

Literature Review: Transitions to Adulthood for Disabled Young People

**Report by The Diffley Partnership prepared
for the Scottish Government**

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Scottish Government Foreword

Scottish Ministers have committed to delivering a National Transition to Adulthood Strategy during this parliamentary term “to support disabled young people as they make the transition to adult life, and provide them and those who look after them with joined-up guidance and support to unlock better educational and employment opportunities and health outcomes”. This was announced in A fairer, greener Scotland 2021-2022 Programme for Government, published on 7 September 2021¹.

There is already good evidence that transitions and the planning for disabled young people who require support going into adulthood could be improved. There is also recognition and endorsement by many stakeholders that the Getting It Right For Every Child (GIRFEC)² approach and the Principles of Good Transitions³, produced by the Association for Real Change (ARC) Scotland, can guide and support professionals in all sectors involved in providing transition support for young people.

The Scottish Government, however, wanted to develop a more comprehensive picture of what a good transitional experience from school to adulthood would look like for all disabled children and young people, to help inform future stakeholder engagement and to support the development of a National Transitions to Adulthood Strategy.

In February 2022, The Diffley Partnership were awarded a short-term social research contract by the Scottish Government to undertake a literature review of Scottish, UK and international evidence on the main challenges and experiences faced by young disabled people during their transition to adulthood. The research also included a review of evidence of best practice when supporting people on this journey.

The specific scope of this project was to deliver:

- A literature review of transitions to adult life, with a particular focus on what disabled children and young people have said to date;
- Gaps in evidence analysis; and
- Topic guides to assist further engagement.

The Scottish Government wishes to thank Nicholas Heslop, Mark Diffley, Chris Creegan and Dawn Griesbach, from The Diffley Partnership, for the research they have undertaken which has culminated in this report. These findings will now form part of the evidence base for the development of Scotland’s first National Transitions to Adulthood Strategy.

¹ [A Fairer, Greener Scotland: Programme for Government 2021-22 - gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/programme-for-government-2021-22/pages/introduction.aspx)

² [Getting it right for every child \(GIRFEC\) - gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/getting-it-right-for-every-child/pages/introduction.aspx)

³ [Principles of Good Transitions - Scottish Transitions Forum](https://www.scottishtransitionsforum.org.uk/principles-of-good-transitions/)

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Summary of findings

This literature review outlines the findings of a review of Scottish, UK and international evidence on disabled young people's experiences of the transition to adulthood and best practice within this field.

This period can be an exciting and hopeful time but is also often stressful and difficult. Common challenges faced by individuals and their families include:⁴

- Stress and uncertainty for the young person
- Difficulties transferring from child to adult services
- Changes in eligibility for services, and support arrangements
- A sharp drop in support
- Inadequate transition-planning and a lack of clear information with regards to the transitions process
- Inadequate account being taken of young people's views, needs and aspirations
- Stress and difficulties faced by family members relating to the transition process.

On the basis of research conducted with young people in Scotland and beyond, stakeholders' outputs, and a number of academic reviews, there is consistent evidence that positive transitions are characterised by:⁵

- Early and sustained transition planning
- Holistic and coordinated wrap-around support
- Services delivered in partnership
- Designated keyworkers as a coordinating point of contact and continuity
- Person-centred support and preparation
- Family involvement in planning and decision-making
- Parental and familial support throughout the transition
- The provision of clear and accessible information
- Adequate services, resources and staffing.

Institutional transitions (i.e. from child to adult health and social care services) raised particular challenges, both personal and logistical. It can be taxing for young people to leave familiar and trusted environments and practitioners – with an established understanding of their personal, clinical and communication needs – for often-inferior and disjointed adult services.⁶ This landscape can be difficult to navigate, and

⁴ (ARC Scotland, 2017b; Health and Social Care Alliance Scotland, 2017)

⁵ Ibid.

⁶ (Health and Social Care Alliance Scotland, 2017; Lugasi, et al., 2011; Scottish Parliament, 2020)

established services and arrangements may be imperilled by this change, with support typically falling during this time.

Within institutional transitions, advanced planning with young people and their families again occupies a central place in transition-smoothing. This in turn relies on clear inter- and intra-agency communication and coordination, with a keyworker ensuring continuity and coordination from the perspective of disabled young people.⁷ Trust and positive relationships are also central to effective transitions, so introductory sessions and consistency of staffing are essential.⁸ There is some evidence that the integration of health and social care could help to lessen the challenges associated with transitioning, though this will likely require concerted planning.⁹

Disabled young people's educational, professional and personal outcomes also appear to lag behind those of their non-disabled counterparts.¹⁰

When leaving secondary education, it can be distressing to leave behind friends and teachers, and many disabled young people report a limited range of options, and a common loss of support as they move on to more independent forms of learning and/or living.¹¹ Disabled young people often report that they do not feel adequately consulted on their aspirations, with some placed into college courses of limited interest or value to them, and others anxious about their employment opportunities and prospects.¹²

Disabled young people and stakeholders have voiced concern at their below-average employment outcomes.¹³ There are seen to be limited options and routes into paid employment, as well as evidence of limited progression.¹⁴ Low societal and employer expectations can constrain people's opportunities, and there are limited tailored training opportunities.¹⁵ Targeted vocational training, along with work experience and supported employment are seen as effective routes into employment within the literature, though there is evidence of limited and inconsistent opportunities in Scotland.¹⁶

The transition to adulthood is closely associated with greater independence, though there are a number of obstacles to achieving this. There appears to be inadequate support for young people to manage their own disability/condition(s) and to live independently.¹⁷ Housing is also often poorly planned, and young people may struggle to secure their own home.¹⁸ There is a broad consensus that best practice

⁷ (NDTI, 2011)

⁸ (Butterworth, et al., 2016; Welch, et al., 2014; Zhou, et al., 2016)

⁹ (Fisher & Elnitsky, 2012; Mitchell, 2012; Fraser of Allander Institute, 2021)

¹⁰ (Scottish Parliament, 2020)

¹¹ (Fraser of Allander Institute, 2021)

¹² (Scottish Parliament, 2020; DIVERgent INfluencers, 2021)

¹³ (Scottish Parliament, 2020)

¹⁴ (Fraser of Allander Institute, 2021; DIVERgent INfluencers, 2021)

¹⁵ (Scottish Parliament, 2020; ARC Scotland, 2017)

¹⁶ (Flexer & Baer, 2008; Greene, 2009; Papay & Bambara, 2014; Bambara, Wilson, & McKenzie, 2007; Wehman, 2006; Fraser of Allander Institute, 2021)

¹⁷ (SCLD, 2017)

¹⁸ (SCLD, 2017)

includes effective life-skills training and guidance relating to self-management, housing, and financial management.¹⁹

Finally, disabled young people often lack confidence with regards to social situations and personal relationships, are disproportionately likely to suffer from social isolation, and report that they lack opportunities to be active members of their community.²⁰ In line with best practice, transition support and planning should support young people's psychosocial development to establish healthy adult relationships. It has been observed, however, that young people in Scotland lack such opportunities, and that there is little attention paid within research and practice to romantic and sexual relationships.²¹

Broadly, there is a high degree of consistency within the literature on effective practice. However, there is a correspondingly high level of duplication, with limited evidence and knowledge on more granular practice and detail.

¹⁹ (Baer, et al., 2011; Papay & Bambara, 2014)

²⁰ (DIVERgent INfluencers, 2021; Di Rezze, et al., 2016; Maslow, et al., 2011)

²¹ (NDTI, 2011; SCIE, 2017; Henninger & Taylor, 2014; Fisher & Elnitsky, 2012; Di Rezze, et al., 2016; Stewart, 2009; Scottish Parliament, 2020)

Glossary & Clarifications

In this section we briefly define certain key terms that recur throughout the review. However, it should be noted that these and other terms are used across the evidence base in different ways and with competing definitions. Therefore, our definitions are intended to be general and broad, and they may not conform to how individual authors cited use the same terms. We have, for the most part, designed our own broad and flexible definitions rather than employed fixed or given ones. They should therefore be interpreted as a helpful steer, rather than a rigid definition.

Transitions – The term ‘transition’ to adulthood is defined by the Association for Real Change (ARC) Scotland as referring to “the period when young people [aged 14-25] develop from children to young adults. This is not a single event, such as leaving school, but a growing-up process that unfolds over several years and involves significant emotional, physical, intellectual and physiological changes. During this period young people progressively assume greater autonomy in many different areas of their lives and are required to adjust to different experiences, expectations, processes, places and routines. Transitions also impact on the family or on those who care for the child or young person.”²²

Disabled young people – we refer to disabled young people throughout this report, with a focus on people between adolescence and early adulthood. ARC Scotland defines this as between the ages of 14-25, which we adhere to as much as possible, though other sources may set different parameters or not specify these. We note that different authors and sources will have competing definitions of disability, and exercise varying levels of discretion and/or selectivity in their language-use and inclusion in their research. We have broadly considered studies that refer to people with disabilities of various kinds (including developmental, physical, learning and sensory) as well as certain studies on young people with ‘additional support needs’ where it has been judged that these are suitable. ‘Additional support needs’ are defined by Education Scotland and the Scottish Government as “requir[ing] support that is additional to, or different from, that received by children or young people of the same age to ensure they benefit from education, whether early learning, school or preparation for life after school [...] Additional support needs can be both long- and short-term, or can simply refer to the help a child or young person needs in getting through a difficult period. Additional support needs can be due to disability or health, learning environment, family circumstances [and/or] social and emotional factors.”²³

Institutional transitions – Within this review, these refer to transitions from child to adult services within specific clinical, healthcare and social care settings.

²² (ARC Scotland, 2017, p. 7)

²³ (Education Scotland, n.d.)

Life-course transitions – For the purposes of this review, life-course transitions refer to the changes that occur as a result of a young person attaining a new life-stage. This might be a result of reaching a specific age (e.g. leaving school) or due to the young person choosing to change their circumstances (e.g. choosing to pursue independent living).

Independent living – This refers to the process by which a young disabled person takes on greater responsibilities and self-sufficiency, including in managing their own clinical care (i.e. self-management), and/or living alone. Independent living does not refer to complete self-sufficiency (or living alone), but rather the extent to which “independent living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives”.²⁴

Active Citizenship - This term is occasionally referred to in the literature, but without any clear or consistent definition provided. We consider that the term is likely to refer to a young person's involvement in their local community – both geographical and communities of interest.

²⁴ (European Network on Independent Living, n.d.)

Introduction

This literature review summarises and synthesises the most consistent and pertinent findings with regards to disabled young peoples' experiences of the transition to adulthood, and the existing evidence on best practice in supporting young people through this process.

