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Many persons noted problems and issues due to lack of coordination of care among multiple care providers.

"ONE PHYSICIAN INSTRUCTED ME TO LEAVE AN ARTIFICIAL EYE OUT FOR ONE MONTH DUE TO EYELID INFECTION, WITHOUT CONSULTING A SPECIALIST--AS A RESULT THE EYE SOCKET SHRANK AND I HAD A LOT OF PAIN IN REINSERTING THE PROSTHESIS WHICH ULTIMATELY HAD TO BE RE-MADE SO IT WOULD FIT PROPERLY. ALSO MEDICATION GIVEN TO PREVENT A FURTHER EYE PROBLEM HAS HAD NEGATIVE REACTION WITH OTHER MEDICATIONS I WAS TAKING."

Over and over people wrote that no one was coordinating their care among multiple doctors/specialists, that the doctors never seemed to be communicating with one another, and there was no one health care provider tracking all the medications involved which often resulted in negative health reactions.

Many persons who are presently in HMOs noted they were not free to go to doctors they had seen for many years because the doctor was not a member of the HMO and the consumer could not afford to pay the out-of-pocket costs for seeing a doctor outside of the plan. When proper referrals are made it can take an inordinate amount of time to see the needed doctor.

"I SOMETIMES WAIT 3-4 MONTHS BEFORE A REFERRAL APPOINTMENT CAN BE MADE--IT TOOK ME 4 MONTHS TO GET A REFERRAL APPOINTMENT FOR THE PAIN CLINIC TO GET A SHOT FOR MY BACK PAIN."

"I OWE SO MUCH MONEY TO HEALTH CARE PROVIDERS THAT IT IS DIFFICULT FOR ME TO ARRANGE TO HAVE A TEST THAT I HAVE BEEN GIVEN A PRESCRIPTION FOR--I FEEL LIKE A SABER IS HANGING OVER MY HEAD AND IT IS GOING TO FALL ANY TIME, THEN I WILL GET NO MORE HEALTH CARE TREATMENT AND/OR HAVE NO MONEY TO LIVE ON AFTER ALL THE BILLS ARE PAID."

Because there are so few doctors who accept Medicare/Medicaid, many persons do not get the health care they need until they become so ill that they must go to emergency rooms or are directed by doctors to go to emergency rooms because the doctor will not see them in his/her office.

"THE DOCTOR HAS TOLD ME TO GO TO THE EMERGENCY ROOM WHEN HE IS TOO BUSY TO SEE ME IN HIS OFFICE, THIS COSTS MORE AND MAKES ME FEEL THAT THE DOCTOR IS UNCONCERNED ABOUT ME."

Medicaid had to authorize payment for a person's transportation to the doctor when the closest doctor was in another town, not once but for each doctor visit.

**"I MUST HAVE MEDICAID OK EASTERN
TRANSPORTATION TO PROVIDE TRANSPORTATION TO
FALMOUTH, MAINE TO BE TREATED BY THE ONLY
DOCTOR IN THE STATE WHO TAKES MEDICAID--I NEED
HELP."**

Services and/or treatments needed but not covered:

- Prescription medicines
- Personal assistance services
- Chiropractic services
- Dental care
- Purchase and/or repairs to durable medical equipment
- Preventative treatments (such as flu shots, mammograms, routine preventive checkups)
- Health maintenance services
- Alternative medical treatments (such as acupuncture, chiropractic services holistic medicines)
- Hearing tests and hearing aids
- Medical supplies
- Mental health services
- Physical therapy
- Vision testing and eye glasses
- Assistive technology

How the Current System Affects People with Disabilities

The types of services respondents said that they needed in order to maintain optimal health included:

- 79% needed services for disability related health problems and illness;
- 69% needed general health maintenance services;
- 65% needed general preventive/health promotion services;
- 61% needed services for routine health problems and illness;
- 60% needed dental health services;
- 54% needed disability-related health maintenance services;
- 32% needed personal assistance services;
- 29% needed acute care services;
- 24% needed disability-related acute care services;
- 22% needed psychiatric, psychological, or other mental health services;
- 16% needed durable medical equipment or assistive technology.

How Satisfied Were the Respondents With the Current Health Care System?

Other problems identified by respondents included:

- 48% cited inadequate insurance coverage;
- 45% cited lack of understanding of the health care needs and concerns of people with disabilities by physicians and other health care professionals;
- 38% cited inadequate preventive and health maintenance services;
- 34% cited inadequate coverage for assistive technology services;
- 32% cited problems with access to treatment and services;
- 30% cited unresponsive insurance companies and rude and discourteous providers and administrators; and
- 24% cited inadequate personal assistance services to maintain optimal health.

How Satisfied Were the Respondents With the Current Health Care System?

When asked to identify the biggest problem with the current health care system, 73% of the respondents said that the high cost of treatment represents the biggest problem that they had encountered with the system.

How Satisfied Were the Respondents With the Current Health Care System?

When asked if the health care system in this country had gotten better, worse, or stayed the same over the last five to ten years, 47 percent of the respondents indicated that the system had gotten worse.

Types of Insurance Coverage Reported by the Respondents

- 34% had Medicare or SSDI;
- 26% had Medicaid;
- 25% had employer-provided insurance;
- 16% had personal health insurance;
- less than 3% had military or veterans health care benefits; and
- a number of other sources of health care coverage were cited, including federal employee disability health care, state high risk programs, and other special public and private programs.
- 7% had no health insurance coverage

How the Current System Affects People with Disabilities

Other key findings -- Continued

- 24% had been denied health care services because of lack of health insurance;
- 46% had been faced with not buying items that they wanted or needed in order to save money to pay for health care services;
- 21% had developed disability-related health problems because health care coverage was lacking or inadequate;
- 16% had experienced additional functional loss because of inadequate health care coverage for needed services; and
- 23% had experienced limitations in work or recreational activities as a result of lacking or inadequate health care.

How the Current System Affects People with Disabilities

Other key findings related to health care coverage included:

- 26% had been denied insurance coverage;
- 16% had been dropped or canceled by an insurance company;
- 23% had been denied employment because of a health-related problem;
- 21% had chosen not to work so that they could remain eligible for public health insurance;
- 35% had been unable to change jobs because of concerns about being covered for pre-existing conditions, limitations in health care coverage imposed by a new employer, and/or lack of coverage by a new employer;

How the Current System Affects People with Disabilities

Over two thirds (67%) of respondents reported that they were not receiving the kinds of health care services that they needed to maintain optimal health. The range of reasons cited for this included limited insurance coverage, lack of access to health care providers, and exclusions based on pre-existing conditions.

How the Current System Affects People with Disabilities

Over two thirds (67%) of the respondents indicated that they were not receiving the kinds of health care services needed to maintain optimal health.

Intro/Background Page

- ILRU with support from RWJ conducted an informal, self-respondent survey of persons with disabilities.
- Nearly 750 people with disabilities completed and returned the 12 page 49 item survey to ILRU.
- The overall picture appears to suggest that the current health care system is particularly hard on people with disabilities and chronic health conditions.