Jane Griffin, MPH, Case Studies from HCBS Snapshot Survey, MCH Evaluation, Inc., February 9, 2010.

## Case Studies From HCBS Snapshot Survey

- Sister, who is caretaker of client, said her sister was brought home on Mother's Day by the police for shoplifting at CVS. Client is bipolar and in a wheelchair. She assaulted her caretaker sister and ended up in Butler and then a nursing home. Sister says she can no longer take care of her because she has to go on dialysis 3 days a week. She thinks her sister needs her own apartment with a 24 hour companion.
- Woman is losing her vision, has glaucoma and cataracts. She will be completely blind soon and needs someone to help her read official letters and notices for health insurance and other government notices. She just received letter that she will lose her Blue Cross/Optima coverage. She is very nervous.
- He received all services when he was in a coma. His case manager is very helpful and got him a roll-to bed that keeps him moving left to right and helps his circulation. He has lost both legs and has everything he needs to stay in his apartment. He does not want helpline because it calls his sister not "911" when he has an emergency.
- Woman who had a stroke whose adult son (age 52 with Cerebral Palsy) is her caretaker. She is very worried about what will happen to him when she dies. She can't find anyone to fix/repair her hand held shower. She got an electric wheelchair but it is too large for her apartment. She would like to exchange it for a smaller scooter.
- Client needs repair of her electric wheelchair, battery only lasts 1-2 hours. She cannot get it repaired until January 2010. She needs guard rails for her bed, but cannot pay out of pocket.
- Woman is living with bipolar daughter who is her caretaker. She would like to join YMCA for pool therapy for arthritis. Things that would help her stay at home 1) landline phone so she could have "Lifeline" 2) her old car needs repair and tune-up 3) needs washer and dryer laundry is a dilemma and 4) Basic Cable TV.

- Client with severe morbidity would really like to be in a day program. She is alone during the day. She needs chucks, but cannot get them paid for. She also cannot put her groceries away.
- Client is severely disabled, blind with chronic diseases and has no sense of taste or smell. She is petrified of fire and wants to be moved from the 4<sup>th</sup> floor to a 2<sup>nd</sup> floor apartment in case of a fire.
- Client says she is a fighter and although nothing works from the neck down, her brain is strong and she does not want to go to a nursing home, and wants to die at home. Needs wheelchair repaired that she uses to go from bed to bathroom.
- Woman with several chronic conditions including osteoporosis, several surgeries, heart attack, diabetes. She has a wheelchair, but would also like a walker with seat to exercise her legs. Her raised toilet seat is broken and would like to get out of the house. She was recently attacked in her apartment and fought off intruder with a phone.
- Client has lived with his mother for 20 years. He is main caretaker and just built her a ramp. He cannot afford to take care of her anymore and has to put his house up for sale and plans to find her housing.
- Does not understand why she does not qualify for meals on wheels when she is disabled and homebound. Needs her tub cut to make bathing easier, but cannot find anyone to pay for it. She finds the RIDE scheduling service "grumpy". They have poor attitudes and never listen to her concerns. She has missed several appointments because there was not enough time allotted to pick her up.
- Client is on oxygen 24/7, has diabetes and heart failure. She has a wheelchair that she paid for out of pocket, because she already has a scooter. If she doesn't get more CNA hours (only has 3 hours a day) she will have to go to a nursing home.

