



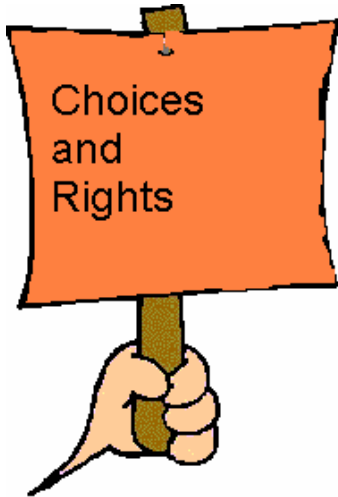
## Appendix F

Presented by Asmila Acharaya

# Speaking Up For Yourself In Brent

## **Against the cuts**

# Our rights are important



- People with learning disabilities are discriminated against by the health service.
- We die earlier than other people. We are not treated, we are not screened for cancer, we are not resuscitated.
- The government tried to change the system, they wanted us to get services quicker for the services to be accessible. For us to be involved. They wanted services to listen to us.
- Now two or three years later services are being taken away. Why?

# Community Intervention team

- We were consulted about this. We said we wanted a community intervention team. We chose to be treated at home. We don't want to be locked up in hospitals anymore..
- Kingsbury Hospital has fewer beds. The mental health wards at Central Middx have no skills in working with people with learning disabilities. They don't want to understand. They send us away. Will we lose treatment. What will happen when things go wrong.
- If behavioural problems are not treated we will be at risk. They will get worse and people will lash out at us.
- We want exercise, we want to do sports. What happened to the sports plan we discussed. How are you going to involve us in sport.
- Are our person centred plans and health action plans at risk? There is a long waiting list for PCP's. My PCP has gone to the toilet.



# Speech and Language



- Speech therapists also help carers find ways to feed us. What will happen if someone cannot feed themselves?
- I learned how to help people who cannot speak. We need the skills. Where are we going to learn from. What will happen to people if people cannot understand what people are saying, if they can't say what they want. Will these people just be shouted at because people don't understand.
- Who is going to tell staff how people communicate when they are new to a centre or moving on.
- What about the accessible information group? Who is going to lead on this if the therapists go?

# Physiotherapy

- The therapist comes every Friday. They do exercises with me. She takes three students. One of us uses the exercise bike. We do work on the mat. Sometimes in the gym, sometimes in our classroom. It helps me feel good.
- For me they took me to my limits. They took me to the point where I could not do things. I can now carry on as I am and I can accept this. Who will find out what other people can do when there isn't a physio?
- I can keep on moving because the physio comes to the centre. They keep me supple. My muscles move. What if they stop coming. Are my muscles going to stop. Am i going to have to crawl.



# Epilepsy



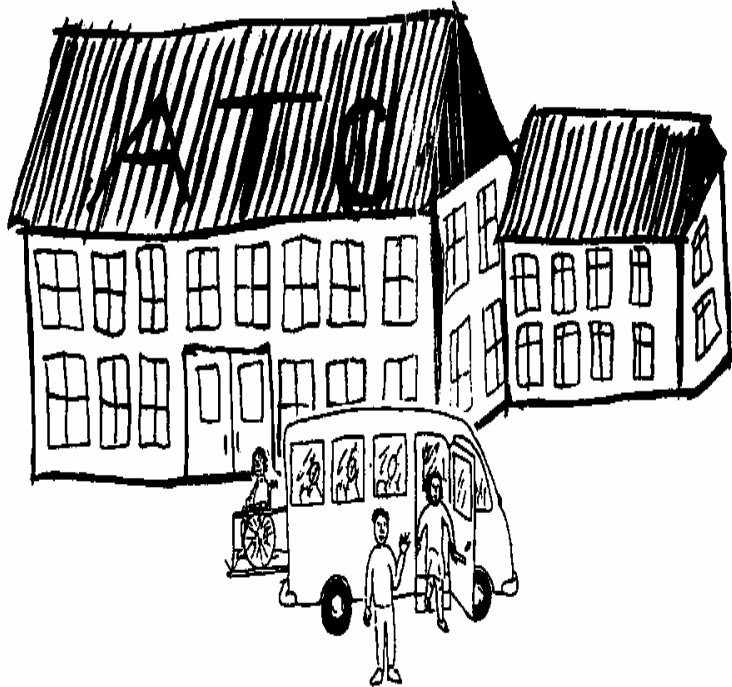
- The nurse asks me if I have any worries. The more I worry the more I have epilepsy. Flashing lights will set off an attack, When I am having an attack, I go to the floor, my body goes stiff, I do not know what has happened, I forget what happened before the fit started. When I am angry I might have a fit. My heart pumps. I shake. I can also get fits if it's too hot. The nurse identified these things. She helped me to find ways to deal with it. I can now go and talk to others about it. I am an expert patient. It would devastate me if I lost the nurse. The fits would continue. My life would be in jeopardy, I would simply be taken to hospital. When I go there it shocks me and shocks my family.
- Who will be there to advise? Who can I talk to? Who can I work with now? Why are my services getting worse?

# Loss and Bereavement

- He helped me learn to cope with my bereavement. He helped me stop taking it out on others. I can control how I think about things. I can remember the good and the bad about the person I lost. I would have been worried, taking it out on everyone else and I would be really, really hurt without this service.
- He helped me when I lost my father, Nan and granddad. I told him about losing a student friend. If you have any worries you have to talk to someone about it. It's no good just sitting there and bottling it up. It won't help. It helped me because i could talk to my mom a lot. It would have been worse for me without him.
- it will be a shame if he lost his job. It is not fair on the workers who lose their jobs. We have worked with them a lot. Why are you being mean to them and to us.?



# Neasden Day Centre



- Its likely to close. It was run by the NHS. They want to sell the building and the site. There is nothing in the plan about the people who go to Neasden. Some people may go to Albert Road. Those who live in residential accommodation will be supported by carers in the home to do things in the community. Friendship groups may be set up. People who live at home will be assessed for other services. .
- What will happen to our centres.
- What will happen to all those plans we've made over the years about day service modernisation?



# Where we stand today



- You want us at these meetings, you want us there but are you really listening to us. Do you have any respect? Do you care that these services are important to us?
- We are ready to take action. We should not suffer because of the cuts.