

# New Models for Learning Disability Day Support Collaborative

## Design Persona: Karen

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Improvement Hub

Enabling health and  
social care improvement

## Introduction

Hi my name is Karen; I am 17 and soon to be 18. I am about to leave school.

I live with my parents in the North of Scotland in a semi rural place. My mum and dad are very supportive and great advocates. They also provide all my personal care and support. I also have 8 hours self directed support to employ a support worker to go out for a few hours at the weekend. My support worker also helps me with my study when I was studying for my Highers. She helps me write and helps to support me going into town and do things. We found this person through friends and parent works connections because we didn't know how to advertise for these jobs and social work didn't support us through this process. So, we did it ourselves. I am also going through health care changes as I move from paediatrics into adult health care.

I need help to do things due to my medical condition so I'm not able to do things physically for myself. So, I need support to do that. I call my carers and support workers "my hands" as that is what I need them to do for me. I also have medical machinery and medical procedures that need done and they help me with this along with everyday things.

## My communication

- I find it hard to speak up for myself as I don't know what to say. I'm scared to say the wrong thing and challenge the views people have about me.
- People misunderstand me when I speak about independence. They think I don't want carers, but I need them to be independent.
- I am nervous and anxious about speaking up for my own wants and needs. There's a lot of people in meetings and it intimidates me. It's not just people it's professional people and they cause me to be worried and anxious that they are judging me.

## My motivations

- To live independently from my parents and get the support I need
- I want to move into student accommodation and move out of my family home
- I want to go to university and live a student life and just be like my peers.

## My frustrations

- Not feeling like I am being listened to and heard by everyone
- Hearing the phrase “its not what you want its what you need” when it comes to discussions around my future.
- People not understanding me and thinking I'm unique is not helpful.
- Lack of information around university and how they can help me
- People pushing me into day services or college because they don't think I'm capable of going to university.
- Health care transitions are really complicated - miscommunication is really hard to deal with and manage.

## My short-term ambitions

- To leave school and start new.
- To go on holiday with my friends for my graduation holiday. This is my first holiday without my parents.
- To be heard and listened to by the people supposedly supporting me
- To have a smooth transition through health care
- To work out if I can move further away than what I'm used to because of the limitations in the health care team around me – I ask myself will the same support and service be available elsewhere? Its challenging.

## My long-term ambitions

- To move out of the family home
- To have the right care I need to go to university that I can control myself
- To finish university and get a job

## My experience of how I spend my day

- I have support at school and at home from my parents/grandparents/siblings and a group of friends I socialise with.
- Managing health stuff in the morning and evening is important.
- A typical day would be:
  - getting up for school,
  - managing health stuff,
  - going to school, hanging out with friends,
  - after school is time to relax and do homework.
  - At the weekends I am with my parents, friends or Personal Assistant.
  - My parents must drive me everywhere if I need to go out.
  - Sometimes in the year I would have respite at a children's hospice.