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Transition from child to adult health services

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Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities

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Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities

Abstract

Aims and objectives: To explore the experiences of the families of young adults with intellectual disabilities (ID) at the point of transition from child to adult health services.

Background: The population of people with ID is changing rapidly, with young people with increasingly complex needs surviving into adulthood and requiring transition from child to adult health services.

Design: An interpretative qualitative design.

Method: Semi-structured interviews were held with ten family carers of young adults with ID and complex care needs, who were in the process of or had recently completed a transition from child to adult health services in Scotland. Data was analysed using thematic analysis. The COREQ checklist was used.

Results: Transition emerged as a highly emotional and challenging period for family carers. Their experiences were captured in five main themes: “a deep sense of loss”, “an overwhelming process”, “parents making transitions happen”, “a shock to the adult health care system” and “the unbearable pressure”. Nurses were often seen as instrumental to counteracting some of these challenges.

Conclusion: There is an urgent need to respond to the challenges experienced by carers at the point of transition and beyond, by ensuring early and coordinated planning, effective information sharing and communication and clear transition processes and guidelines. A person-centred and family-centred approach is required to minimise negative impact on the health and wellbeing of the young adult with ID and their carers.

Relevance to clinical practice: Registered nurses have a key role in providing information and support, along with coordinating care at the time of transition from child to adult health services for young adults with complex ID. It is vital that their input is person-centred and responds effectively to the expert knowledge of family carers, whilst at the same time ensuring their needs for information and support are also addressed.

Key words: Intellectual disabilities, transition, complex needs, carers, nursing, qualitative research

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3 What does this paper contribute to the wider global clinical community?
4

- 5 • Young adults with ID and complex needs and their family carers continue to
6 experience multiple challenges at the point of transition to adult health care and
7 beyond
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- 9 • Carers' experiences highlight the areas of support that need addressed in order to
10 ensure a more coordinated process and minimise the negative impact of transition
11 on people with ID and their carers
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- 13 • Registered nurses can play a key role in enabling person-centred and family-
14 centred care at the point of transition and beyond
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For Peer Review

INTRODUCTION

There is an established body of research evidence regarding health transitions from child to adult health services for young people with a range of health conditions, including diabetes, epilepsy and cystic fibrosis (Sheehan et al., 2015; Camfield et al., 2017; Coyne et al., 2017). All point to this period presenting challenges for the individual and their families, as a result of biological, sociological and psychological changes for the young person as well as significant changes in the organisation of their care. Due to advances in medicine, the number of young adults with intellectual disability (ID) and complex health needs living into adulthood is increasing (Jarjour, 2015). As a result, they require specialist health care provision extending beyond child health services. For young people with complex needs planning for transition to adult health services is recommended to start around the age of 14 (NICE, 2016). However, evidence suggests that internationally the overall health transition process presents numerous challenges for people with ID and their carers (Brown et al., 2019). Given the central role that family carers play in the care of young people with complex ID, it is essential to understand their experiences of health transitions, to ensure that nurses and other professionals respond to their needs.

BACKGROUND

Health care transition is defined as “*a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems*” (Department of Health, 2006 p.14). Given the high prevalence of specific health conditions in people with ID, such as respiratory, gastro-intestinal and neurology conditions (Cooper et al., 2015), individuals and their families are likely to encounter a wide range of health services. Continuity of care can be disrupted during this period, which can result in problems with the management of existing conditions or a lack of detection of new conditions (Young-Southward et al., 2017a). This also extends to mental health needs, as Cvejic and Trollor (2018) highlight young adults with ID are at an increased risk of mental health disorders during the period of transition to adulthood.

Evidence from international studies indicates that carers often feel a sense of loss and abandonment during the transition from child to adult health services (Bhaumik et al.,

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3 2011; Davies et al, 2011; Schultz 2013; Young-Sutherland et al., 2017b), with
4 concerns that it may result in poorer health outcomes for the young person (Camfield
5 et al., 2011; Woodward et al., 2012; Bindels-de Heus et al., 2013; Jensen & Davis
6 2013). A recent systematic review on transitions from child to adult health care for
7 young adults with ID identified a theme of “*parents as advocates in emotional turmoil*”
8 (Brown et al., 2019 p.11). Some parents described the need to ‘fight’ for effective
9 health care following transition and achieving a successful outcome was often
10 dependent on their own resourcefulness and persistence.
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18 Meleis et al. (2000) developed a theory of nursing transitions that recognises the
19 complexities of the concept, which occurs in a wide variety of health care contexts.
20 Examples include age-related transitions such as moving from child to adult services,
21 role-related issues, including adult children assuming responsibility for older parents,
22 or location-related, such as moving from home to a care home. Meleis et al. (2000)
23 identify three main elements within the theory: the nature of transitions, transition
24 conditions and the patterns of response. Whatever the transition, it generally involves
25 multifaceted systems, protocols and personnel. The health care elements can occur
26 at critical points in people’s lives that are already characterised by anxiety and
27 uncertainty. By developing an understanding of the experience of transition in the
28 context of the theory by Meleis et al. (2000), nurses can more effectively influence
29 transition planning and support for those involved.
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40 This paper reports on one component of a Scotland-wide study to explore the
41 transition from child to adult health care for young adults with complex ID from the
42 perspective on nurses and family carers. The overall aims were to identify examples
43 of good practice and to develop and pilot an educational resource on transitions for
44 both child and adult nurses.
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49 The objectives of this element of the study were to:

