

Supplementary File 2. Themes and additional support quotes for subthemes

Theme 1: Transition expectations – “I’m not going to be in the little kids’ section [anymore]”	
Subtheme 1: The unknown - “I didn’t really know what to expect”	“Knowing that there is no smooth transition, that was a little bit unsettling for me.” (P/C 2, post-transition)
	“They didn’t really give you a guideline.” (YP 5, post-transition)
Subtheme 2: Growing up - “they won’t treat you like you’re a little kid”	“I just wanted to get out of the children’s hospital and get more opportunity.” (YP 3, post-transition)
	“[YP 7] is going to be an adult. They’ll be 18. They’ll be driving ... so there’s a lot more that [YP 7] is going to need access to in the community.” (P/C 4, pre-transition)
Theme 2: The transition experience – “I felt a bit like they kicked me out the minute I turned 18”	
Subtheme 1: Transition - “it happened, very quickly”	“They just said, you’re finished up with the children’s hospital now [YP 6]’s 16.” (P/C 1, transitioning)
	“I felt like the children’s hospital sort of just gave you the paperwork and just said ... ‘You’re in the adult system now. Here you go. On your way.’” (YP 5, post-transition)
	“We just got a letter out of the blue saying [paediatric] neurosurgery were no longer working with [YP 6] and someone from [the adult hospital] would be.” (P/C 1, transitioning)
Subtheme 2: Navigating the transition – “going back and forth”	“There could have been more communication between the children and adult system because there were times where the children’s hospital had things and then the adult’s hospital didn’t and there were times where the adult hospital had things and the children’s hospital didn’t.” (YP 5, post-transition)
	“We had to go back to the [paediatric] hospital for letters and reports and that kind of thing before we could move further, going back and forth.” (P/C 3, post-transition)
Subtheme 3: Changing roles and responsibilities – “we wanted him to have a voice in what was going on for him”	“You’ve sort of got to be in that mindset where, you know, you’re 18 now. You’ve got to mature a bit, but I mean, at the same time, I still felt like a kid and I wasn’t following up on all the procedures and stuff, like what Mum was doing.” (YP 5, post-transition)
	“When [YP 3] got to sort of 16-17 they then expressed that they wanted to do that [take on responsibility for their healthcare], which was great and we just asked that they was part of that. When [YP 3] hit 18 they were very much around their own care now but we get cc’d because they are not the best at remembering all of that kind of level.” (P/C 3, post-transition)

Theme 3: Needs and recommendations – “Do you know how stressful it is for me to ... tell the story again and again from scratch?”	
Subtheme 1: Knowledge is powerful – “explain what services were going to be handed over, when and to whom”	“Like what each doctor does in the hospital. What they talk to clients about, what they need to know about the client.” (YP 4, post-transition)
	“What procedures are different for adults versus children. Like for urology [YP 4] had some screening they have never had in children's and it is standard in adult but I didn't know that so when they told me [YP 4] needs that I thought it's drama ... but that's not the case, it was standard in adult.” (P/C 2, post-transition)
Subtheme 2: Transition specific meetings – “I felt like they both could have come together in a meeting and just explained ... what is really involved”	“It'd be helpful if my old doctors I've had since I was a child could have come to the first appointments with the new doctor. So they could do a proper handover of all my information.” (YP 1, post-transition)
	“For [YP 6] to see and participate in that handover process ... to be able to meet with both the teams ... perhaps some kind of link up between PSOS [Paediatric Spinal Outreach Service] and the SOS [(adult) Spinal Outreach Service] team ... to have that conversation about ‘Well, this is a handover, how it's going to work, what we do for you that's different to PSOS’ those sorts of things.” (P/C 1, transitioning)
	“If there is another team that takes over, it would be nice to meet them ... and ... let them know about [YP 7]. Getting to know [YP 7] and let [YP 7] know them.” (P/C 4, pre-transition)
Subtheme 3: Building skills and confidence - “I also want to do that by myself”	“I felt like they could have just split it up a little bit because, when they threw it all in at once, I think it was just so confronting that you just didn't know what to really think.” (YP 5, post-transition)
	“They [parents] helped me with the paperwork and all that but also like my mum mostly helps talking for me, not talking for me, but like helps me with my words ... but I also want to do that by myself.” (YP 3, post-transition)
Subtheme 4: Support from someone like me – “to talk to somebody that had been through it”	“Having access to the peer support workers was critical.” (P/C 1, transitioning)
	“It's the social interaction that's often missing, I would say, the people contact that's not necessarily always medical ... that's often missing.” (P/C 3, post-transition)