We begin by outlining common experiences of transitions to adulthood in general. These include the stress that this process can entail for young people and their families, the often-inadequate planning that goes into this, and the paucity of accessible information and guidance on navigating this difficult journey. We then turn our attention to common elements of good practice with regards to transitions in general. These are grouped around a series of guiding principles, including early, sustained and wraparound planning, in concert with the young person in question, their family and carers, and all relevant practitioners. There is a high degree of consistency within the literature – regardless of source or sector – in support of these key guiding principles, but more mixed evidence on their practical application in Scotland and the wider UK.

We then turn our attention to specific transitions and provide greater detail on these. These include institutional transitions (from child to adult services within health and social care) and life-course transitions (relating to education, employment, independent living, and personal relationships). For each one in turn, we again outline common experiences and challenges faced by disabled young people, and identify examples of effective practice.

We conclude by reflecting briefly on these findings, as well as the amount and quality of the evidence pertaining to each facet, and outline a gap analysis and areas for future research and engagement with disabled young people.

Methodology

A review of the existing evidence on transitions to adulthood was conducted, with a particular focus on what young people, their families and carers (in Scotland and beyond) had said about this process, and the aspects of best practice identified within the literature.

Searches were conducted to identify relevant sources, including:

- Outputs from relevant stakeholders operating in the fields of disabilities and transitions in Scotland and the wider United Kingdom
- Research conducted with young people on their experiences, and expressed needs and preferences
- Academic sources, with a focus on literature reviews, systematic reviews, and meta-reviews

Most sources related to disabled young people, though where appropriate and relevant, sources were also consulted relating to young people with additional support needs and/or chronic conditions where it was established/deemed that the findings were generalisable to transitions more broadly. Within the existing literature there are a range of competing definitions and classifications, and in various instances no definition at all, so we have exercised discretion in selecting relevant sources.

These sources were consulted and, where relevant, notes on their findings were taken and data points recorded. These were subsequently subjected to a thematic analysis, with thematic codes applied. These broadly related to recurring overarching principles identified in transitions and transition-planning, and to specific transitions (within given sectors or fields) where further sub-themes emerged.

On this basis, a comprehensive literature review was produced outlining the key findings of previous research in this field, common experiences and best practice with regards to transitions – both in general and with regards to specific sectors or settings.

The review concludes with some reflections on the relative amount, depth and quality of this information and how it varies between sectors/themes. On this basis, a gap analysis was conducted, identifying areas where evidence and knowledge is more sparse or inconsistent.

Common Experiences in Transitions

This section outlines common experiences relating to transitions in general. Later sections of the review will explore experiences relating to more specific (institutional and life-course) transitions (e.g. within healthcare or education).

The term ‘transition’ to adulthood is defined by ARC Scotland as referring to “the period when young people develop from children to young adults. This is not a single event, such as leaving school, but a growing-up process that unfolds over several years and involves significant emotional, physical, intellectual and physiological changes. During this period young people progressively assume greater autonomy in many different areas of their lives and are required to adjust to different experiences, expectations, processes, places and routines. Transitions also impact on the family or on those who care for the child or young person.”²⁵

Transitions to adulthood can be a rewarding and exciting time for disabled young people as they seek to gain independence,²⁶ and many disabled young people in Scotland express optimism and excitement about this time in their lives.²⁷

However, it is established within the literature that transitions to adulthood and adult services can be extremely challenging and stressful.²⁸ A number of shortcomings in the service and policy landscape in Scotland and the UK have been identified over time, and these are outlined throughout this review.²⁹ Experiences of transitions to adulthood have been variously described by those with experience of the process as ‘terrifying’, ‘a black hole’, and ‘a scary void’.³⁰

While the literature suggests that there are generally positive experiences of children’s services (especially but not exclusively with regards to child health and social care), there is a consensus that experiences of the transition to adulthood are decidedly more negative.³¹

There is a high degree of consistency to the findings within the existing literature, whether domestic or international, on young people’s experiences of transitions. Common challenges faced by young people, both in Scotland³² and beyond,³³ include:

- General stress and uncertainty for the young person
- Difficulties transferring from child to adult services
- Changes in eligibility for services, and support arrangements
- A sharp drop in support

²⁵ (ARC Scotland, 2017)

²⁶ (McBride & McDicken, 2012; SPICe, 2019)

²⁷ (ARC Scotland, 2017)

²⁸ (Chamberlain & Kent, 2005)

²⁹ (Heslop, et al., 2002; Stalker & Moscardini, 2012)

³⁰ (Stalker, et al., 2013, p. 43)

³¹ (McBride & McDicken, 2012)

³² (Scottish Parliament, 2020; Stalker & Moscardini, 2012)

³³ (Colver, et al., 2018; Zhou, et al., 2016)

- Inadequate transition-planning and a lack of clear information with regards to the transitions process
- Inadequate account being taken of young people's views, needs and aspirations
- Stress and difficulties faced by family members relating to the transition process.

Moving from children's to adult services (in general)

According to the literature, a key challenge within the transition to adulthood relates to the move from child to adult services, as this process is often disjointed and poorly coordinated. The move to new adult services can prove challenging on various fronts.

It can be stressful and emotionally difficult to leave behind familiar and trusted practitioners who have an established rapport with the young person and their family, and an in-depth knowledge of their condition(s), medical needs, and clinical preferences. Many young people and carers struggle with concerns that new service providers may not fully understand their needs,³⁴ and it can prove frustrating and distressing for young people to repeatedly have to explain their circumstances to new people.³⁵ This applies in particular to clinical settings, but similar experiences are reported with regards to education and other sectors.

Young people and their families can find adult services difficult to navigate, as they are often delivered in a more disjointed fashion.³⁶ Where paediatric health and social care services tend to operate in a more joined-up manner, adult services tend to involve individual specialisms operating more autonomously and often located on different sites.³⁷ Adult services (in general) also tend to assume a greater level of autonomy, with a greater onus placed on the service-user to arrange and manage their support. It is also common for disabled young people to engage with multiple services to meet all their distinct needs. However, during their transition to adult services, poor inter- and intra-agency communication, coordination and collaboration have been highlighted in the evidence from Scotland,³⁸ the UK,³⁹ and beyond.⁴⁰ In Scotland, this has been observed not only by disabled young people, but also by practitioners who have reported that a lack of joined-up working is the largest impediment to supporting smooth transitions.⁴¹

It can thus often fall to the young person in question or their family to attempt to coordinate disjointed services and supports. Given the complexity of the health and

³⁴ (Stalker & Moscardini, 2012; Welch, et al., 2014; Stalker, et al., 2013)

³⁵ (Young Minds, 2020)

³⁶ (Colver, et al., 2019; NDTI, 2011; Zhou, et al., 2016)

³⁷ (Scottish Parliament, 2020; Scottish Government, 2018)

³⁸ (ARC Scotland, 2017; Health and Social Care Alliance Scotland, 2017; Stalker & Moscardini, 2012; Stephen, et al., 2015; Welch, et al., 2014)

³⁹ (Heslop, et al., 2002; Colver, et al., 2019)

⁴⁰ (Zhou, et al., 2016)

⁴¹ (ARC Scotland, 2017b; Social Work Scotland, 2018)

social care service landscape, and the absence of clear, accessible information and advice, this can result in considerable stress for young people and their families.⁴²

Differences in culture can compound these challenges. Adult services tend to treat service-users as more autonomous, and thus expect a much greater degree of self-sufficiency than young people and their families may be accustomed to.⁴³ If parents / carers are not adequately involved in discussions and decision-making about the transition process, this can result in stress for young people and their families.⁴⁴

Young people's eligibility for services and supports may change when they move into adult services, even when this is neither necessary nor desired⁴⁵ (this is particularly common in social care where eligibility can shift considerably). Hard-won arrangements that suit the young person and their family may have to be renegotiated when moving to new services.⁴⁶ Eligibility criteria often vary between child and adult services and / or between local areas,⁴⁷ which can lead to a sudden cessation of support, especially with regard to day services and respite services.⁴⁸ Adult social care, in particular, may be limited to only the most critical cases.⁴⁹

Inadequate planning and information

In a recent review of the Scottish transitions landscape, the Fraser of Allander Institute reflected that "transitions do not need to be difficult if they are well planned and well managed. However, the evidence suggests that this is rarely the case"⁵⁰.

While thorough, early and sustained transition planning is widely accepted as best practice,⁵¹ there is evidence that this is routinely not achieved in practice in Scotland.

In a survey of parents and carers of disabled young people carried out by ARC Scotland, three-quarters of respondents reported that their child had no formal written plan to support their transition.⁵² A recent Scottish Parliament consultation on transitions also heard that transition planning for disabled young people in Scotland lacks a consistent, coherent approach.⁵³

Some studies and commentators have suggested that clear accountability for transition planning and preparation is lacking.⁵⁴ This responsibility often falls between child and adult services. In the absence of a designated professional, this

⁴² (Stalker & Moscardini, 2012; Scottish Parliament, 2020)

⁴³ (Stalker, et al., 2013; Young Minds, 2020; Zhou, et al., 2016)

⁴⁴ Ibid.

⁴⁵ (Scottish Parliament, 2020)

⁴⁶ (Welch, et al., 2012)

⁴⁷ (ARC Scotland, 2017; Scottish Parliament, 2020)

⁴⁸ (McBride & McDicken, 2012; Health and Social Care Alliance Scotland, 2017; SPICe, 2019)

⁴⁹ (Scottish Parliament, 2020)

⁵⁰ (Fraser of Allander Institute, 2021)

⁵¹ (Bindels-de Heus, et al., 2013; Zhou, et al., 2016; SPICe, 2019)

⁵² (ARC Scotland, 2017)

⁵³ (Scottish Parliament, 2020)

⁵⁴ (ARC Scotland, 2017b; Cross-Party Group on Autism, 2020; NDTI, 2011; Colver, et al., 2019; Welch, et al., 2014)

responsibility can fall variously to children's services,⁵⁵ educational establishments,⁵⁶ and the young person's parents. A lack of clear accountability for transition planning can mean that nobody takes the necessary action to ensure that transitions take place in a coordinated way.