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52 1) Explore the experiences of transition from child to adult health care from the
53 perspective of family carers of people with ID and complex needs.
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55 2) Investigate best practice, including the contributions of registered nurses
56 experienced by family carers and individuals with ID and complex needs at the
57 point of transition to adult health care.
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3 3) Identify the support needs of young adults with ID and their carers at the point
4 of transition from child to adult health services.
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8 **METHODS**

9 **Design**

10 The wider study employed an interpretative qualitative design involving semi-
11 structured interviews with family carers of young adults with ID (n=10), registered
12 nurses (n=43) and other health professionals (n=3) across Scotland. The data
13 presented in this paper is drawn from the interviews with family carers and analysed
14 using thematic analysis (Braun and Clarke, 2006). The Consolidated Criteria for
15 Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007) were
16 adhered to during the reporting of this study (See Supplementary File 1).
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25 **Recruitment and participants**

26 A number of independent sector organisations and carer groups, such as the Scottish
27 Consortium for Learning Disabilities (SCLD) and Promoting A More Inclusive Society
28 (PAMIS) in all 14 National Health Service (NHS) Health Boards in Scotland provided
29 support with recruiting family carers. Using purposive sampling, they shared a
30 Participant Information Sheet with carers in their networks whom they deemed suitable
31 for this study. Carers interested in participating were asked to contact the research
32 assistant (AH), who fully briefed them about the purpose of this study and screened
33 against the inclusion criteria. These included having a child with a complex ID and
34 being in the process of or having recently completed a transition process from child to
35 adult health services. In total, ten family carers from seven NHS Health Boards in
36 Scotland were identified and agreed to participate. Table 1 gives details of
37 demographic information for carers and young adults with ID. The young adults with
38 ID had a range of diagnoses and comorbid health conditions, including epilepsy, visual
39 impairment or blindness, musculoskeletal conditions, kidney and metabolic issues,
40 gastrointestinal and respiratory problems, speech and language difficulties and mental
41 health issues.
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56 (Table 1 here)
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Data collection

A semi-structured interview schedule (Box 1) was developed for the purpose of this study drawing on current literature and the expertise of the research team and the study Advisory Group. The group included representatives from carers, voluntary and professional organisations associated with people with ID and academia. The schedule was piloted with two carers and these interviews are included in the study results. Interviews ranged from 40 minutes to over one hour. They took place between November 2016-July 2018 and were conducted by the research assistant (AH), who is experienced at qualitative data collection. Based on participants' personal preference or travel distance, the one-to-one interviews were conducted in the participants' homes (n=5), workplace (n=1) or over the telephone (n=4). Data saturation was reached after eight interviews and two more interviews were conducted. All interviews were audio recorded and transcribed verbatim by a professional transcription service. The interviewer (AH) anonymised the transcripts and returned to participants for comments. All carers were ascribed a code number and pseudonyms were given to the young person with ID to preserve anonymity.

(Box 1 here)

Ethical considerations

The University Research Ethics and Governance Committee independently reviewed the study and granted approval, with all research ethics and governance procedures adhered to in each NHS Health Board.

Data analysis

Thematic analysis, inspired by the step-by-step guide by Braun and Clarke (2006) was employed to systematically identify recurring themes. Thematic analysis is used to identify, analyse and report patterns within data and can be extended to interpret various aspects of the research topic. This method is independent of epistemology and theory and can be applied flexibly to produce a rich and complex account of data (Braun and Clarke, 2006). The analysis was focused on describing and interpreting carers' experiences, attitudes and meanings related to the transition process.

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3 The research assistant (AH) generated initial codes for individual transcripts and
4 collated them into initial themes. These were then reviewed and refined into main
5 themes and subthemes. QSR NVIVO 11 software was used to manage the data and
6 support the systematic approach to analysis. To ensure rigour, the analysis was
7 systematically discussed and reviewed by two other members of the research team
8 (MB, JM). Additionally, findings were shared and reviewed by the study Advisory
9 Group to support peer debriefing.
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17 **RESULTS**

18 For most of the young adults in this study transition from child to adult services had
19 commenced after the age of 14 and was complete by the age of 19, although for one
20 individual transition had taken place between the ages of 24-26. Although one of the
21 aims of the study was to identify positive examples of practice related to transition, the
22 majority of experiences reported by parents were largely negative. This had a clear
23 impact on their overall perception of transition, their own wellbeing and in some cases
24 had a detrimental effect on their child's health and experience of care. Five themes
25 with associated sub-themes were identified and are reported in Table 2.
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34 (Table 2 here)
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37 **A deep sense of loss**

38 *Losing the sense of safety*

39 Parents expressed feelings of deep trust towards their child health team, which
40 provided them with a strong sense of safety. The introduction of the concept of
41 transition to adult services was often sudden and unexpected and parents commonly
42 viewed transition as a loss of the entire professional support network and relationships
43 that had been built over many years:
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49 *There's very little emotional support for parents, and it's a very scary process where*
50 *you feel...you feel you're going into a very vulnerable situation, to let go of a doctor*
51 *that you deeply respect, like, there's real affection for each other and mutual respect*
52 *for each other, and all of a sudden it's like somebody taking a rug and just pulling it*
53 *out [C05].*
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59 *Loss of integrated services*

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3 Parents expressed feelings of fear and anxiety about losing access to what they
4 viewed as vital services and expertise, often provided by a single clinician and
5 specialist nurses. Their concerns about the ability of adult services to meet their child's
6 complex needs were driven by the move to a range of specialists and had often been
7 reinforced by negative stories from other parents, who had already gone through
8 transition:
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13 *I've heard these horror stories of parents being told, 'you're off paediatrics now, you're*
14 *back to the GP', and of course the GP in our case doesn't know our son. All of a*
15 *sudden, you've been a parent of a little lad, and this is a boy that had people at a major*
16 *UK children's hospital, and you've had that level of expertise. [Now] you have a*
17 *different person for the bones, you have a different person for the spine, you have a*
18 *different person for the gastric, you have a different person for neurology, you have all*
19 *these people. [C05]*
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26 27 *A sense of isolation and vulnerability*

