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| **Higher-order qualitative theme** | **Example quote** |
| Physical aspects | “… so basically the ability to do things with the upper body as well so that is hands and fingers err … Yeah, I think that’s quite important." (P3, adult). |
| Social relationships | "Because I can't play at all with my friends … (I: what would your ideal day look like?) Playing with my friends on the X-box." (P5, child). |
| Autonomy and independence  | "Sometimes it just means having a choice over certain things (I: yeah) and, you know, just like sometimes really basic stuff about what you do with your time and (I: yeah) what clothes you wear and stuff like that. It's about just having a general say in your life I think (I: yeah), which, which is really important..." (P4, adult) |
| Identity  | "… because I sometimes feel like I'm less attractive, like compared to other men because they would get the attention whereas me like I kind of don't get as much as other people …" (P1, adult) |
| Feelings and emotions | "… cause I think, worrying's the worst thing really (I: okay) cause If everyone accepts it then they're not really upset about it (I: okay), which is always (I: and that's …), in the end it's all about enjoying life I suppose." (P6, child). |
| Daily activities | "… (I: Are there any, you know, are there any other, er, activities that, that you find you can't do because of your condition that bother you?) … Drive, drive a car? … Oh wait. I would be able to drive a car because I would get a special one ..." (P9, child) |

**File I – Stage 1 qualitative higher-order themes and example quotes**

*Note*. PX = Participant number X. I = Interviewer.