Poor planning and preparation can have various adverse consequences; it can result in young people being placed into inappropriate settings, including young people receiving support and treatment alongside much older and sicker individuals;⁵⁷ it can constrain opportunities with regards to education and employment if the necessary prerequisites are not achieved in advance;⁵⁸ and it can lead to inadequate resourcing of services.⁵⁹

Difficulties can also arise when transition plans are not referred to or updated over time, rendering them obsolete.⁶⁰ Some commentators in Scotland have pointed out that transition planning is often treated by practitioners as a singular event rather than a process.⁶¹ However, transitions are rarely simple and linear, and the benefits of flexibility, 'tasters' and trialling different approaches and services have been noted in the evidence.⁶² Transition plans inevitably need to be updated to remain relevant and targeted as a young person's needs, expectations and aspirations change. Young people can find it difficult to maintain their plan by themselves, and support to do so is not always forthcoming from practitioners/professionals.⁶³ Indeed, young people in Scotland report that planning sessions are often not ultimately used for these purposes.⁶⁴

When it is carried out, there is evidence that transition planning routinely lags behind established best practice. Disabled young people and researchers frequently report that only a narrow range of options are presented to them,⁶⁵ at times in an apparent and/or perceived effort to keep them supervised/occupied, rather than to provide stimulating or valuable opportunities.⁶⁶ This can, for instance, see young people placed into educational courses that are of little value or interest to them. There is some evidence that practitioners and professionals can underestimate the abilities, assets and aspirations of young people, and that they may consequently not achieve their full potential.⁶⁷

There is further evidence that young people's voices are routinely not taken into consideration within transition planning.⁶⁸ Some have reported that they are routinely not asked even fundamental questions relating to their interests, hobbies or

⁵⁵ (Colver, et al., 2019; Welch, et al., 2014)

⁵⁶ (NDTI, 2011)

⁵⁷ (Scottish Parliament, 2020).

⁵⁸ (Stalker & Moscardini, 2012)

⁵⁹ (Scottish Government, 2018)

⁶⁰ (Colver, et al., 2018; ARC Scotland, 2017b; NDTI, 2011; SCIE, 2017)

⁶¹ (Scottish Parliament, 2020)

⁶² (DIVERgent INfluencers, 2021; ARC Scotland, 2017)

⁶³ (Colver, et al., 2018)

⁶⁴ (Health and Social Care Alliance Scotland, 2017)

⁶⁵ (Stalker & Moscardini, 2012)

⁶⁶ (Scottish Parliament, 2020; DIVERgent INfluencers, 2021)

⁶⁷ (Francis, 2006; NDTI, 2011)

⁶⁸ (Social Work Scotland, 2018; ARC Scotland, 2018)

aspirations.⁶⁹ This can result in frustration, disengagement and apathy, and is evidently incompatible with person-centred ‘strengths-based’ planning.⁷⁰

A further issue is one of inadequate information, advice and guidance to navigate the complex transitions landscape. Young people and their families are routinely left unprepared as to how their support services and treatments are likely to change. A survey of parents carried out by ARC Scotland reported that a quarter of parents of disabled children said that a lack of support and information had been the most difficult thing about their child’s transition from school.⁷¹

It has been suggested that there is broad support from young people and their families for the various policies and initiatives relating to transitions to adulthood, but their sheer number can prove overwhelming and there is no clear or accessible guide for navigating these.⁷²

Parental & familial challenges

Transitions to adulthood and adult services are difficult not only for disabled young people themselves, but also for their families.⁷³ This process can put enormous emotional strain on parents who worry about their child and often, of necessity, take on considerable work in addition to their other parental and professional commitments. While there is limited research exploring the relationship between poverty and engagement with transitional support interventions for young disabled people, it has been noted that those with limited resources face challenges with transitions.⁷⁴

The literature suggests that the transition to adulthood can be a hopeful and exciting time for parents, though it is also common for them to worry about their child, particularly their social transition, educational and professional opportunities, and potential isolation.⁷⁵

Parents can find the process emotionally taxing due to concerns for their child’s wellbeing, opportunities and outcomes. Leaving behind familiar practitioners and services can be stressful for parents, especially if they fear that adult services lack a clear understanding of their child’s condition(s) and needs.⁷⁶ They may experience a tension between wanting to protect their child and wanting to promote independence.⁷⁷ (There is, however, also some evidence that overly protective parents can hinder effective transitions or constrain opportunities.⁷⁸)

The transition process can also have serious adverse impacts on parents themselves. In the absence of clear accountability on the part of service providers,

⁶⁹ (DIVERgent INfluencers, 2021)

⁷⁰ (National Institute for Health and Care Excellence (NICE), 2016)

⁷¹ (ARC Scotland, 2017)

⁷² (Health and Social Care Alliance Scotland, 2017; Stalker & Moscardini, 2012)

⁷³ (Stalker & Moscardini, 2012; Scottish Parliament, 2020; SPICe, 2019; Leonard, et al., 2016)

⁷⁴ (Allcock, 2019)

⁷⁵ (ARC Scotland, 2017; Leonard, et al., 2016)

⁷⁶ (Health and Social Care Alliance Scotland, 2017; Stalker, et al., 2013)

⁷⁷ (Lewis & Noyes, 2013)

⁷⁸ (Zhou, Roberts, Dhaliwal, & Della, 2016; Fraser of Allander Institute, 2021)

parents often become charged with the role of managing and coordinating diverse and disjointed services. This can lead to overload and burnout.⁷⁹

This can prove especially stressful when arrangements, resulting from negotiation and experimentation over many years, are imperilled or brought to a halt by the transition to adult services. Parents who have secured a balance of appropriate supports of mutual benefit to themselves and their child can find themselves back at square one.⁸⁰

These challenges can be compounded by the loss of care, support and respite services that leaving paediatric services and/or school often entails. There is evidence that some parents may feel pressured to leave work to care for their child, thus resulting in significant adverse financial impacts on the family.⁸¹

Finally, despite the importance of involving parents in transition planning,⁸² parents (like young people themselves) can find themselves excluded from transition planning discussions and decision-making which can be emotionally distressing.⁸³

⁷⁹ (ARC Scotland, 2017b)

⁸⁰ (Colver, et al., 2019)

⁸¹ (Health and Social Care Alliance Scotland, 2017; Scottish Parliament, 2020; Carers UK, 2019)

⁸² (Zhou, et al., 2016)

⁸³ (Stalker, et al., 2013; Young Minds, 2020; Zhou, et al., 2016; ARC Scotland, 2017b; Cheseldine, 2010)

Best Practice in Transitions

There is a broad consensus across the literature in support of certain guiding principles within transitions and transition-planning. These are discussed in relation to all sectors and are sometimes formalised as guiding principles (as in the Principles of Good Transitions⁸⁴) or referred to more generally as good practice.

There is a high degree of commonality in the principles, with a large number of evidence reviews and meta-reviews drawing broadly consistent conclusions about the enablers of good transitions which have been identified. These include:

- Early and sustained transition planning
- Holistic and coordinated wrap-around support
- Services delivered in partnership
- Designated keyworkers as a coordinating point of contact and continuity
- Person-centred support and preparation
- Family involvement in planning and decision-making
- Parental and familial support throughout the transition
- The provision of clear and accessible information
- Adequate services, resources and staffing.

However, the counterpoint to this consistency is a degree of duplication within the evidence base. Much of the established consensus and evidence on best practice reflects broad (and at times imprecise) concepts rather than specific examples of effective practice. Such examples are outlined in sections below.

There is a paucity of rigorously evaluated empirical 'best practice', with guiding principles instead based in large part on endorsements or validation by practitioners within different sectors, and/or by disabled young people.^{85, 86} This seems to be, at least in part, due to wide variations in the structure and delivery of interventions, and the multiplicity of possible outcome indicators which makes comparative evaluation difficult.⁸⁷

This section will outline the main findings relating to good practice in supporting transitions and transition planning, delineating the key factors, noted gaps or challenges in Scotland, and any details of best practice. Findings relating to best practice or challenges within specific sectors (such as healthcare, education, or personal development) are outlined in later sections.

⁸⁴ (ARC Scotland, 2017b)

⁸⁵ (Greene, 2009; Test, et al., 2009; Papay & Bambara, 2014)

⁸⁶ (Papay & Bambara, 2014)

⁸⁷ (Papay & Bambara, 2014; Doug, et al., 2011)

Transition planning

A large body of research – both UK⁸⁸ and international⁸⁹ – has found that preparing a young disabled person for the transition process can significantly improve outcomes in a range of domains.

The creation of a formal transition plan enables advanced planning and coordination of the transition process, and provides information to young people and their families about what they can expect from this process.⁹⁰ Transition planning thus has evident benefits for both young people (in terms of improving transitions and outcomes and reducing uncertainty/anxiety) and for service delivery (increasing efficiency and ensuring effective planning and resourcing).

A meta-summary of qualitative and quantitative research on best practice stressed the importance of “presenting transition as a normal event; clarifying and discussing the [young person’s] expectations about the process [and] planning with [them] the specific steps involved in transition”.⁹¹ This approach has been validated by young people themselves; in a recent survey, disabled young people in Scotland who had gone through or were going through a transition to adult services reflected on the importance of knowing what is coming and what to expect.⁹²

This transition plan should set out clearly the services that young people will need and how the activities of these various agencies and practitioners will be coordinated.⁹³ The plan should also outline a route map to the young person’s desired aspirations, specifying (and linking them to) the services that will help them to make these aspirations a reality.

The evidence strongly indicates that a young person should have a unified transition plan that encompasses and coordinates the various different supports and services that they are likely to engage with. However, in practice, many young people in Scotland lack a formal and/or single transition plan.⁹⁴

It has been observed by stakeholders that professionals will tend to make different plans (relating to their specialism) for different but often overlapping aspects of the young person’s life. This can force parents and young people to repeatedly explain their circumstances, can lead to miscommunication, and/or can duplicate work across public agencies.⁹⁵

Effective coordination of services is therefore important, not only to ensure a positive experience of transition for young disabled people and their families, but also efficient service-delivery.⁹⁶

⁸⁸ (ARC Scotland, 2017; SPICe, 2019)

⁸⁹ (Bindels-de Heus, et al., 2013; Zhou, et al., 2016)

⁹⁰ (SCIE, 2017)

⁹¹ (Lugasi, et al., 2011)

⁹² (DIVERgent INfluencers, 2021)

⁹³ (McBride & McDicken, 2012)

⁹⁴ (ARC Scotland, 2017)

⁹⁵ (ARC Scotland, 2017b)

⁹⁶ (SCIE, 2017)

Transition planning should aim to smooth the transition from child to adult services (largely, but not exclusively in institutional transitions) where relevant, for instance by scheduling visits to adult services and introductions to new practitioners, with a view to fostering positive relationships early on.⁹⁷ The evidence indicates that a gradual introduction and integration into adulthood, and adult services specifically, helps to provide reassurance and stability to young people and is preferable to rushed or abrupt transitions.⁹⁸

For this reason, as noted above, there is a strong consensus across the existing evidence base in support of early and sustained transition planning, both domestically⁹⁹ and from an international perspective.¹⁰⁰ However, there is some evidence that this is often not the case in practice in Scotland.¹⁰¹