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29 This stressful time had a negative impact on parents who expressed feelings of
30 isolation and being overwhelmed while continuing to deal with their child's highly
31 complex needs. There was a sense that transition to adult services also meant a loss
32 of emotional support from professionals who had known their family for many years:
33
34 *[Children's Community Nurse] would drop off the supplies, but she would say, 'how's*
35 *it going?' or whatever, so I'd see her approximately once a month, and she was always*
36 *at the end of the phone. If I hadn't seen her every six months approximately, she would*
37 *come and have a cup of tea and just chat how things are. (...) if you were admitted to*
38 *hospital, she would know about it and she'd pop in to see you. [C07]*
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46 **An overwhelming process**

47 *Re-establishing a care team*

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49 These parents described the process of establishing a new care team in the adult
50 services as complex and confusing, with multiple meetings and what they felt was a
51 'minefield' of information:
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54 *(...) obviously, you have to move on at some point. So, then that involved more people,*
55 *more information given, more meetings, things like that. [C01].*
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3 Parents reported a lack of continuity or information sharing between professionals and
4 felt drained by having to continually repeat the same information to different health
5 care teams:
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8 *(...) it's just the sheer fact that you almost have to start again with referrals in many*
9 *cases, there doesn't seem to be any continuity or a good transition period... [C10]*
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13 One carer, however, did experience effective continuity through having a named
14 transition nurse and found them to be an invaluable source of information and support
15 to navigate the transition process:
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18 *I don't think it would have been half as easy without the transition nurse, you would*
19 *just have these appointments arriving, telling you to turn up at the health centre for*
20 *your first vent team. You wouldn't know who...quite what it was for or who it was. (...)*
21 *the transitions nurse was a really good resource. [C07]*
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28 *Lack of coordinated planning*

29 Parents described a lack of coordination, which created uncertainty about who would
30 take over responsibility of care or actions to take in a crisis situation. This in turn
31 increased their child's vulnerability:
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34 *(...) there was to be one meeting where the [Adult Hospital] nursing staff were to come*
35 *up to the [Children's Hospital] to meet Hannah, that they called off that morning, that*
36 *never happened. So, we were discharged from [Children's Hospital] having not met*
37 *anyone from the [Adult Hospital], and all this time Hannah's legs were getting worse*
38 *and worse and Hannah was getting worse and worse. [C09]*
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45 There was often a sense of there being a lack of responsibility for multiagency
46 coordination, resulting in a transition being largely service-driven rather than person-
47 centred. This gave parents little confidence in the quality of this process:
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50 *(...) we used the tool book in person-centred planning that I had provided because I*
51 *had been away on a course and everybody filled things out, but nobody wanted to take*
52 *responsibility for it and nobody wanted to collate it. So that process has not been*
53 *followed through, so I don't think for Richard his transition has been person-centred at*
54 *all. [C04]*
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3 However, some carers gave examples of excellent coordination and multiagency
4 planning between health and social care, who worked together to ensure a well-
5 managed transition process:
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8 *There was a lot of multiagency planning in the run up to Mark's transition, which as I*
9 *said was both health and social care. I think that is a really key thing to have and if*
10 *you can have the same people and people who know them well and that plans are put*
11 *in place as best they can. [C02].*
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18 *Confusion and the state of unknown*

19 This feeling of confusion and uncertainty about future care seemed to be further
20 reinforced by the lack of access to reliable and consistent information:
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23 *I know what's happening with regards to therapy, but I don't know what's happening*
24 *exactly and the paediatrician when I spoke to her she thought it was the paediatric*
25 *orthopaedic surgeon that would see Richard and she did write to him. It's only since*
26 *then that we've discovered that that's not the pathway, so she didn't know. [C04]*
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32 Parents expressed feelings of confusion about accessing services and expert advice,
33 and were often excluded from communication between professionals or not provided
34 with clear points of contact in adult services:
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37 *(...) you're not quite sure which route you're supposed to be going. You know, who to*
38 *contact? Who's you're first port of call? [C01]*
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42 **Parents making transition happen**

43 *Parents as transition coordinators*

44 The poor coordination and management of the transition process led to many carers
45 having to take responsibility for ensuring there were no gaps in their child's care.
46 Parents in this study were found to take initiative on anything from initiating the
47 transition process and handover between professionals to organising training for staff,
48 daytime activities and referrals to adult services:
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54 *It's taken me sort of saying 'I'm really worried about this', for them to say we'll refer to*
55 *the spasticity service who will refer to a neurologist locally. (...) Things like that should*
56 *happen without me having to ask for it; you know, she's got an ongoing condition, it's*
57 *never going to get any better. [C10]*
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3 Taking a very proactive approach and becoming the driving force behind transition
4 planning demanded focus and perseverance, however it was often the only way to
5 ensure a successful outcome. Although the majority of the participants appeared to
6 have the skills and ability to act as strong advocates for their children, as one carer
7 pointed out some people with complex ID can be disadvantaged if their parents are
8 not in this position:
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13 *(...) not everybody has the skills, and that's not a criticism. Not everybody has the*
14 *time, people are working full time. We were semi-retired when we came up here, so*
15 *this could be our life's work. Other people, they've got other children, we've only got*
16 *Duncan. It's easier to make that our entire focus. [C05]*
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22 One carer highlighted how having support from a dedicated professional, in this case
23 a transition nurse, can make a significant difference to the experience. Some of the
24 areas of support that this mother appreciated most included identifying suitable day
25 care provisions, making specialist care and training arrangements, preparing letters
26 and reports to support funding decisions, liaising with consultants, helping identify
27 appropriate adult health care services, advocating for the family, providing emotional
28 support and guiding the family through the transition process:
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33 *She met with us, she was involved in the transition from school to adult services to*
34 *adult day services, I suppose, really, from a social work point of view, but she was also*
35 *involved in the sort of health aspect, and she was like your sort of champion. [C07]*
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40 41 *The battle of transition*

