a referral from your primary care doctor to the Adult PKU Clinic. Jan Garretson, MSW will help you with this process. Some referrals may last for 6 months, while others may last for a year. You will need to keep a record of your referrals and the date, so that you know when to get it renewed.

What are my insurance options if I have lost or will be laid off from my job?

It is important to talk with the Human Resources person at your job site before your termination date and ask specific questions about continuation of insurance. Depending on the circumstances of your termination may be possible to continue with the group plan of your company if you pay the premium; it may be possible to file for unemployment insurance; or it may be in your best interest to purchase a COBRA (**see Health Insurance Terms and Acronyms).** These questions are best answered by your company's Human Resources representative.

If I am having difficulties with my insurance coverage or problems understanding the terms of my insurance and formula coverage, what are the steps to take to get help?

1) Check with your parents, if you are still covered by their insurance policy, and ask for their help.
2) Look up your insurance provider on the web or call the company and ask for the reference materials they provide about your coverage. Read this material.
3) Contact Jan Garretson and describe your problems and ask for assistance or contact the Department of Health, Division of Genetics and describe your problems and ask for assistance.

Do I need to obtain a referral from my primary care doctor to the Adult PKU Clinic?

Yes, in most cases a referral from your primary care doctor to the specialty clinic (Adult PKU Clinic) is required. The referral should be obtained prior to your first Adult PKU Clinic visit. Referrals may be 'good' for a year or they may only be valid for 6 months. Ask you primary care doctor to write the referral to cover the longest time frame allowed by your insurance.

How do I obtain information about what services my policy covers?

There are many resources available on the web. We have provided you printouts of two websites as examples. Both http://kaisernetwork.org and http://wwwkff.org/consumerguide describe on-line resources. These may be directly helpful to you or serve as examples of the type of information to look for from your insurance company.

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Health Insurance Terms

Adapted from: Spokane County Parent Coalition website,
http://www.spokaneparentcoalition.org/health_insurance_acronyms.htm

Acronym or Term	Definition
Acute Care	Medical care provided in direct response to an illness, injury, or other condition. Acute care contrasts with preventive care, which tries to reduce the chances of acquiring a condition.
Allowable expenses	The necessary, customary, and reasonable expenses that an insurer will cover.
Ambulatory care	Health care that does not require a hospital admission, also called outpatient care. Commonly provided in a doctor's office, clinic, or health center, but can also be provided in a hospital.
Anniversary date	The date on which a health plan with an employer or an individual is renewed each year. It is the date when premium costs and benefits are most likely to change. It may be preceded by an "open enrollment period," when employees have the option to switch health plans.
Annual maximum limits or caps	The limit an insurance plan sets on a given service. It may be a certain number of visits or a dollar amount. If you need more of a given service than is allowed by the limits in your plan, you will need to request an exception.
Behavioral health care firm	Specialized (for profit) managed care organizations, focusing on mental health and substance abuse benefits, which they call "behavioral health care." These firms offer a managed mental health and substance abuse benefit.
Benefits or benefit package	The health care services covered by a health plan or health insurance company, under the terms of its member contract. Terms of the contract also include any cost sharing required (e.g., co-payments, deductibles, or coinsurance), limitations on the amount or length of coverage, and conditions (e.g., the requirement to have care authorized in advance and delivered within the HMO network).
Certificate of insurance	A description of health benefits included in a group health plan, usually given to insured members by the employer or group.
Claim	The documentation of a medical service that was provided to a covered patient by a doctor, hospital, laboratory, diagnostic service, or other medical professional. A claim is filed with the insurer by the provider or the patient to request payment (or reimbursement) for the service.
Clinician	A term that is often used to describe all types of medical professionals who care for patients: doctors, nurse, physicians' assistants, therapists, etc.
Co-payments (or coinsurance)	An amount a health insurance policy requires you to pay for medical service, after payment of a deductible. Some plans require a co-