The literature indicates that late transitions (i.e. delayed introductions to adult services) are associated with poor outcomes in terms of achieving independence.¹⁰² Specifically, there is evidence that late transition planning can constrain future opportunities (e.g. educational opportunities) though there is not conclusive agreement on what 'early' or 'late' mean (see below).¹⁰³ In contrast, the National Institute for Health and Care Excellence (NICE) Transitions Guidelines points out that early transition planning is associated with improved life chances.¹⁰⁴

However, the timing and framing of a transition plan is important; it has been found that a premature transition can be associated with an increased risk of psychological issues,¹⁰⁵ and the Scottish Transitions Forum report that their work with young people, parents and carers has found a common perception that early planning can imply that a transition is imminent which, in turn, causes stress. Therefore, the purposes and gradual nature of early transition planning should be clearly communicated.¹⁰⁶

There is some disagreement in the literature, albeit within relatively consistent parameters, about the optimal age at which to begin the transition planning process.¹⁰⁷ Some academic research has suggested that healthcare transition planning should begin in the early teens,¹⁰⁸ while other researchers/commentators have suggested that age 14 is optimal.¹⁰⁹ The latter conforms with the view of ARC Scotland, who argue in their Principles of Good Transitions that "planning should start early [aged 14] and continue up to age 25".¹¹⁰

⁹⁷ (McBride & McDicken, 2012; ARC Scotland, 2017)

⁹⁸ (ARC Scotland, 2017b)

⁹⁹ (ARC Scotland, 2017; SPICe, 2019)

¹⁰⁰ (Fegran, et al., 2014)

¹⁰¹ (Stalker & Moscardini, 2012; Jaquet, 2015)

¹⁰² (Van Staa & Sattoe, 2014; Paul, et al., 2013)

¹⁰³ (Stalker & Moscardini, 2012)

¹⁰⁴ (National Institute for Health and Care Excellence (NICE), 2016)

¹⁰⁵ (Helgeson, et al., 2013)

¹⁰⁶ (ARC Scotland, 2017b)

¹⁰⁷ (Zhou, et al., 2016)

¹⁰⁸ (Price, et al., 2011)

¹⁰⁹ (Sebastian, et al., 2012)

¹¹⁰ (ARC Scotland, 2017b)

With regards to transitions themselves, there is a broad consensus in the international and/or academic literature that mid-teens to early twenties is the optimal time to transition from paediatric to adult services.¹¹¹

Others, however, have countered that age itself is too arbitrary a basis and that the young person's maturity, self-efficacy and developmental stage should determine this.¹¹²

In any case, the evidence suggests that transition planning should not be a 'one-off' event as it often is in practice.¹¹³ Rather, it should be an ongoing process in which plans are refreshed and updated, (at least yearly according to the Social Care Institute for Excellence),¹¹⁴ particularly as successful transitions may require experimentation to arrive at the optimal range of supports.¹¹⁵

The evidence on best practice supports the development of transition 'passports' or 'profiles' as practical tools supporting a transition plan. The purpose of these passports is to provide a short and accessible summary of the young person's history, preferences and needs. This provides all relevant practitioners with the necessary information to provide high-quality services and establish positive relationships, and it saves the young person from having to repeatedly explain their circumstances and history.¹¹⁶ Passports might include information relating to:¹¹⁷

- The communication needs and preferences of the young person
- Their medical history and self-management experiences
- Their preferences with regards to parental involvement
- Their clinical needs and preferences
- Their strengths, interests and aspirations.

Young people themselves have noted that formalised documents such as a passport can be helpful, albeit on the condition that it is valued, used, read and updated by practitioners.¹¹⁸

While the literature suggests that there is consensus among young people, practitioners, and researchers in support of transition planning, there is nevertheless some evidence that even in cases where (healthcare) transition planning was carried out, a degree of stress and anxiety were recorded, and therefore may be somewhat inevitable.¹¹⁹

¹¹¹ As per a meta-review of existing evidence (Zhou, et al., 2016)

¹¹² A number of meta reviews have found developmental stage to be important (Fegran, et al., 2014) (Zhou, et al., 2016)

¹¹³ (Scottish Parliament, 2020)

¹¹⁴ (SCLD, 2017)

¹¹⁵ (ARC Scotland, 2017)

¹¹⁶ Ibid.

¹¹⁷ (McBride & McDicken, 2012; SCIE, 2017)

¹¹⁸ (Colver, et al., 2018)

¹¹⁹ (Chaudhary, et al., 2013)

Holistic support

Typically, disabled young people will come into contact with multiple practitioners and services (from health, education, social care, and others). Wrap-around support, and effective coordination and planning between these services, are therefore critical, and especially so for young people with multiple or complex needs.¹²⁰ The importance of holistic supports arises consistently in a number of reviews and meta-reviews of the existing evidence.¹²¹ Disabled young people in Scotland were themselves found to take a holistic view of their aspirations and needs, but (often disjointed) services tended to operate along more service-specific metrics and goals.¹²²

In addition to health and social care, an effective transition will adopt a 'life-course approach' that seeks to support (and plan for) the young person to pursue educational, professional and other opportunities.¹²³

Within health and social care, it is commonplace for paediatric services to adopt a more holistic approach and perspective, whereas adult services may operate in a more siloed manner. Even within these fields, adult services may be fragmented, so wrap-around support and planning are necessary.

However, in addition to these services, a consistent thread in the literature highlights the importance of personal development in any effective transition support. This should include supporting disabled young people to self-manage their condition, facilitating independent living, and providing support with regards to personal relationships.¹²⁴

Partnership working

From the perspective of services, an efficacious and holistic approach to transition support and planning is widely seen to require effective partnership working between relevant services, agencies and practitioners.¹²⁵ This is associated within the literature on children's services with improved outcomes for young people,¹²⁶ and there is evidence from Scotland that young people and their families credit this type of approach with improved outcomes.¹²⁷

Effective partnerships are seen to bring together individuals and their families with statutory, private and third sector services to ensure that all the young person's needs are addressed in an integrated fashion.¹²⁸ The value of multi-agency working

¹²⁰ (Carter, et al., 2014; SCIE, 2017)

¹²¹ (Di Rezze, et al., 2016; Health and Social Care Alliance Scotland, 2017)

¹²² (Welch, et al., 2014)

¹²³ (Gorter, et al., 2014)

¹²⁴ (NDTI, 2011; SCIE, 2017; Colver, et al., 2018b)

¹²⁵ (Health and Social Care Alliance Scotland, 2017; SPICe, 2019)

¹²⁶ (Frost, 2017; Cooper, et al., 2016)

¹²⁷ (Social Work Scotland, 2018; ARC Scotland, 2017)

¹²⁸ (McBride & McDicken, 2012)

is widely noted in the academic literature,¹²⁹ and a report by the Scottish Government argued that “Partners who plan in a joined-up way are more likely to ensure that young people can access the support they need to make effective transitions. This means having an effective multi-agency approach and the involvement of universal services, with clearly defined responsibilities”.¹³⁰

Effective partnership working appears especially important within health and social care, given the challenges associated with transitions within and between these, and the established landscape of disjointed services.¹³¹ The international literature also suggests that joint planning between adult and paediatric services, and primary care can improve the transfer of young people from one to the other.¹³²

The evidence suggests that third sector organisations and advocacy services are especially important in smoothing transitions between paediatric and adult services. The third sector was associated, among professionals and practitioners, with “extraordinary creativity”, and was seen to flexibly fill gaps in service-provision (especially with regards to life-course transitions and personal development).¹³³ The third sector has been described as having specific strengths and positive working practices/styles, including person-centred communication, effective partnership working and specific knowledge/expertise.¹³⁴

However, there are a number of barriers to partnership working identified within the UK and international literature. Some commentators have lauded Scotland’s positive efforts and progress with regards to improving partnership working,¹³⁵ although a number of cultural, financial and organisational barriers are seen to persist.¹³⁶

Barriers consistently identified in the literature that can stymie partnership formation and working include differing working cultures and practices between sectors (such as health, education, and social care),¹³⁷ resource constraints, poor inter-agency and inter-personal relationships, and inadequate information-sharing.¹³⁸ Performance metrics often do not align between services, further complicating issues.¹³⁹

By contrast, the evidence indicates that the enablers of effective partnership working include:¹⁴⁰

- Leadership and shared values
- Financial (rather than simply structural) integration

¹²⁹ (Flexer & Baer, 2008; Greene, 2009; Papay & Bambara, 2014; Bambara, et al., 2007; Wehman, 2006)

¹³⁰ (Scottish Government, 2014)

¹³¹ (SCIE, 2013; CELCIS; Children in Scotland; Care Inspectorate, 2018)

¹³² (Colver, et al., 2019)

¹³³ (Health and Social Care Alliance Scotland, 2017, p. 115)

¹³⁴ *Ibid.*

¹³⁵ (Stephen, et al., 2015)

¹³⁶ (CELCIS; Children in Scotland; Care Inspectorate, 2018)

¹³⁷ (NDTI, 2011)

¹³⁸ (Cooper, et al., 2016)

¹³⁹ (Mason, et al., 2015)

¹⁴⁰ (CELCIS; Children in Scotland; Care Inspectorate, 2018)

- Community-based, bottom-up partnership formation and service-delivery
- Good communication between professionals and services
- Inter-agency and inter-personal trust
- Opportunities for shared learning, information and practice sharing, and co-location
- Effective information-sharing and the use of appropriate outcome metrics (rather than service inputs and outputs)
- A focus on disabled young people and their needs.

Knowledge-sharing occupies a central role in partnership formation and working, though poor inter-agency communication and poor data-sharing have been seen to undermine partnership working.¹⁴¹ Workshops allowed for the exchange of knowledge and practice between service providers, allowing for and facilitating multi-agency working.¹⁴² One example from Scotland, the Scottish Transitions Forum, was reported to provide peer-learning and mentoring opportunities for practitioners to share good practice across professional disciplines.¹⁴³ This may include effective interventions, and knowledge of the relevant service landscape and policy context that might impact on transitions.

As noted above, a passport containing important information relating to health, care and communication needs, as well as the young person's circumstances and aspirations, can facilitate information-sharing between practitioners and help to build efficient and person-centred services. The use of a passport allows for seamless referrals and helps to foster positive relationships, while at the same time avoiding the frustration for the young person and their family of having to repeat their story to multiple practitioners. However, maintenance and use of the passport in practice was not always realistic or forthcoming.