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43 Despite taking responsibility for coordinating many aspects of the transition process,
44 parents reported an overwhelming feeling of having to “fight” or “battle” for services
45 that their children were not only entitled to but were often essential to their health and
46 wellbeing. This included accessing appropriate treatments, care service provisions,
47 funding or timing of leaving education:
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51 *So, once we had quashed this age 16 leaving school, no sooner had we done that*
52 *than we were battling leaving at age 18 (...). So, we then found ourselves in a battle*
53 *on when would his transition begin. Although a council funding issue, the date*
54 *obviously impacts on NHS as well. Paediatrics need to know. [C05]*
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3 Parents described many struggles to access services and appropriate care, needing
4 to act as strong advocates for their child's rights. This demanded stamina for what
5 they often perceive as a continuous fight:
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8 *I've just come to the conclusion everything is a struggle. Everything is arguing the toss,*
9 *sort of on bended knee, 'could we do this? could we do that? it would be really*
10 *helpful...', (...) and I think it is sad, it's quite sad that it's not a standard. [C07]*
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15 **A shock to the adult health care system**

16 *Unprepared adult services*

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18 Parents' first experiences of adult hospitals were rarely described as positive and the
19 participants gave the impression of the young adults with complex ID causing a
20 "shock" to the adult health care system. Parents viewed services as being unprepared
21 for their level of complex needs and lacking essential adaptations, including
22 appropriate hoists, changing facilities, suitable beds or monitoring equipment. This
23 placed additional pressure on parents, who sometimes had to source the essential
24 equipment themselves.
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33 Adult hospitals tended to lack facilities for parents to stay overnight, even though most
34 parents did not feel able to leave their child alone. They reported instances where
35 adult health care professionals lacked training or knowledge of the specific medical
36 equipment or technologies that had been commonplace in the paediatric settings:
37
38

39 *(...) the PEG came out three times while he was in the hospital and this is a PEG that*
40 *had never come out before ever in like the ten years he'd had a PEG in. We were a*
41 *bit concerned they weren't maybe...and they admitted themselves they'd never seen*
42 *a PEG like that before. [C02]*
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48 *(...) quite often when I'm with Andrew I feel I'm ground breaking sometimes, thinking,*
49 *what, have you never come across somebody with an established trachie? [C07]*
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54 Such experiences reinforced parent's perceptions that many adult health care
55 professionals might lack essential knowledge of ID, nor have skills and experience to
56 recognise and appropriately respond to the complex needs of this population.
57 Furthermore, they felt that the staffing resource to provide adequate care was often
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3 not there. This increased parents' anxiety and further diminished their confidence in
4 the quality of care their children received:

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6 *(...) my 20-year-old doesn't speak, can't move, can't press buttons, can't get*
7 *anybody's attention, (...) she could be just left there if nobody's seeing to her. She's*
8 *not able to say that she needs changing or she's hungry or thirsty or that, you know,*
9 *and that really worries me, and that's down to lack of numbers to be honest, lack of*
10 *staff. [C10]*

16 17 *The paradox of adult hospitals*

18 The interviews revealed that standard hospital procedures were not always adapted
19 to take account of legal guardianship. Parents often felt dismissed and not listened to,
20 such as during hospital admissions, where they might have been asked to wait in
21 another room while their child was undergoing assessment:

22
23 *It did feel like that was unnecessary. We could have helped them. They didn't know*
24 *anything about Mark. They didn't know anything about physically what he would be*
25 *like or his communication other than what we filled in which would be quite basic when*
26 *we first went into A&E. [C02]*

27
28 Although some health care staff were described as open and receptive to parents'
29 suggestions, others were perceived as very resistant to accepting their guidance:

30
31 *(...) it was a long process to get a person who could actually listen and take on board*
32 *what I was saying...to go through the notes to find out what happened on the previous*
33 *occasion. [C01]*

34
35 Excluding parents and cares from the process of assessment, decision-making and
36 care did on some occasions lead to serious, potentially life-threatening mistakes:

37
38 *(...) the day before he was due to leave, we realised they actually hadn't been giving*
39 *him the right medication. (...) We then realised he hadn't been getting the right amount*
40 *of bolus feeds because again nobody had really asked us and in fairness, I hadn't*
41 *really thought about it. It was partly our fault as well. [C02]*

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43 At the other end of the spectrum, parents could sometimes be made to feel fully
44 responsible for medical decisions, which diminished their confidence in the adult team
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3 being able to provide appropriate care. As a consequence, some even turned to their
4 old paediatric team for support:

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6 *They didn't hoist Hannah out of her wheelchair. They didn't feel her [tone]. They*
7 *asked me what did I want to do? And I kind of looked at them to say, well, yes, I am*
8 *the best person who knows Hannah, but that was always a decision made by a*
9 *clinician at [the Children's Hospital] (...). So, in the end we didn't really do anything.*
10 *Came home. (...) and in desperation I picked up the phone to our old neurologist, who*
11 *was absolutely fantastic. He said, bring her in. [C09]*
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19 Some parents gave examples of excellent practice in the adult hospitals, with nurses
20 and other staff readily adapting standard procedures and working with them to ensure
21 that their children's stay was as smooth and comfortable as possible:

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23 *They even said we can get a bed down from the children's ward so you can stay over,*
24 *(...) but actually they managed to reassure me that...I was sufficiently close to the*
25 *hospital, a ten-minute drive, and they were going to take good care of him, that I felt*
26 *that I could leave him. [C07]*
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33 *Lack of continuity of care*

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35 The interviews highlighted lack of continuity of care between children and adult health
36 and social care services, with limited availability and access for young adults with ID.
37 In some cases, this threatened the continued therapeutic input and monitoring of
38 conditions:
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42 *Richard was also seen by the vision service because he has an eye condition and a*
43 *processing condition and again their priority is 0 to 19. So, he's not going to get that*
44 *same level of input just because he's become an adult. [C04]*
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49 This sudden drop in services, which seemed to be guided by arbitrary age criteria
50 rather than a clinical need, made parents feel abandoned and that their child's health
51 was not a priority anymore, despite their ongoing very high levels of needs. Parents
52 described falling between the gaps of services due to poor coordination and rigid
53 criteria resulting in them being left without support for extended periods of time:
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57 *(...) she ended up in hospital for three months, she came home having a central chest*
58 *line in, having antibiotics that I was doing (...). And the [children's community] nurse,*
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3 *that time I could have done with some support, but I never saw her again.... [She]*
4 *stopped seeing her at 16, but the adult nurses don't pick them up till they're 18. [C10]*
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8 There was an overwhelming sense that young adults with complex ID do not readily
9 fit into the adult health and social care systems including day centres, respite and
10 complex care facilities, and that parents encounter multiple barriers when trying to
11 access services and resources:
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15 *(...) everything that I do for Andrew ... I feel it's ground breaking. They make decisions*
16 *for Andrew and Andrew alone, because that's what they told me when they did his day*
17 *centre. They said, 'this is for Andrew and Andrew alone', presumably to sort of cover*
18 *themselves to say, well, if somebody else comes along and says, how come Andrew's*
19 *going there? they say, well, that was a unique one-off decision. [C07]*
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25 However, there were also examples of good continuity of care, with nurses helping
26 parents establish points of contact in specialist adult health services. This seemed to
27 give them more confidence that they would be able to access help when required:
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30 *Very much the specialist nurse, who is a lovely, lovely person. She has linked to the*
31 *spasticity management consultant, and obviously a lot of Hannah's issues are tone*
32 *based, or can be tone based, and she can always be contacted on our behalf. We*
33 *don't see her every time, but she can also be contacted. So, we now have the two*
34 *prongs, so to speak, through the specialist nursing staff that hopefully would access*
35 *us up, yeah. [C09]*
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44 **The unbearable pressure**

45 *Parents taking responsibility for health monitoring*

46 Diminished services that were more difficult to access, coupled with a lack of regular
47 input from the adult health team led to parents having to take more responsibility for
48 monitoring their child's general health and complex conditions. Even with successful
49 transitions to specialist services, the young person was sometimes immediately
50 discharged from the adult service with nobody charged with monitoring their condition:
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52 *We did get referred to the adult service well in time, we saw the adult doctor once, had*
53 *us back another time and then discharged us. And that I find hard, I mean, she's got*
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3 *ngoing problems, she's on a really high dose of one drug to keep her gut working,*
4 *and yet nobody's now looking after it but me, so you're left high and dry. [C10]*
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9 However, there were also examples of excellent practice, with one carer highlighting
10 how good communication and agreeing a clear plan can help manage parents' anxiety
11 about monitoring the young adult's health conditions and minimise waiting time:

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13 *We sometimes just need that instant access to the doctor to say, look, this is*
14 *happening, do you think we should increase this drug?, because we know there's*
15 *parameters within certain meds. The doctor will say, right, I would like you to do this,*
16 *and I'm going to send you an appointment for three week's' time, and then we'll review*
17 *how it's going. Rather than you go for the meeting and then you've got to make a*
18 *change, and then you still don't know if it's going to work. So, all of the doctors agreed*
19 *that I can contact them. [C05]*
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27 There were also excellent examples of General Practitioners taking a leading role in
28 ensuring continuity of care, both in terms of managing general health as well as acute
29 care:
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32 *This GP said to me, I would like to be Hannah's named GP. And now we just see him*
33 *all the time and it's just...the difference is huge. [C09]*
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38 *Alone in a new environment*

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40 Following the transition to adult health services, the pressure experienced by parents
41 seemed to increase significantly. The first admission to a general hospital was often
42 not only a stressful but also an isolating experience, with little support available to help
43 parents navigate this unfamiliar environment:
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47 *There was no help, no advice. I have never felt so isolated in my entire life. (...) We*
48 *did meet some very nice people along our way. But at the point where we were at the*
49 *lowest we could possibly be was when we were going from the [Children's Hospital]*
50 *to the [General Hospital] with nothing in place to back us or help us in the adult hospital*
51 *situation. [C09]*
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57 This feeling seemed to be reinforced by the loss of the practical support offered by
58 child health nurses, leaving parents responsible for most aspects of everyday personal
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3 care while their child was in hospital. Even when a level of support was available in
4 the form of ID Liaison Nurses, poor referral practices led to parents being missed and
5 unable to take a break from caring responsibilities.
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10 One parent who received support from an ID Liaison Nurse while her daughter was
11 admitted to hospital, saw this role as invaluable and felt that the nurse was able to
12 advocate for the family and help adult staff adapt their procedures:
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14 *I was able to explain the situation to her, and obviously she had a better understanding*
15 *than the actual doctors had, so she could go and speak to the doctors, and then*
16 *obviously, things kind of relaxed a bit and they were a bit more helpful. Which shouldn't*
17 *have been the case, you know. [C01]*
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23 One mother described the gap in support she experienced after being discharged from
24 the children's community nursing service, which left her feeling isolated:
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26 *There's no equivalent [to children's community nurse] in the adults, and they're a great*
27 *source of reassurance and talking to...especially through things that are just everyday*
28 *things, stupid things like bowel habits (...). But it does affect him if he doesn't go to*
29 *the toilet, but also if you were concerned about him health-wise, his breathing or*
30 *whatever, you could speak to anybody in the CCN office. [C07]*
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37 *Impact on parents' health*