- Client says services take too long to get so had to buy "Lifeline" out of pocket, also worried about paying more for drugs in January. She is 82, lives alone and is on a fixed income. She weighs almost 400 pounds and her raised toilet seat is cracked and her wheel chair is broken.
- Client has trouble getting out of chair and needs a "stand-up" chair. This was denied so she is confined to bed. She needs an overnight CNA and bedrails. Right now she uses her walker to block her in at night.
- Rent was just raised for this male who is paralyzed. The increase makes it hard for him to buy food for himself and his service dog. Pays for a lot out of pocket including Chucks and his wheelchair.
- Woman is bedridden with several health problems and weighs 80 pounds. She can't stand very long and falls a lot. Her daughter stays with her a lot and her son shops and pays bills. She gets very depressed because she can't get out. She needs a small regular wheelchair, not a scooter. She has not heard from social worker in a long time. She feels she would benefit from a hospital bed and a visiting nurse to take her vital signs and do blood work since she can't get out. She loved to read.
- Woman with MS who lives in handicap accessible high-rise. Due to her MS she falls a lot and broke her ankle. Needs a "Lifeline" but can't afford land line phone. The RIDE schedulers are "nasty" when you call for service.
- Daughter lives with mother and both are in wheelchairs. She would like someone who could do heavy housework and clean kitchen appliances, scour bathroom floors and wash curtains. Right now she says it is a 'guessing game" to figure out what Medicaid pays for. "No one will tell you anything" she says, she would a booklet that tells what you are eligible for. NHP gives a booklet that tells her the benefits she is eligible for. She needs a manual wheelchair to use when she goes food shopping with her friend. She would like to go to senior centers but was asked to leave (Providence & Cranston) because she is <65.
- Elderly woman who is very frail and only wants to stay in her apartment. She cannot go out. She likes to use scooter around her apartment, can not operate a wheelchair.

- Client has had several strokes. She lives in a high rise building that is handicap accessible. She likes Fox Point Center, but they won't allow her back because she doesn't live in the community. Her CNA is unreliable and does not show up for days at a time. She stopped Meals on Wheels because there is too much salt.
- Client is a frail, elderly, blind 90 pound woman who cannot stand. She has a CNA for three 2 hour shifts and is satisfied. She said "Everything is gone, but my brain, but as long as I can listen to my radio programs I'm happy." "I just don't want to fall."
- Client got a wheelchair that was not the one she needed, but she is not able to send it back (that makes her crazy). If she can keep her wheelchair operating and she is mobile then she will be fine.
- Client is a diabetic with one leg. Her wheelchair needs repair. She does not feel safe in it and lives alone. She has asked her case manager for help but has not heard back from her in three months.
- Woman with Multiple Sclerosis who needs more CNA hours. Currently CNA comes 9-2, but she needs early evening hours for dinner and bed. She needs her electronic wheelchair repaired. It only lasts 1-2 hours with an overnight charger. She got stuck at doctor's office. Her bathroom is a mess and the tiles are loose.
- Husband, whose wife has MS and Bipolar Disorder, has been his wife's caretaker for 45 years. She can never be left alone. He is extremely positive and is very thankful for homecare services and equipment from Medicaid. The biggest barriers to receiving services were filling out original forms to determine eligibility. He found the forms misleading. He attended a two week seminar and then reapplied and was accepted. His wife gets CNA services 40 hours a week and he gets respite. His wife has an electric wheelchair and bathroom and bedroom lifts which are a great help.

• Sister responded to survey and said her sister had just been admitted to a nursing home due to severe mobility problems. She had a CNA two hours in

the morning to help her eat and get dressed. Meals on Wheels brought her lunch and then CNA came to fix her dinner and put her to bed. She needed someone at night to help her get up to go to the bathroom, but they couldn't get that so she went to a nursing home.

- His wife is bedridden and contracted so cannot do anything or go anywhere. She relies on a feeding tube. She needs a podiatrist to come to the house and treat her feet. He watches her toenails for infection and will have to take her to the ER if she needs treatment. She cannot leave the house for medical care so he has to call an ambulance to bring her to the hospital if she needs to be seen. Wishes a doctor could make an annual visit to check on her and evaluate if husband is making right medical decisions. He is very grateful for Medicaid services.
- Two sisters, both disabled, live in family home. One has a tracheotomy and a g-tube to eat. Caretaker sister has COPD and heart disease. They cannot afford to stay in family home and SSI payment was just cut. The equipment they have (gerry chair and lift) is old and breaking. Medicaid only pays for one trach mask a month and sister needs one a week. They have enough CNA hours but need equipment and supplies.
- Daughter answered survey. Mother has alzheimers and lives with daughter and 4 year old granddaughter. She needs a new shower stall because CNA cannot wash mother in the one they have. When daughter had a mastectomy and was recovering at home she wished someone could have helped her at night with mother, but she was told she wasn't eligible.
- Both husband and wife are disabled and on Medicaid. She has had MS since age 19 and husband has spinal cancer. Husband can no longer get wife in and out of car and needs a lift. Husband's worst fear is when he goes for surgery there will be no one to take care of his wife while he recovers. He finds petitioning process extremely exhausting.