Keyworkers

There is broad support within the existing evidence base for a keyworker model that provides continuity and coordination during this complex and often stressful process; this spans clinical guidelines¹⁴⁴ and (meta-)reviews of the existing evidence,¹⁴⁵ as well as young people and stakeholders' endorsements.¹⁴⁶

This approach is seen to have various benefits: the keyworker model provides young people and their families with a single point of contact, improving the navigability of services and reducing stress on the families;¹⁴⁷ it supports the coordination of

¹⁴¹ (Social Work Scotland, 2018)

¹⁴² (McBride & McDicken, 2012)

¹⁴³ (Jacquet, S., 2015)

¹⁴⁴ (SCIE, 2017)

¹⁴⁵ (Health and Social Care Alliance Scotland, 2017; Colver, et al., 2018b; Zhou, et al., 2016)

¹⁴⁶ (Talking Mats, 2015)

¹⁴⁷ (SPICe, 2019)

services, and provides accountability for transition planning;¹⁴⁸ it is seen as good value for money;¹⁴⁹ and it has been associated with improved outcomes.¹⁵⁰

Young people and their families in Scotland have associated the keyworker model with improved outcomes in both qualitative¹⁵¹ and quantitative research.¹⁵² In a survey of parents and carers in Scotland, 20% of respondents identified a keyworker as the single biggest enabler of a smooth transition.¹⁵³

The keyworker model provides young people and their families with a designated professional to answer their questions and coordinate transition planning. There is evidence from stakeholders that keyworkers can provide much needed emotional support, and build positive rapport and trust with young people,¹⁵⁴ which is in turn associated with improved outcomes in transitions.¹⁵⁵ This model also facilitates accountability. It has been argued that in the absence of a designated professional, parents routinely end up taking responsibility for transition management (and may have to give up work to do so), prompting considerable familial stress.¹⁵⁶ Alternatively, the responsibility may fall on schools or children's services, with little regard to what happens when the young person leaves these behind.¹⁵⁷ There is also some evidence that that some healthcare practitioners are resistant to devising a plan, and some parents and young people reported practical difficulties maintaining it.¹⁵⁸ It has thus been suggested that a lack of clear accountability for transition planning can mean that nobody takes the necessary action,¹⁵⁹ an eventuality that the keyworker model can insure against.

For these reasons, both clinical guidance and stakeholder groups have called for the assignation of a designated keyworker.¹⁶⁰ There is a broad consensus that young people should have a role in choosing their keyworker, though assignation may also involve bodies such as local authorities.¹⁶¹ Also consistent within the existing evidence is an acknowledgement that the keyworker reflects a role rather than a job title,¹⁶² and that this professional may be drawn from a range of professional settings. The Social Care Institute for Excellence stipulates, for instance, that "This person should be one of an existing keyworker/transition worker, a health, social care or education practitioner, a GP, a youth worker, an allied health professional or

¹⁴⁸ (McBride & McDicken, 2012)

¹⁴⁹ (Colver, et al., 2019)

¹⁵⁰ (Health and Social Care Alliance Scotland, 2017; National Institute for Health and Care Excellence (NICE), 2016; Zhou, et al., 2016)

¹⁵¹ (Health and Social Care Alliance Scotland, 2017)

¹⁵² (ARC Scotland, 2017)

¹⁵³ (ARC Scotland, 2017)

¹⁵⁴ (ARC Scotland, 2017)

¹⁵⁵ (Butterworth, et al., 2016)

¹⁵⁶ (Health and Social Care Alliance Scotland, 2017)

¹⁵⁷ (NDTI, 2011; Welch, et al., 2014; Health and Social Care Alliance Scotland, 2017)

¹⁵⁸ (Colver, et al., 2018)

¹⁵⁹ (NDTI, 2011)

¹⁶⁰ (ARC Scotland, 2017b; National Institute for Health and Care Excellence (NICE), 2016; SCIE, 2017)

¹⁶¹ (ARC Scotland, 2017b; National Institute for Health and Care Excellence (NICE), 2016; SCIE, 2017)

¹⁶² (National Institute for Health and Care Excellence (NICE), 2016)

a nurse.”¹⁶³ There were mixed findings relating to who young people are most likely to choose as their keyworker, but the importance of involving young people in this process was stressed consistently.

Person-centred support

Person-centred support is a consistent thread through much of the evidence. This is advocated by stakeholder groups,¹⁶⁴ as well as in a large body of academic research¹⁶⁵ wider reviews,¹⁶⁶ and clinical guidance.¹⁶⁷

Person-centred support is seen as an often-imprecise term that is not always applied in practice.¹⁶⁸ According to NICE guidelines, person-centred approaches should treat the young person on an equal footing, supporting them and their families to make decisions about their own support, and addressing all relevant aspects of their transition to adulthood.¹⁶⁹

There is evidence that person-centred and/or co-produced services are more effective and bring about improved outcomes (in a range of settings from healthcare to education and employment), and that they help to secure the most needed and appropriate services.¹⁷⁰ Evidence points to positive outcomes for children who take a more empowered role in their transitions.¹⁷¹

Relatedly, strengths-based planning, advocated by the National Institute for Health and Care Excellence, should work with young people and draw on their interests, assets and strengths in transition-planning.¹⁷² This positive framing is important given previous research findings (both domestic and international) that attitudes and expectations towards transition are partially predictive of transition outcomes.¹⁷³

However, it has been noted that person-centred planning may require communication support,¹⁷⁴ and/or support to develop young people’s confidence to engage in complex and often technical decision-making.¹⁷⁵

Research with disabled young people in Scotland supports the importance of person-centred planning and services to a smooth transition. A survey of young people found that 43% identified more person-centred support as the single thing that would be helpful in improving their transition from school,¹⁷⁶ and young people

¹⁶³ (SCIE, 2017)

¹⁶⁴ (ARC Scotland, 2017b; NDTI, 2011)

¹⁶⁵ (Stewart, 2009; Di Rezze, et al., 2016; Welch, et al., 2014) (Flexer & Baer, 2008; Greene, 2009; Papay & Bambara, 2014; Bambara, et al., 2007; Wehman, 2006)

¹⁶⁶ (SPICe, 2019; Health and Social Care Alliance Scotland, 2017)

¹⁶⁷ (NICE, 2016)

¹⁶⁸ (ARC Scotland, 2017b)

¹⁶⁹ (National Institute for Health and Care Excellence (NICE), 2016)

¹⁷⁰ (Cook & Miller, 2012; Stewart, 2009; Welch, et al., 2014; Miceli, 2008; Papay & Bambara, 2014)

¹⁷¹ (Viner, 2008)

¹⁷² (National Institute for Health and Care Excellence (NICE), 2016)

¹⁷³ (van Staa, et al., 2011; Health and Social Care Alliance Scotland, 2017)

¹⁷⁴ (Scottish Parliament, 2020; Stalker & Moscardini, 2012)

¹⁷⁵ (ARC Scotland, 2017b)

¹⁷⁶ (ARC Scotland, 2017)

themselves have highlighted the importance of being/feeling listened to in transition-planning, especially in their mid-teens.¹⁷⁷

However, despite the evidence supporting the effectiveness and importance of person-centred support, there is also evidence that this ideal is not always achieved. For example, it has been reported that disabled young people and their carers do not have their voices taken into consideration and routinely feel disconnected and/or excluded from the planning and delivery of services that affect them.¹⁷⁸ Disabled young people in Scotland also reported that they are routinely not asked even basic questions relating to their interests or aspirations, contrary to the principles of person-centred and strengths-based planning, resulting in them being placed into unsuitable or suboptimal settings.¹⁷⁹ A recent consultation heard from stakeholders that transition planning and support are routinely resource- and service-led rather than person-centred.¹⁸⁰

Family involvement

Relatedly, there is widespread evidence that family involvement and inclusion are seen as being central to effective transitions and transition-planning. Families are hugely important to disabled young people and often their main source of support,¹⁸¹ especially among young people with learning and developmental disabilities.¹⁸²

This echoes the findings of a recent survey of disabled young people in Scotland, which found that parents played a larger role than any practitioners in giving advice and guidance.¹⁸³ Their active inclusion in discussions, transition planning and decision-making is therefore widely seen as essential, and this features in clinical guidance.¹⁸⁴

Families often serve a vital care-giving role during and beyond the transition process, and a large proportion of disabled young people continue living with their family until later in life.¹⁸⁵ Families therefore have an indispensable role to play in planning and logistics.

Reviews of international evidence have also found that parental expectations and familial involvement are significantly associated with transition outcomes (including education, employment and general wellbeing).¹⁸⁶ There is, however, evidence that parents' expectations of disabled children's post-school opportunities lag behind those of the parents of their non-disabled counterparts.¹⁸⁷

¹⁷⁷ (DIVERgent INfluencers, 2021)

¹⁷⁸ (Cheseldine, 2010)

¹⁷⁹ (DIVERgent INfluencers, 2021)

¹⁸⁰ (Scottish Parliament, 2020)

¹⁸¹ (Stalker & Moscardini, 2012)

¹⁸² (Boehm, et al., 2015)

¹⁸³ (ARC Scotland, 2017)

¹⁸⁴ (National Institute for Health and Care Excellence (NICE), 2016)

¹⁸⁵ (SCLD, 2017; ARC Scotland, 2017)

¹⁸⁶ (Carter, et al., 2012; Papay & Bambara, 2014)

¹⁸⁷ (ARC Scotland, 2017)

Various academic reviews and meta-reviews have found family involvement to be a common enabler of successful transitions.¹⁸⁸ The Health and Social Care Alliance have therefore called for a Family Group Decision Making model of transition partnership, in partnership between young people, their families and service-providers.¹⁸⁹

While self-management and independence are seen as important factors in transitions to adulthood for disabled young people, it has been noted that “family members remain important in this process [and that] such involvement is normal, not dysfunctional.”¹⁹⁰

Nevertheless, excessive parental involvement has been identified in certain sources and reviews as a barrier to smooth transitions; it has the potential to sour relationships with services and practitioners, and obstruct transitions to adult services.¹⁹¹ It is therefore argued that parental and familial involvement should be ‘appropriate’¹⁹² and NICE guidelines stipulate that a young person may not want their family to be (overly) involved in transition planning.¹⁹³ (‘Appropriate’ parental involvement has been defined as meaning “that the young person and their parents were happy with how much and the way in which the parents were involved.”)¹⁹⁴

Parental & family support

Underpinning much of the above, positive family relationships are seen as key bridging factors in a smooth transition.¹⁹⁵ However, transitions can be a time of considerable stress and anxiety for parents and family members of disabled young people.¹⁹⁶ Previous research has found that transitions are often perceived negatively by parents,¹⁹⁷ and can prompt uncertainty and anxiety.¹⁹⁸ Parents frequently report concerns about the capacity of the young person in question to adapt to adulthood, their difficulty navigating often disjointed services, pressures on family wellbeing and finances, and concerns about the long-term outlook.¹⁹⁹

It often falls to parents to coordinate their child’s transition, which can prompt considerable stress as they seek to navigate and negotiate with disjointed services.²⁰⁰