38 The increasing pressure placed on parents as a result of transition and the reduction
39 of services such as respite, complex care and hospice support was seen to impact on
40 their own mental and physical health. Losing valuable support to deal with the
41 workload of the hugely challenging task of caring for a person with complex ID had a
42 significant effect on parent's quality of life, ability to continue working and could put a
43 strain on their marriages and relationships.
44

45 *I get 42 nights respite a year which is a hell of a drop down. My children's hospice is*
46 *gone, so I don't get my three weeks there, and complex care, rather than having three*
47 *or four visits a week or somebody helping out in the evenings for a few hours from half*
48 *five to half nine. I'm lucky, I count myself lucky if I get one shift a week, and that just*
49 *means that Andrew goes in the bath once a week, because I don't always have time*
50 *to bath him. [C07]*
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3 Furthermore, the pressure of providing continuous care and support to their child in
4 the hospital setting, along with a deep sense of isolation, could sometimes lead to a
5 rapid decline of parents' mental health and affect their ability to look after their child:
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8 *They're very, very, very nice people down in the wards, but there was not enough of*
9 *them to be able to say to me, go away for an hour, do something. So, I was with her*
10 *constantly the whole time, physically drained and mentally on the verge of...I really*
11 *was toiling hugely. [C09]*
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17 Given that the needs of the individual with complex ID remain the same or can
18 sometimes increase, the demands placed on the aging parents was felt to be
19 unrealistic and damaging to their health:
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22 *I get sore backs, I'm exhausted because there's no support. (...) The other thing, this*
23 *year especially, I'm never ill, never ill, don't even get colds in the winter, but this year*
24 *I have been ill and I'm sure it's because physically I'm so tired. (...) I could barely get*
25 *off the settee, but I still had to shower two severely disabled young adults. [C10]*
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32 **DISCUSSION**

33 The population of young adults with ID living into adulthood is increasing, and is a
34 phenomenon that will continue. Many have a range of lifelong, multiple physical and
35 mental health conditions (Truesdale & Brown, 2017). As a result, more young adults
36 with complex ID will require access to health care across their lifespan and will
37 transition to adult health services (Hughes-McCormack et al., 2018).
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43 The findings from this Scotland-wide study demonstrate that transition from child to
44 adult health services often presents momentous challenges for people with ID and
45 complex health needs and their carers. Although most of the carers in this study rated
46 their overall experience of health transition as positive, the language associated with
47 the emerging themes is evocative of largely negative experiences, as they described:
48 "a deep sense of loss", "an overwhelming process", "a shock to the adult health care
49 system" and "the unbearable pressure".
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56 From the family carers' perspective, transition to adult health services is a highly
57 emotional time of major changes and the results from this study underline the areas
58 of support that could be most helpful and meaningful for parents. Nurses were
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3 identified as an important source of support during this period, with opportunities for
4 involvement in transition planning, communication, ensuring continuity and providing
5 support.
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9 Carers repeatedly emphasised the sense of loss of long-standing relationships with
10 nurses and other health professionals within child health services, echoing other
11 studies focussing on transition for young adults with ID (Bindels-de Heus et al., 2013).
12 As a result, they frequently viewed future care in adult services with great uncertainty.
13 For most carers the process of transitioning from child to adult health services was
14 stressful and bewildering, which mirrors findings from previous studies (Leonard et al.,
15 2016; Young-Southward et al., 2017a). The lack of coordinated and person-centred
16 planning and limited access to reliable information while trying to establish a new care
17 team in adult health services often left parents feeling confused and anxious about
18 future care (Schultz, 2013; Okumura et al., 2015; Bhaumik et al., 2011).
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27 Parents of young adults with ID often viewed their children becoming more vulnerable
28 following transfer to adult services. As well as needing more information about new
29 services, they lacked detail on the legal dimensions (such as guardianship) that would
30 allow them to remain fully involved in decisions about their child's health care (Davies
31 et al., 2011; Betz et al., 2015). Putting these legal processes in place can take time,
32 yet the findings from this study indicate that the actual transfer to adult services could
33 often be quite rapid, with little or inadequate preparation for this essential matter.
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40 Many carers felt they needed to assume responsibility for the transition process in
41 order to ensure the needs of their children continued to be met. These findings
42 correspond to those in a recent systematic review of the international evidence (Brown
43 et al. 2019), that identified a theme of "parents as advocates in emotional turmoil". This
44 theme captured carers' sense of having to "fight" for services while navigating a maze
45 of confusing information. While families want to be at the heart of the transition
46 process, they do not want to assume full responsibility for every aspect of it (Crowley
47 et al., 2011). Similarly, the findings echo previous studies indicating that faced with
48 health care professionals' lack of proactive preparation, it is often parents' own
49 resourcefulness that ensures a successful transition outcome (Davies et al., 2011).
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58 However, carers in this study also highlighted the positive impact of some nurses'
59 involvement in the process of transition, suggesting that they can play a central role in
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3 preparing, educating and supporting young adults with ID and their families at the start
4 of and throughout the transition process (Fegran et al., 2014). For instance, due to
5 their involvement with the young person and their families over many years, child
6 health nurses develop a wealth of knowledge and expertise in their needs (Betz,
7 2013). By collaborating with adult health nurses and other professionals, they are in a
8 position to ensure person-centred care planning and handover. An integral part of the
9 transition process should involve nurses providing opportunities for emotional support
10 for young adults with ID and their families, to enable them to explore and discuss their
11 concerns, hopes and future aspirations (Chu et al., 2015).