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Acronym or Term	Definition
	payment to be a percent of the charge for the service (e.g. 20%). It may vary based on the type of service or when the service was received (for example within a certain number of days of an emergency) or where the service was received (outpatient vs. inpatient). It can also be a fixed amount (e.g., $20), regardless of the cost of the service.
COBRA (Consolidated Omnibus Budget Reconciliation Act)	A federal law that includes important benefits for individuals who lose their employee health insurance because of a loss of job or a death or because they are too old to be covered by their parents' policy. This law provides the opportunity to continue the same insurance coverage for 18-36 months. The individual is responsible for paying the full insurance premium. There may also be language in your policy on provisions for continuing the same coverage. The Insurance Commissioner in your state or your employer may offer information on your rights for continuation.
Coinsurance	A cost-sharing arrangement typical of traditional health insurance, in which patients pay a portion of the cost of certain covered medical procedures, usually on a fixed percentage basis. For instance, patients might be required to pay 20-30% of the cost of their doctor's office fees or hospital charges for services they received. Usually coinsurance payments begin after an annual deductible is met.
Coordination of benefits	The process for how benefits will be applied if you have more than one private health coverage plan. Regulations on coordination of benefits may exist within your state, or your insurance plan may describe how such coordination should happen. Usually one plan is designated to pay all claims first and the remaining bills are the responsibility of the secondary carrier. These provisions are to prevent individuals from collecting more than once for the same medical charge.
Deductible	The amount that you must pay out-of-pocket for covered medical care before the benefits of the coverage begins. Check what this amount is per family member. There may also be a total family limit. Deductible amounts vary a great deal from policy to policy. Deductibles are usually set as an annual amount.
Documenting	Keeping written records relating to your family's medical care and insurance. You may need detailed records to support your case if you disagree with your insurer.
Effective date	The date on which coverage under a health plan or insurance contract begins.
Employer contribution	The amount of money an employer pays toward the health benefit plans of its employees. The employee's portion of the health plan premium is typically paid through a payroll deduction.
Enrollment Area	The geographical area within which a health plan member must reside in order to be eligible for coverage. Most HMOs place a limit

Acronym or Term	Definition
	on the length of time members (except students) can live outside the enrollment area each year and still be covered.
Estimate of benefits (EOB)	The statement from your insurance plan that itemizes the actions taken on claims that have been submitted.
Exclusion	A treatment or service that is not covered by a policy.
Exclusive provider organization	A health care payment and delivery arrangement in which members must obtain all their care from doctors and hospitals within an established network. If members go outside, no benefits are payable.
Experimental treatment	Medical treatment not covered by insurance companies or public programs because it is considered unproven. Insurance companies may reject claims when they decide that the treatment is experimental. Individuals have won claims by proving that other insurance companies have paid for the treatment in question, or that the treatment has been beneficial in other instances.
Fee for service	A form of payment where a provider is paid for each service, supply, or equipment.
Formulary	A list of prescription drugs and their recommended doses, which have been selected by a health plan, insurer, or group of doctors as the best choices, in terms of effectiveness and value. Formulary drugs may be required as a condition of HMO prescription drug coverage (unless individual circumstances make a different drug a more appropriate choice for the patient).
Gatekeeper	A term given to a primary care physician in a managed care network who controls the patient access to medical specialists.
Gatekeeper PPO	A health care payment and delivery system consisting of networks of doctors and hospitals. Members must choose a primary care physician, use doctors in the network, or face higher out-of-pocket costs.
Grace period	A period of time after a premium is due but before payment is received during which your health coverage is still in effect. States may have laws requiring health insurance policies to allow a set number of days of "grace".
Health screening	A method used by some insurers and health plans to determine whether applicants are likely to create high medical costs, either because they are already sick or because they are likely to have a costly illness in the future. Health screening is used to detect preexisting medical conditions and to determine whether the applicant is at risk for illness because of factors like excessive weight or a past history of drug abuse.
Inpatient	Medical care that requires the patient to occupy a bed in a hospital. Not all hospital care is inpatient care; a patient can also receive "outpatient" care in a hospital's emergency room or ambulatory care center.