Another common source of stress occurs when young people leave school, as this can often entail a sudden drop or cessation in care they receive. As a result, parents

¹⁸⁸ (Flexer & Baer, 2008; Greene, 2009; Papay & Bambara, 2014; Bambara, et al., 2007; Wehman, 2006)

¹⁸⁹ (Health and Social Care Alliance Scotland, 2017)

¹⁹⁰ (Colver, et al., 2019)

¹⁹¹ (Zhou, et al., 2016)

¹⁹² (Colver, et al., 2019)

¹⁹³ (National Institute for Health and Care Excellence (NICE), 2016)

¹⁹⁴ (Colver, et al., 2019)

¹⁹⁵ (Health and Social Care Alliance Scotland, 2017)

¹⁹⁶ (ARC Scotland, 2017; SPICe, 2019)

¹⁹⁷ (Zhou, et al., 2016)

¹⁹⁸ (Chaudhary, et al., 2013)

¹⁹⁹ (Leonard, et al., 2016)

²⁰⁰ (Scottish Parliament, 2020)

may find themselves under pressure to leave work to provide substitute care, which can in turn prompt serious financial difficulties and/or concern.²⁰¹

For these reasons, parental support is a commonly identified aspect of best practice in transition smoothing and planning. In practical terms, this may entail the provision of respite care to support parents and carers,²⁰² as well as emotional support,²⁰³ training in stress management, relaxation exercises, supporting them to build self-efficacy and self-esteem.²⁰⁴

Information-provision

A widely observed challenge for disabled young people and their families is difficulty navigating the complex landscape of services, funding and policy initiatives with regards to transitions.²⁰⁵ The issue appears particularly pronounced at the interface between paediatric and adult services.²⁰⁶ Best practice therefore encourages the sharing of clear, accessible and timely information with young people and their families.²⁰⁷

A review of this context in Scotland reflected that “It is difficult for families and sometimes professionals to map a clear path through the raft of policy initiatives in this area and to understand how these join up. The lack of a concise policy guide setting out service providers’ responsibilities and young people’s rights is a barrier to smooth transition.”²⁰⁸ While the research found a broad consensus that individual transition policy initiatives were positive and appropriate, it noted that disabled young people, planners and practitioners often struggle to understand how these relate to one another. Support for existing initiatives tended to be framed in very general terms, often relating to agreed guiding principles.

Research with disabled young people and their parents found that they routinely lack appropriate and accessible information, with a quarter of parents and carers identifying a lack of support and information as the most difficult thing about transitioning, and 26% said that clearer explanations of their options and supported opportunities would make the single biggest difference.²⁰⁹

In general, young people in Scotland have reported a lack of information about leaving school, complex bureaucratic processes (including educational applications and exams) and a shortage of work opportunities and guidance.²¹⁰

Disabled young people in Scotland are appreciative of clear information relating to their transition, though the information needed varied somewhat with age: the need

²⁰¹ (Health and Social Care Alliance Scotland, 2017)

²⁰² (Talking Mats, 2015; Health and Social Care Alliance Scotland, 2017)

²⁰³ (Talking Mats, 2015)

²⁰⁴ (ARC Scotland, 2017b)

²⁰⁵ (McBride & McDicken, 2012; Scottish Parliament, 2020; Zhou, et al., 2016)

²⁰⁶ (CELCIS; Children in Scotland; Care Inspectorate, 2018; Welch, et al., 2014)

²⁰⁷ (Baxter, et al., 2008; SPICe, 2019; Health and Social Care Alliance Scotland, 2017; Stalker, et al., 2013; NDTI, 2011)

²⁰⁸ (Stalker & Moscardini, 2012, p. 48)

²⁰⁹ (ARC Scotland, 2017)

²¹⁰ (DIVERgent INfluencers, 2021)

for information in general was greatest among 18–20-year-olds, and often referred to practical information about life going forward. Respondents aged 14-17 focused largely on information relating to life-skills and leaving school, while respondents aged 21-25 prioritised information about their rights and opportunities.²¹¹ The transition process is a long one, incorporating institutional, life-course and personal changes, and the relative needs and priorities of these change accordingly.

Others have suggested that information should move from being generalist/broad to more technical/specific over the course of the young person's transition.²¹²

In addition to causing anxiety and stress, the inadequate provision of information can cause young people and their families to be/feel excluded from (informed and effective) decision-making with regards to their transition to adulthood.²¹³

In line with best practice, there are calls for improved information and transparency with regards to local services and pathways (including both statutory and voluntary sector services) to assist people to navigate an often-complex landscape, including through effective signposting.²¹⁴ (This may be a responsibility of a designated transition worker or keyworker.) The exact extent of this may, however, vary between disabled young people depending on their needs; in some cases, this may refer to intensive one-to-one guidance, while signposting or information packs may suffice for others.²¹⁵

Asset mapping, developed in partnership between practitioners, local and national government, and wider statutory services, has been shown to be effective at improving transparency and awareness of services available at a local level. Local transitions fairs can also provide a forum for practitioners and third sector organisations to showcase and share information on the supports available to young people and their families/carers.²¹⁶

The evidence underlines the importance of such information using consistent, common and accessible language to simplify services to young people and their families/carers. It has been noted that certain terms (e.g. 'keyworker' and/or 'co-production') used in transitions practice can have unclear, multiple and/or competing meanings.²¹⁷ Best practice guidance states that any information must conform to the communication needs and developmental stage of the young person in question (including provision in accessible formats where necessary).²¹⁸

²¹¹ (DIVERgent INfluencers, 2021)

²¹² (NDTI, 2011)

²¹³ (McBride & McDicken, 2012; Mitchell, 2012)

²¹⁴ (Health and Social Care Alliance Scotland, 2017)

²¹⁵ (ARC Scotland, 2017b)

²¹⁶ (ARC Scotland, 2017b)

²¹⁷ (Health and Social Care Alliance Scotland, 2017; ARC Scotland, 2017b)

²¹⁸ (ARC Scotland, 2017b)

Adequate services, resources and staffing

There is substantial evidence that services for disabled young adults during their transition from paediatric to adult services are not always appropriate, sufficient, or available.²¹⁹ The transition to adult services can often result in changes to service-eligibility up to and including complete loss of service provision (particularly common in social care, but not exclusively),²²⁰ There is also evidence of inconsistencies in the application of eligibility criteria between areas, and between children's services compared to adult services.²²¹

A survey of young people found that the availability of support was the most important factor in their transition, but respondents also cited a lack of support in general, and support to enter work and/or gain experience of work more specifically.²²²

A report by the Scottish Government highlighted difficulties faced by adults with learning disabilities and complex needs, finding evidence of a lack of specialist local services, and urging advanced planning to ensure that adequate services and resources are available ahead of time.²²³

Stakeholders and young people themselves report that the already difficult transition can be exacerbated by "organisational processes taking priority over individual needs."²²⁴

In order to deliver these high-quality services, resourcing is seen as essential.²²⁵ Stakeholders have similarly argued that to achieve the best outcomes for young people, it is good practice to separate the assessment process from budget considerations.²²⁶

Nevertheless, some stakeholders have suggested that transitions (and associated supports) are often resource-led rather than person-centred.²²⁷ There is also evidence that inadequate resourcing can undermine partnership working,²²⁸ and it has been suggested that recent cuts to local authority funding mean that only those with more substantial/critical needs are eligible for much-needed support.²²⁹ Recent research has shown that services in certain local authority areas in Scotland are already operating at full capacity or face funding constraints, ultimately limiting the provision that is available in practice to young people and their families.²³⁰ The

²¹⁹ (Ko & McEnery, 2004; Lewis & Noyes, 2013; Taylor, et al., 2010)

²²⁰ (Health and Social Care Alliance Scotland, 2017; Zhou, et al., 2016)

²²¹ (SCCYP, 2013)

²²² (DIVERgent INfluencers, 2021)

²²³ (Scottish Government, 2018)

²²⁴ (ARC Scotland, 2017b, p. 10)

²²⁵ (Health and Social Care Alliance Scotland, 2017)

²²⁶ (ARC Scotland, 2017b)

²²⁷ (Scottish Parliament, 2020)

²²⁸ (Social Work Scotland, 2018)

²²⁹ (Asenova, et al., 2013)

²³⁰ (Jacobs, et al., 2020)

Health and Social Care Alliance, for instance, has called for improved resourcing of services beyond the age of 17, including respite services for parents and carers.²³¹

The central importance of highly trained and skilled staff is widely recognised.²³² Positive relationships and maintaining interpersonal trust are identified across the literature as a further enabler of positive transitions.²³³

‘Youth-friendly care’ is similarly seen to depend largely on appropriate staffing, with staff attitudes, communication and medical competency identified as key prerequisites for a high-quality service within the literature.²³⁴ Knowledgeable, sensitive and approachable staff were validated by young people themselves, and are associated with improved outcomes and services.²³⁵ Accessing knowledgeable and relevant staff with an understanding of complex health conditions has been identified as a further enabler or barrier to successful transitions.²³⁶

There is evidence, however, that practitioners in Scotland do not always have a clear understanding of the needs or abilities of disabled young people, and especially those with learning disabilities.²³⁷ For this reason, a number of stakeholders have called for – and noted a shortage of – training packages and materials for practitioners and professionals to work with, understand and support disabled people and those with complex needs.²³⁸

Robust evaluation and monitoring

It has been noted that at present there are inadequate evaluation and monitoring procedures in place in Scotland and the United Kingdom.²³⁹ There is evidence of scepticism from young people, families and practitioners with regards to the effectiveness of existing evaluation processes, and it has been suggested that current metrics track “destinations rather than outcomes” (such as the proportion of disabled young people in employment, rather than the “extent to which the young person was being supported into becoming an active citizen”).²⁴⁰

In the absence of these, it is difficult to identify further best practice or to derive more granular detail beyond what is already known. It has been noted that interventions and outcome metrics are often not standardised across different programmes and that evaluation procedures are not always robust, which can limit opportunities for learning.²⁴¹

²³¹ (Health and Social Care Alliance Scotland, 2017)

²³² (SPICe, 2019; Talking Mats, 2015)

²³³ (Zhou, et al., 2016; Butterworth, et al., 2016; CELCIS; Children in Scotland; Care Inspectorate, 2018)

²³⁴ (Ambresin, et al., 2013)

²³⁵ (Health and Social Care Alliance Scotland, 2017; ARC Scotland, 2017)

²³⁶ (Zhou, et al., 2016)

²³⁷ (Francis, 2006; NDTI, 2011)

²³⁸ (NDTI, 2011; Talking Mats, 2015; ARC Scotland, 2017; Health and Social Care Alliance Scotland, 2017)

²³⁹ (NDTI, 2011; ARC Scotland, 2018)

²⁴⁰ (ARC Scotland, 2018, p. 8)

²⁴¹ (Stewart, et al., 2006; Di Rezze, et al., 2016)

Institutional & Life-Course Transitions

This section of the literature review will summarise findings related to common experiences, and best practice within more specific transitions. This includes 'institutional' transitions (i.e., between paediatric and adult health and social care services) and 'developmental' or 'life-course' transitions (i.e. those relating to education and employment, as well as independent living, among others). Some of these may echo issues and findings outlined in the previous section, but will provide greater and more specific detail pertaining to the sector in question.