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20 Some carers in this study benefited from the involvement of dedicated transition
21 nurses, who they felt helped them navigate the transition process, provided support to
22 access suitable adult services, advocated for the family and offered emotional support.
23 The benefits of a “transition service coordinator” as an advanced practice role for
24 nurses has been promoted by Betz and Redcay (2005), who argue that they can take
25 a leadership role, act as clinical experts, consultants, promote change and educate.
26 However, while such role development might be welcome, more evidence on its
27 impact is needed (Brown et al., 2019).

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34 Findings from this study support previous research suggesting that parents worry
35 about availability and access to adult services (Woodward et al., 2012), or where they
36 might feel excluded while their child is receiving care from adult care providers
37 (Bindels-de Heus et al., 2013). Both current and existing studies suggest that parents
38 view adult health services as ill-prepared for the multifaceted needs of people with ID,
39 including knowledge of specialist medical equipment, necessary environmental and
40 communication adaptations, or legal aspects of health care related to guardianship.
41 Parents in this study highlighted the importance of their continued involvement in their
42 child’s care in adult services, along with recognition for their expertise in their child’s
43 health and other needs.

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52 ID Liaison Nursing roles have been developed in many acute hospitals. They offer a
53 potentially important area of support and advice before, during and after transitioning
54 and improve continuity of care (Brown et al., 2016). Several parents in this study
55 highlighted the role of the ID Liaison Nurses in hospital settings, in ensuring
56 appropriate adaptations are made and acting as points of contact for easy access to
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3 specialist health services. Whilst these roles exist in some countries, evidence
4 indicates that there remains widespread issue in addressing the barriers to accessing
5 health care (Hepburn et al., 2015). Given the concerns regarding unmet health needs
6 and access to health care, further developments are needed if the population of people
7 with ID and their families are not to be further disadvantaged, particularly at the point
8 of transition from child to adult health care and beyond (Cheak-Zamora & Thullen
9 2017).

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16 Another important issue highlighted by the current study is the detrimental impact of
17 transition to adult services on the health and quality of life of family carers of people
18 with ID. The negative experiences of transition as well as pressures experienced as a
19 result of decrease of services following transition can affect parents' physical and
20 mental health and consequently their ability to care for their children.

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26 The findings from this research can be contextualised in Meleis et al.'s (2000)
27 Transitions Theory, which has been widely utilised in nursing research and practice
28 (Arrowsmith et al., 2016; Munck et al., 2018; Brown et al., 2019; Lindmark et al., 2019).
29 This theory recognises transition as a complex and multidimensional process and
30 provides a framework for characteristics and indicators of healthy transition processes.
31 It suggests that better understanding of transitions could lead to development of
32 "nursing therapeutics" or interventions to assist individuals and their families with
33 managing transition (Meleis et al., 2000). The theory focuses on the role of nurses in
34 increasing awareness and facilitating engagement throughout and providing support
35 at the key points during the process. The findings of this study emphasise nurses' role
36 in recognising stress, anxiety and confusion often experienced during the transition
37 process. Furthermore, by drawing on their extensive knowledge and skills they can
38 support patients and families to significantly reduce these feelings.

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49 This study adds to the body of international research on transition by highlighting the
50 complexity of relationships and interactions between family carers of people with
51 complex ID and health care professionals. Similar observations were made by Davies
52 (2005), who tested Meleis' transition theory in the context of relatives' experiences of
53 move to a nursing home. They found the relationship among the care home staff, the
54 resident and their relatives to be reciprocal rather than the family and the resident
55 simply being passive recipients of care. The current findings suggest a similar
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3 perception among parents of people with complex ID and highlight the urgent need to
4 acknowledge both the needs as well as the role of family carers at the point of
5 transition. This is not only to facilitate a more effective transition but also to ensure
6 carers' health and wellbeing is not affected as a result.
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10 11 12 **CONCLUSION**

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15 The majority of young adults with ID continue to live at home with their families who
16 play a central role in their on-going care and support. International research evidence
17 highlights that this population is living longer with a range of interrelated complex
18 physical, psychological and behavioural support needs, and more will transition from
19 child to adult health services. There are therefore important implications for nursing
20 practice. For some, the transitions process is complex and poorly coordinated, leading
21 to stress and anxiety and the potential for poor health outcomes. Families want to be
22 involved in the transition process, however they do not want to feel that they are
23 responsible for ensuring that all the needs of the young person are met. Young adults
24 with ID and their families can experience a sense of loss when trusted and well-known
25 practitioners are no longer involved following transition. There is an opportunity for
26 nurses to play a central role in coordinating the transition process, thereby helping to
27 ensure that the needs of young adults with ID and their families are effectively
28 identified and met.
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41 **Relevance to clinical practice**