Acronym or Term	Definition
Lifetime maximum	The total amount that an insurance policy will pay out for medical care during the lifetime of the insured person. Check into other options (e.g., enrolling in another group plan during an open enrollment period) well before you approach a lifetime maximum.
Limitations	Factors (such as preexisting conditions) which allow an insurer to avoid paying for a service that would normally be covered.
Lock-in	The requirement that members of an HMO or other managed network health plan must have all of their covered services provided, arranged, or authorized by the plan or its doctors, except in life-threatening emergencies or when members are temporarily "out of area." This contrast with a "point-of-service" plan, which allows patients to receive covered services without prior authorization but at a high cost, outside the plan's network.
Managed care	A health care system that includes arrangements with providers to supply health care services to members, criteria for the selection of health care providers, significant incentives for members to use providers in the plan, and formal programs to monitor the amount of care and quality of services.
Mandated benefits	Specific benefits that insurers are required to offer by state law. Each state has its own legislation on mandated benefits.
Medically necessary services	A clause in a health insurance policy that states that the policy only covers services needed to maintain a certain level of health. The clause also defines what those services are. Be sure to find out exactly what those services are. This information will help you to present your request in the most appropriate way.
Open enrolment period	A period when you may sign up for a health coverage plan without waiting periods or consideration for preexisting conditions. Many employers offer these periods yearly. You may be offered an open enrollment opportunity when you begin a new job.
Opt-out	The option available through some managed care network plans to choose to receive care from providers outside the plan's network, at a higher cost, and still be covered.
Out of area	Beyond or outside the geographical area served by an HMO or other managed network plan. When HMO members are inside their HMO's service area, they must have their care provided, arranged, or authorized by their HMO or HMO doctor in order to get full coverage; when they are temporarily out of area, different coverage rules apply.
Out-of-plan services	Services furnished to patients by providers who are not members of a patient's managed care network.
Out-of-pocket costs	All the health expenses that you pay yourself, including deductibles, co-payments, and charges not covered by any health plan.
Outpatient benefits or coverage	Treatment or services received in a setting (such as a clinic or doctor's office) where no room and board is charged. Check the outpatient benefits in any plan you are considering carefully, since

Acronym or Term	Definition
	most of your care will take place on an outpatient basis.
Participating providers	A physician who signs a contract with a traditional, PPO, or HMO plan and agrees to accept the plan's allowable charges.
Point of service	A term that applies to certain HMOs and preferred provider organizations. Members in point of service HMO or PPO can go outside the network for care, but their reimbursement will be less than if they had remained inside.
Preexisting conditions	Physical or mental conditions that have been treated or would normally have been treated before enrollment in an insurance plan. Policies may exclude coverage for such conditions for a specified period of time. In some cases, preexisting conditions exclude a person completely from buying health insurance; or the insurance company may decide to charge higher premiums or offer the insurance but refuse to cover any treatment relating to the specific condition.
Preferred provider organization (PPO)	A form of managed care plan in which a group of providers agree to provide services at pre-negotiated fees. Members must have a primary care physician who is a member of the PPO. Members are given incentives to use providers within the organization, but may use providers outside the plane for higher out-of-pocket costs.
Premium	The charge that you pay to the insurer for the health coverage. This may be paid weekly, monthly, quarterly, or annually.
Prepaid plan	A health insurance plan where you (or your employer) pay a fixed premium to cover much of the care you receive. Prepaid plans include HMOs and PPOs.
Preventive care	Medical services that try to reduce the chances of illness, injury, or other condition. This contrasts with acute care, which is given after the condition has occurred.
Primary care	Routine medical care, usually provided in a doctor's office.
Prior authorization	Before services are rendered, approval from the insurance plan or a designated primary care physician must be obtained or the service will not be reimbursed.
Prolonged illness clause or extended benefits	A possible option in your coverage for 100% reimbursement (instead of partial) for all services relating to your condition. This option may also add to your child's lifetime maximum.
Provider	A hospital, outpatient facility, physician, practitioner, or other individual or organization that is licensed to provide medical or surgical services and accommodations.
Referral	A formal process by which a patient is authorized to receive care from a medical specialist or a hospital. HMOs usually require a referral from the member's primary care doctor or the HMO in order for specialty care to be covered.
Renewal	The clause in your insurance plan that describes how you might

Acronym or Term	Definition
	renegotiate the contract after the term is finished. Guaranteed renewability of an insurance policy protects you from losing your coverage, although the insurer may still raise the premiums.
Report card	A published report for consumers on the premium costs for a plan and overall quality of a health plan or provider. Report cards generally include measures of the plan's delivery of appropriate services, patient outcomes, patient satisfaction and cost structure.
Rider	A legal document added to an insurance plan that either restricts or adds to coverage. States may have regulations about riders.
Self-insured	Some places of employment write their own plans to cover health care costs for employees. Benefits and costs are determined by the employer. These plans may be administered by an insurance company, or involve and insurance company.
Self-referral	The ability for an HMO patient to refer himself or herself, under certain circumstances, for specialty medical care, without receiving a formal referral or prior authorization form the patient's HMO or primary care doctor.
Service Area	The geographical area within which an HMO or other managed care network plan provides and arranges medical care for its members. This area is sometimes the same as the plan's enrollment area, but not always.
Single-point of entry	An individual can gain access to services only through a primary-care provider who decides what services are needed (see Gatekeeper).
State insurance regulations	Every state has laws and regulations that govern insurance companies operating within the state. There is also a state process for filing complaints and appeals. Check with your state Commissioner of Insurance for information.
Stop-loss	A clause that limits your liability to a specified amount on medical expenses covered by the policy. After expenses reach that amount, the insurance company would pay all of your remaining covered medical expenses for the year including deductibles and co-payments.
Waiting period	The period of time required by the insurance company after a person is covered by a policy before specific health services are covered by the plan. This time can vary from a number of months to a number of years.