Our review reinforces previous findings that much of the existing evidence and literature relates to health-related transitions, with much lesser attention to life-course transitions.²⁴² Health and social care are often not clearly delineated in the existing literature; much of the evidence relates to healthcare specifically, though with an implicit relevance to other clinical settings such as social care. It is, however, not always clear to which institutional/clinical settings authors are referring.

Within the literature on life-course transitions, there is also a greater focus on employment and education than independent living, personal relationships and active citizenship where the evidence is more limited.

The transition from child and paediatric to adult health and social care services can be fraught and challenging. This issue is not isolated to Scotland and the United Kingdom, but commonly observed across the international literature.²⁴³ The following sections will explore these transitions in greater depth. While they have been thematically separated for the purposes of this report, there is (seen to be) a fair degree of overlap between these.

Healthcare

Common experiences

At an emotional and personal level, it can prove difficult for young people and their families to leave behind familiar and trusted practitioners and professionals with a thorough understanding of the young person's (clinical and communication) needs and preferences. Young people often form a strong rapport and sense of trust with paediatric practitioners, and it can prove distressing to leave these behind.²⁴⁴ A reluctance to do so has been observed among young people as well as their parents and practitioners, though this can hinder a smooth transition.²⁴⁵

It can also be distressing for young people to lose contact with their peers, and to suddenly find themselves instead receiving care alongside much older and more infirm patients.²⁴⁶

²⁴² (Stalker & Moscardini, 2012; Di Rezze, et al., 2016)

²⁴³ (Colver, et al., 2019; Zhou, et al., 2016; Lugasi, et al., 2011)

²⁴⁴ (Health and Social Care Alliance Scotland, 2017)

²⁴⁵ (Zhou, et al., 2016)

²⁴⁶ (Lugasi, et al., 2011; Scottish Parliament, 2020)

A considerable body of literature points to the disorientation that many young people and their families face when attempting to navigate new services. In contrast to children's services, working practices and cultures within adult healthcare services are characterised by more siloed working,²⁴⁷ and an assumption of greater self-efficacy of disabled young people in managing their care.²⁴⁸ This can present logistical challenges with young people receiving treatment and support at a range of different locations, sometimes situated far from their homes.²⁴⁹

It has also been widely observed that communication and coordination between child and adult services and between specialisms is often poor.²⁵⁰ This can make services difficult to navigate particularly given adult services' tendency to treat young people as independent and autonomous.

These procedural and cultural changes can be difficult to adjust to and, having established an understanding of and familiarity with child services over years, it can be disheartening and stressful for young people and their families to lose this knowledge.²⁵¹ Relatedly, established arrangements are often the result of concerted effort and experimentation; with the move to adult services and changing eligibility, these hard-won arrangements can be lost.²⁵² It is common for young people to lose eligibility for certain supports when moving to adult healthcare services, which leaves them with more limited care and support options.²⁵³ While this is an arguably larger and/or more common issue within social care, there is evidence that it can also apply to healthcare. Children and young people with complex care needs and their families who experience many transitions over the life course may be especially vulnerable to discontinuity or gaps in care.²⁵⁴

Planning for healthcare transitions is also often inadequate. In the absence of advance planning, the transition can come as an unwelcome surprise, though conversely, delays to handover can leave young people and their families in a state of limbo in-between child and adult services.²⁵⁵ There is evidence that transition planning lacks clarity and consistency, and that accountability for it is unclear. Healthcare practitioners were found to resist formal planning,²⁵⁶ and/or to deem other services responsible for this.²⁵⁷

Best practice

It has been argued that best practice can be difficult to identify conclusively, in part given variation in delivery and evaluation,²⁵⁸ and that findings may not generalise

²⁴⁷ (Scottish Parliament, 2020)

²⁴⁸ (Zhou, et al., 2016; Young Minds, 2020)

²⁴⁹ (Scottish Government, 2018)

²⁵⁰ (Heslop, et al., 2002; Colver, et al., 2018; Scottish Parliament, 2020)

²⁵¹ (Colver, et al., 2019)

²⁵² (Welch, et al., 2014)

²⁵³ (Zhou, et al., 2016; ARC Scotland, 2017b; SPICe, 2019; Scottish Parliament, 2020)

²⁵⁴ (Doucet et al., 2020)

²⁵⁵ (Scottish Parliament, 2020)

²⁵⁶ (Colver, et al., 2018)

²⁵⁷ (Colver, et al., 2019)

²⁵⁸ (Di Rezze, et al., 2016)

beyond specific fields/specialisms.²⁵⁹ However, a number of common elements of effective practice have been identified within the literature with regards to smoothing institutional transitions including adequate planning, resourcing and coordination.²⁶⁰

Advanced preparation and planning are a key component of best practice, and it is argued that both child and adult services should be involved in this process,²⁶¹ and that it should include both health and social care services at the least.

Positive relationships and maintaining trust are widely seen as important in institutional transitions.²⁶² For this reason, joint sessions and introductory meetings between child and adult services where needs and preferences can be explained to new practitioners, and positive inter-personal relationships formed, are beneficial.²⁶³ Joint sessions have been shown to help reduce the chances of disengagement by the young person in question.²⁶⁴ There is also some evidence that paediatric practitioners can be reluctant to pass young people on to adult services, and also that adult practitioners may be reluctant to take on young people, which introductory sessions and gradual handovers can ease.²⁶⁵

As part of the planning process, it has been suggested that a keyworker and GP should be identified to ensure that young people have a point of contact and continuity throughout their wider transition.²⁶⁶ The involvement of transition nurses is widely identified as an example of best practice in transition-smoothing for young people.²⁶⁷ For children and young people with complex care needs for whom a carefully tailored planning strategy is particularly important, it has been suggested that the potential value of a nurse-led service in delivering the transition process should be explored.²⁶⁸ This role serves to coordinate transitions between services, including through arranging introductory sessions, and provides a consistent point of contact for queries, advice and information.²⁶⁹ Transition nurses/workers have been validated by young people themselves as a valuable support within institutional transitions.²⁷⁰

Coordination may be underpinned by tools such as health passports which are found to be effective at promoting positive relationships, high-quality clinical care, and efficient exchange of data, all of which are appreciated by young people.²⁷¹ However, while young people are supportive of health passports in principle, they are not always clear of their purpose and there is some evidence that they are not routinely used in practice.²⁷²

²⁵⁹ (Kennedy & Sawyer, 2008)

²⁶⁰ (Health and Social Care Alliance Scotland, 2017; Zhou, et al., 2016; Talking Mats, 2015)

²⁶¹ (Health and Social Care Alliance Scotland, 2017)

²⁶² (Butterworth, et al., 2016; Welch, et al., 2014; Zhou, et al., 2016)

²⁶³ (Talking Mats, 2015)

²⁶⁴ (Lewis & Noyes, 2013; Welch, et al., 2012)

²⁶⁵ (Zhou, et al., 2016)

²⁶⁶ (NDTI, 2011)

²⁶⁷ (Zhou, et al., 2016; Colver, et al., 2018)

²⁶⁸ (O'Connell and Petty, 2018)

²⁶⁹ (Colver, et al., 2018; Colver, et al., 2019)

²⁷⁰ (Talking Mats, 2015)

²⁷¹ (Colver, et al., 2019)

²⁷² (Colver, et al., 2019)

Services and practitioners may also benefit from transitions managers who can oversee transitions from an organisational perspective to ensure smooth functioning and adequate resourcing.²⁷³

There is evidence that consistency of staffing is generally appreciated by young people, who respond positively to seeing the same staff at each session. This can save frustrating or demoralising repetition of circumstances. One review, in fact, found that young people valued seeing the same staff at each appointment more than having a keyworker.²⁷⁴

The evidence on best practice also points to a careful balancing act between encouraging independence and self-management, tempered with appropriate parental involvement. Medical and clinical self-efficacy is seen as important for successfully navigating the transition process and gaining independence more generally,²⁷⁵ and excessive parental involvement has been identified by researchers and practitioners as a barrier to smooth transitions.²⁷⁶ However, family involvement in planning and decision-making is also associated within the literature with improved outcomes,²⁷⁷ and indeed, one meta-review suggests that parents can act as vital facilitators in transitions.²⁷⁸ 'Appropriate' parental involvement has been defined as meaning "that the young person and their parents were happy with how much and the way in which the parents were involved."²⁷⁹

Providing support and information to parents appears central to their positive involvement.²⁸⁰ This might include courses and advice on transitions for parents and family members, emotional support, and respite services.²⁸¹

The use of age-banded clinics and transition wards recur in the literature on best practice in healthcare transitions.²⁸² These allow practitioners to develop the necessary skills and knowledge to work with this particular age group, avoids co-locating young people with much older and sicker individuals, and allows them to form relationships and support networks with peers.

Social Care

Common Experiences

A number of the experiences and difficulties commonly faced by young people in social care transitions are consistent with those experienced in healthcare settings. However, overall there is a relative paucity of information and evidence relating to social care as distinct from, and compared to, healthcare.

²⁷³ (Colver, et al., 2018)

²⁷⁴ (Colver, et al., 2018)

²⁷⁵ (Ambresin, et al., 2013; Colver, et al., 2018; Zhou, et al., 2016)

²⁷⁶ (Zhou, et al., 2016)

²⁷⁷ (Colver, et al., 2018; Zhou, et al., 2016)

²⁷⁸ (Zhou, et al., 2016)

²⁷⁹ (Colver, et al., 2019)

²⁸⁰ (Zhou, et al., 2016; Health and Social Care Alliance Scotland, 2017)

²⁸¹ (Talking Mats, 2015)

²⁸² (Ambresin, et al., 2013; Talking Mats, 2015; Zhou, et al., 2016; Colver, et al., 2018)

These include issues associated with leaving behind familiar faces – both practitioners and other young people – and difficulties receiving treatment alongside much older people.²⁸³ Another such example is the difficulty navigating more complex and often disjointed adult services, where information-provision is often inadequate,²⁸⁴ and where a greater degree of clinical autonomy and self-management is assumed.²⁸⁵

This can be an especial challenge given the frequency with which eligibility to certain supports can change between child and adult services. While this is also an issue in healthcare, it is an especial challenge in social care. Eligibility for care is often limited (given cuts to funding) to those whose needs are considered critical.²⁸⁶

Much of day-to-day care (in the informal sense of the word) of young people is delivered by schools given their hours of operation. Thus, there is a close and important connection between education and social care when it comes to transitions, whereby young people - leaving school and moving to, or ineligible for, adult social care - may experience a very sudden drop in or cessation of support. Between the transition to adult social care and leaving school, the support young people receive can fall sharply and young people may rarely come into contact with public services if they are ineligible for local authority social care.²⁸⁷ Respite care is seen as a particularly inaccessible service for many disabled young people and their families, which can prompt considerable challenges for parents.²⁸⁸

Similarly, inadequate social care provision and eligibility can have significant implications for the feasibility, sustainability and desirability of independent living (see sections below).