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43 The findings from this study highlight that nurses have an important role in effectively
44 assessing, planning and coordinating the complex and multimorbid health needs of
45 young adults with ID across all health care settings. Central to an effective transition
46 is the completion of comprehensive assessments and care plans, required to inform
47 future treatments, interventions and support needs (Rochester-Eyeguokan et al.,
48 2016). Nurses are in a key position to ensure collaboration and effective information
49 sharing with other nurses in primary and acute care as well as specialist ID services
50 (Gray et al., 2017).
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58 There are opportunities for nurses to lead on the development of transition pathways,
59 which have been found to be effective in other areas of nursing practice, such as cystic
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3 fibrosis (Coyne et al., 2017; Wells & Manning, 2017; Burke et al., 2018). Such
4 pathways would enable nurses to work with the young adults with ID and their families
5 to provide information about the transition process and how their care and support will
6 be provided in the future.
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11 Nurses and other health professionals do require education and support to respond to
12 the legal context regarding health care decision-making for young adults with ID, to
13 ensure that their practice meets legal requirements and family members are supported
14 effectively through the transition period (Johansen & O'Brien, 2016; Shay and Lafata,
15 2015).
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20 21 **Strengths and limitations**

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23 The strengths of this study lie in obtaining the voices of family carers of young adults
24 with ID who experienced transition across many different health systems. Seeking
25 their views and experiences in order to offer solutions can ensure transition is person-
26 centred and responsive. Recognising the concerns of families presents an opportunity
27 for health services to improve practice. The limitations relate to the sample involved
28 being family members who expressed an interest and had the time to participate, and
29 they may not be wholly representative of all families of young adults with complex ID
30 who have gone through the transition process. Additionally, the study was undertaken
31 in one part of the United Kingdom and may not be reflective of the experiences in other
32 parts of the country or internationally.
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DEMOGRAPHIC INFORMATION		
CARERS		
Relationship to the person with ID	Mother = 9	Father = 1
Age	40-49 = 2	50-59 = 5
	Missing = 3	
Full time carer?	Yes = 8	No = 2
Overall experience of transition	Very positive = 1 Mostly negative = 2	Mostly positive = 5 Missing = 2
PEOPLE WITH ID		
Gender	Female = 4	Male = 6
Age	16-19 = 1	25-29 = 1
	20-24 = 5	Missing = 2
	>30 = 1	
Diagnosis	Genetic condition = 2 Cerebral palsy = 7	Autism = 4 Intellectual disability = 4

Table 1: Demographic information for carers and young adults with ID

A deep sense of loss	Losing the sense of safety Loss of integrated services A sense of isolation and vulnerability
An overwhelming process	Re-establishing a care team Lack of coordinated planning Confusion and the state of unknown
Parents making transitions happen	Parents as transition coordinators The battle of transition
A shock to the adult health care system	Unprepared adult services The paradox of adult hospitals Lack of continuity of care
The unbearable pressure	Parents taking responsibility for health monitoring Alone in a new environment Impact on parents' health

Table 2: Themes and sub-themes relating to family carers' experiences of the transition process

1. What was your experience of the transition process from child to adult health services for your family member? Can you briefly describe what that process looked like?

2. What was the role and contribution of different health professionals in children, primary care and specialist adult learning disability services in facilitating the transition for your family member? *Prompts: nurses, others / carer's role*
3. What has worked well during the transition from child to adult health services in your circumstances? What were the positives? *Prompt: anything else that works well when facilitating transition?*
4. What did the professionals do that you think was particularly helpful in facilitating the transition for your family member?
5. What were the challenges you have been faced with in terms of the transition process for your family member? *Prompt: what do you think health professionals could do to help facilitate a smooth transition / anything else that doesn't work so well in facilitating the transition process*
6. How do you understand person-centred and family-centred care and how important do you feel it is for the health care professionals to be person-centred and family-centred during the transition process? *Prompt: the role of nurses / health care professionals in facilitating PC and FC care*
7. What support would you require to ensure a smooth transition from child to adult services for your family member?

Box 1: Interview schedule

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

From: Tong A, Sainsbury P, Craig J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19 (6), 349 – 357.

For manuscript: *Transition from child to adult health services: The views and experiences of families of young adults with intellectual disabilities*

Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 6
2. Credentials	What were the researcher's credentials? e.g. <i>PhD, MD</i>	Page 1 (title page) and 6
3. Occupation	What was their occupation at the time of the study?	Page 1 (title page) and 6
4. Gender	Was the researcher male or female?	Page 1 (title page)
5. Experience and training	What experience or training did the researcher have?	Page 1 (title page)
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	Page 5
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. <i>personal goals, reasons for doing the research</i>	Page 5
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i>	Page 5

Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Page 1 (abstract) and 5
<i>Participant selection</i>		
10. Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	Page 5
11. Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	Page 5
12. Sample size	How many participants were in the study?	Page 5
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Page 5, inferred
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Page 6
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	No, inferred on page 6 as one-to-one interviews
16. Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Pages 5, 7 and 28 (table 1)
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 6 and 29 (Box 1)
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No, inferred on page 6
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Yes, page 6

20. Field notes	Were field notes made during and/or after the interview or focus group?	No as audio recorded, page 6
21. Duration	What was the duration of the interviews or focus group?	Page 6
22. Data saturation	Was data saturation discussed?	Page 6
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Page 6
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Page 6
25. Description of the coding tree	Did authors provide a description of the coding tree?	Page 28 (Table 2)
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 6-7
27. Software	What software, if applicable, was used to manage the data?	Page 7
28. Participant checking	Did participants provide feedback on the findings?	No – inferred as not described
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? <i>e.g. participant number</i>	Page 7-18
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Page 7-18
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes. they were. From page 7-18
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Discussion of main and subthemes 7-18