RATE YOUR INDEPENDENCE CAPABILITY

Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
PKU and Other Medical Care					
I can describe PKU to others					
I feel comfortable explaining PKU to friends/acquaintances					
I understand how my lifestyle choices affect PKU management					
I am responsible for drinking my own formula					
I am responsible for making my own formula					
I know how many cases of formula I use in a month					
I know who to call to order my formula					
I record my food and formula intake					
I can calculate my daily phe intake					
I know how to order low protein food for myself					
I can do my own Guthrie blood draw					
I know how to obtain genetic counseling					
I have identified a physician for my adult care					
I can call to schedule my own medical and dental appointments					
I keep a calendar of medical and					

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Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
dental appointments					
I can arrange transportation to the medical and dental office					
I can respond to questions from my doctor and nutritionist					
I can prepare and ask questions for my doctor and nutritionist					
I know the steps to get information from my medical records					
I know how to get a prescription filled/ refilled					
I can get referrals for my PKU needs					
I know who to call with medical insurance questions					
I know how to find out what my health insurance coverage is					
I know where to find information and resources about contraception and reproduction					
I know how drugs and alcohol affect PKU management					
I know how to use and read a thermometer					
Household Tasks					
I am responsible for waking myself in the morning					
I know how to use a washer and dryer and can do my own laundry					

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Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
I can perform minor household repairs (change light bulbs, reset the circuit breaker, paint, fill holes in walls)					
I can unclog the sink or toilet					
I can do basic sewing tasks					
I can operate appliances (stove, oven, microwave, toaster, dishwasher**)**					
I know how to use common kitchen tools (can opener, knife, measuring cups and spoons, timer)					
I know how to read food labels and can estimate the amount of phe in one serving					
I can shop for groceries and purchase appropriate foods for myself					
I can cook a meal for myself					
I can cook a meal for others					
I can pack a lunch for myself					
Education and Employment					
I keep track of my assignments and when they are due					
I plan a study time and then study					
I turn assignments in on time					
I know how to make an appointment with my school guidance counselor					

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Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
I have thought about future educational options					
I know how to find out about job opportunities					
I know how to get information from colleges					
I know several people who will write references for me					
I know how to apply for a job and/or for college					
Living Arrangements and Money Management					
I know how to open a checking/savings account					
I balance my checkbook regularly					
I save money in a savings account					
I know how to use a credit and/or debit card					
I budget for my allowance or earnings					
I arrange transportation for myself, e.g., school, job, groceries					
I know how to fill out a rental application					
I can arrange for hook-up of services: electricity, phone, water					
I know the responsibilities of a tenant and landlord					
I understand leases/rental agreements (house, apartment,					

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Skill	I can do this on my own	I can do this with some help	I am working on this	I plan to work on this	My plan to develop this skill
car)					
I know how to apply for renter's insurance					
I know how to apply for car insurance					
Emergency – think about your house now and know you will need to develop a plan when you are living on your own					
I know where to call if an emergency happens					
I know where the closest hospital is located					
I know when to call my insurance company for emergency care					
I have a first aid kit and know where it is					
I know the planned fire exits and emergency procedures					
I have a fire extinguisher					
I can use a fire extinguisher					
I know where candles and flashlights are kept					
I know community emergency telephone numbers (gas company, electric company)					
I know where an extra house key is located					

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Assessment of PKU Adolescent Transition Curriculum

Session 7.

Objective: At this visit you will have the opportunity to explore the skills needed for independent living and dealing with insurance, you will take another look at the 'Rate Your Independence Capability' form, and discuss your plan for living independently of your family.

Post Session Objective: Each participant will be able to explain important skills needed for living independently of family and dealing with health insurance.

I. Please tell us three things that you have learned during this visit
1)
_____
2)
_____
3)
_____

II. How often do you look for health information on the web?
_____

III. How do you decide if the site provides reliable information about PKU or other health concerns?

_____

_____

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