

Living Life to the Fullest – Interview Schedule

By the Co-Researcher Collective
Interview Schedule Co-ordinator: Emma Vogelmann

Introductions

Hello/ introductions

Check in:

1. Let me know if you feel uncomfortable/want to end the interview – you can do so at any time and, if you choose, we won't use any of what you've said as data.
2. You are not obligated to answer every question, just say and we can move on!
3. What disability language would you prefer for the interview e.g. disability, condition, impairment and disabled person or person with a disability?
4. Explain how the information is to be recorded and used: “the data from this interview will transcribed and/or put into a Word document for you to read over and agree (if you want to) that it's an accurate record of your story”.
5. “Following this, the data will be deleted at the original source” (e.g. the message thread or Skype recording).

Disability in Society

Do you think the general public hold an accurate understanding of disability? Why or why not?

Do you think the media portrays disabled people in an accurate way? I.e. on TV, films or the news. Why or why not? Can you think of any examples?

Relationship with Yourself

Do you have a strong sense of identity? What factors contribute to your identity?

Do you identify as disabled? Has this changed over time?

Do you have issues relating to how you perceive yourself?

How do you think others perceive you – does this change depending upon context (e.g. at work; with family; with friends)?

Living with an LL/LTI: Present, Goals and Future

What does 'life-limiting' mean to you?

If your condition is life limiting, how much do you think about this and how do you feel about this? Does it impact any decisions you make?

Do you feel your ambitions/aspirations are respected, and do others involved in your complex care help you to work towards them?

Do you feel like it is important to/ do you set goals? And does anything stop you from doing this?

Are your goals shaped by what support is assumed to be/not be available or by the support you currently receive?

Do you ever feel lonely because of your disability?

Do you ever feel like you "miss out"? What makes you feel this way, i.e. yourself or lack of accessibility?

What worries you about your future with a complex condition? What would you say is your biggest worry?

Are you scared about your future with your condition?

Other People

How has your family been impacted (for better or worse) by your disability? i.e. financially or on family relationships. How do you feel about this?

What makes for a good community in regards to disability?

What for you are the barriers to being or feeling included?

What do you think are the main differences to you between you and your non-disabled classmates/coworkers/friends and family?

Dating, sex, intimate life

How do you feel about dating with a disability?

Do you think it is harder when you're disabled?

Does your disability/condition impact your physical appearance? If so, how do you feel about this? Does it have any impact on how you view yourself?

Do you see yourself as attractive to others?

Are you confident in your body?

Do you think of yourself as a sexual being?

Do you feel society assumes disabled people can't/don't have sexual needs/desires?

Do you have a service or assistance animal? If yes, cover section below (Care, Closeness, and Animals); if no, go to

Care, Closeness, and Animals

What difference does it make to you having an animal care for you as opposed to another person?"

Has having your assistance dog affected your sense of independence?

Has it affected how you think others perceive you?

Has it changed your focus/outlook of your life?

Has having an AD (Assistance dog) changed your sense of well-being?

Are there any benefits [to an assistance dog] you wouldn't expect? E.g. emotional, change in confidence.

Does your assistance dog give you more confidence or/and a chance at being more independent going out etc.?

Does having an assistance dog help you to cope with the emotional struggles of the illness any better/easier?

Care and Closeness

How has your care/care package affected your sense of independence?

Has your care/care package affected how you think others perceive you?

How has your care/care package changed your focus/outlook of your life?

What, if any, are the emotional factors in needing care and support?

Final:

Is there anything I haven't asked that you would like to add?

At the end, thank people for taking part and explain that you will be in touch with their transcript, but that this may take some time.

Assure them you'll 'check in' before then to see how they're doing and if they would like any post-participation support.

Thank you ☺