Communication between health and social care services, as well as between different actors and agencies within social care and social work, is often sub-optimal.²⁸⁹ Poor partnership working is seen to stymie smooth transitions, and can be disruptive and disheartening for young people.²⁹⁰

There was also evidence of shortcomings in social care services. Namely, that certain key services for disabled people are missing; for instance, a recent consultation heard that there is very limited and inconsistent communication support in social care settings for those with sensory disabilities.²⁹¹

²⁸³ (Lugasi, et al., 2011; Scottish Parliament, 2020; Health and Social Care Alliance Scotland, 2017)

²⁸⁴ (ARC Scotland, 2017; Scottish Parliament, 2020)

²⁸⁵ (Colver, et al., 2019)

²⁸⁶ (Scottish Parliament, 2020)

²⁸⁷ (Fraser of Allander Institute, 2021)

²⁸⁸ (Scottish Parliament, 2020)

²⁸⁹ (Heslop, et al., 2002; Colver, et al., 2018; Scottish Parliament, 2020)

²⁹⁰ Ibid.

²⁹¹ (Scottish Parliament, 2020)

Best Practice

As noted with respect to healthcare, but also applicable to social care transitions, a number of common elements of effective practice have been identified within the literature with regards to smoothing institutional transitions including adequate planning, resourcing and coordination.²⁹²

A number of key factors have been identified in ensuring smooth transitions. These include concerted planning, the right supports and systems, highly-trained staff with an understanding of social care and adolescent development, multi-agency partnership-working, and a focus on individuals and their families.²⁹³ Many of these are redolent of the aspects of best practice identified with regards to healthcare transitions, but are expanded upon below.

Scottish Government guidance prescribes such initiatives to smooth transitions; namely, advanced planning and the designation of a coordinating lead professional,²⁹⁴ and it has been suggested elsewhere that this planning should improve young people's understanding of (and manage expectations of) adult social care services.²⁹⁵

It has been suggested that transitional services that span child and adult services can help to protect the wellbeing of young people and reassure them.²⁹⁶ This is also seen to maintain and protect trust in practitioners and services, which is seen as central to effective transitions.²⁹⁷ Partnership working is widely stressed in the evidence on best practice, and it has been suggested that social care transition planning should include both adult and child services.²⁹⁸

Inter-agency communication can, however, often be lacking, including between child and adult services, but especially between health and social care services.²⁹⁹ Advanced preparation and planning are a key component of best practice, and it is argued that both child and adult services should be involved in this process,³⁰⁰ and that it should include both health and social care services at the least.

There is some evidence of poor integration both within social care (between child and adult services), and between social care and other services, due in part to gaps in coordination and budgets.³⁰¹ For this reason, the appointment of a 'lead coordinator' (also termed/analogous to a keyworker or transition coordinator) is seen

²⁹² (Health and Social Care Alliance Scotland, 2017; Zhou, et al., 2016; Talking Mats, 2015)

²⁹³ (Health and Social Care Alliance Scotland, 2017; SCIE, 2019)

²⁹⁴ <https://www.gov.scot/publications/supporting-disabled-children-young-people-and-their-families/pages/transitions/>

²⁹⁵ (ARC Scotland, 2017b)

²⁹⁶ (Butterworth, et al., 2016)

²⁹⁷ (CELCIS; Children in Scotland; Care Inspectorate, 2018)

²⁹⁸ (Health and Social Care Alliance Scotland, 2017)

²⁹⁹ (Heslop, et al., 2002; Colver, et al., 2018; Scottish Parliament, 2020)

³⁰⁰ (Health and Social Care Alliance Scotland, 2017)

³⁰¹ (Health and Social Care Alliance Scotland, 2017)

to be an effective step in transition-smoothing.³⁰² Others have stressed the particular value of social workers and social care practitioners in coordination and planning.³⁰³

Improved communication and information-provision, as well as positive relationships and maintaining trust are widely seen as important in institutional transitions.³⁰⁴ This can also promote information-exchange between child and adult social care services which can improve service outcomes for users. However, information exchange is important not only for service-providers, but also for young people and their families. Especially given the complicated social care landscape, it has been suggested that clear information-provision is effective and helpful for young people and their families.³⁰⁵

More broadly, the benefits of co-production within social care (between disabled young people, providers and wider practitioners/stakeholders) have been identified and stressed within the literature. The Health and Social Care Alliance suggest that “Young people have a direct contribution to make to service improvement” and notes the value of “the expertise and flexibility within the third sector in providing transitional bridges in health and social care services”.³⁰⁶

The paucity and importance of respite services have been noted across the literature, with a clear recognition within the existing evidence base of the need for support for family-members in the form of short breaks.³⁰⁷

Integration

While somewhat distinct from transitions, the issue of health and social care integration has evident and important implications for health and social care transitions that we seek to briefly explore and summarise here.

Given the complexity and fragmentation of the health and social care landscape, it has been suggested that greater integration – of health and social care, and of child and adult services – could be beneficial to disabled young people during their transitions.³⁰⁸ Integration at a local level in Scotland has shown promise in simplifying the landscape and improving young people and practitioners’ experiences and outcomes,³⁰⁹ as has joint-planning and partnership delivery,³¹⁰ though obstacles remain in place. Stakeholders and researchers have also warned that integration is not guaranteed to improve disabled young people’s experiences or outcomes if they are not adequately considered as part of the process.³¹¹

³⁰² Ibid.

³⁰³ (ARC Scotland, 2017; McBride & McDicken, 2012)

³⁰⁴ (Butterworth, et al., 2016; Welch, et al., 2014; Zhou, et al., 2016)

³⁰⁵ (Health and Social Care Alliance Scotland, 2017)

³⁰⁶ (Health and Social Care Alliance Scotland, 2017, pp. 18, 20)

³⁰⁷ (Health and Social Care Alliance Scotland, 2017)

³⁰⁸ (Fisher & Elnitsky, 2012; Mitchell, 2012; Fraser of Allander Institute, 2021)

³⁰⁹ (CELCIS; Children in Scotland; Care Inspectorate, 2018)

³¹⁰ (CELCIS; Children in Scotland; Care Inspectorate, 2018)

³¹¹ (Fraser of Allander Institute, 2021; ARC Scotland, 2018)

Within the literature, a number of barriers and enablers to effective integration have been identified. Impediments include inadequate resourcing, poor inter-agency and inter-professional communication and coordination, IT systems and data-sharing.³¹² It has also been noted that there is a paucity of practical materials to guide integration.³¹³

Common enablers of integration identified, include:³¹⁴

- Keeping the focus of integration clearly on improving experiences for service-users and allowing them to shape their journey
- Strong leadership to oversee integration
- Formulating a shared vision of integration and service-delivery
- Bottom-up consensus building in lieu of top-down reorganisation
- Building trust and understanding between different professional groups and organisations (through shared learning, co-location, among others)
- Developing data sets that give insights into people's outcomes rather than service inputs and outputs
- Communicating the purpose, aims and mooted benefits of integration to practitioners and service-users in advance

Pooled budgets, revised organisational and managerial structures, and joint planning were also deemed necessary to sustain this.³¹⁵

Education

Common experiences

Leaving secondary school is often an exciting and promising time for young disabled people. In a survey of young people in Scotland, half reflected that they felt ready to leave school, and over a quarter expressed excitement at taking greater control of their lives.³¹⁶ While young people have drive and aspirations,³¹⁷ there is evidence that these are not always met in practice.³¹⁸

Leaving school can also be a personally and emotionally challenging time for disabled young people. Uncertainty and anxiety about the future are common; these can impact on people's mental health and wellbeing, and are frequent concerns among parents.³¹⁹

³¹² (Cooper, et al., 2016; CELCIS; Children in Scotland; Care Inspectorate, 2018)

³¹³ (Robertson, 2011)

³¹⁴ (CELCIS; Children in Scotland; Care Inspectorate, 2018; Robertson, 2011; Cameron, et al., 2014)

³¹⁵ (CELCIS; Children in Scotland; Care Inspectorate, 2018)

³¹⁶ (ARC Scotland, 2017)

³¹⁷ The greatest proportion aspired to go on to college/university, followed by those hoping to enter work.

³¹⁸ Ibid.

³¹⁹ (ARC Scotland, 2017; DIVERgent INfluencers, 2021)

It is also common to lose contact with friends and peers which, in addition to being emotionally challenging, can leave them with more limited support networks.³²⁰ In addition, young people can struggle to leave behind familiar teachers who have often developed a strong understanding of their needs.³²¹

Some of the biggest concerns and difficulties flagged by young people leaving school relate to the loss of support and routine that this entailed, and moving into unfamiliar environments.³²² Leaving school often sees a sharp fall in the provision of support, from the high levels provided in schools (and especially in additional support schools) to a much more hands-off approach at colleges and universities and in the workplace.³²³ This was also a common concern among parents.³²⁴ This fall in support is often especially sharp for people with learning and developmental disabilities, especially if they do not qualify for support from social care services.³²⁵ (The shift in pedagogical modes from hands-on to much more autonomous learning can also be a challenge for those continuing to college or university.³²⁶)

It has been observed that upon leaving school, disabled young people are much less likely to engage regularly with public services,³²⁷ and the limited availability of post-school local authority support opportunities has been noted in qualitative research with young people, parents and practitioners.³²⁸ The Fraser of Allander Institute have reflected that many young people feel 'abandoned' upon leaving school, and that the cessation in support they receive does not prepare them for adult life.³²⁹ There are also reports that young people feel that schools wash their hands of them once they leave, with limited attention to ongoing sustained support.³³⁰

Young people and researchers report that they often lack options, control and involvement with regards to their post-school destinations. A survey of disabled young people in Scotland found that while a majority were happy with the choices available to them when leaving school, 3 in 10 were neither happy nor unhappy, and 14% were unhappy in some measure.³³¹

It has also been reported that a failure to take young people's voices and aspirations into account can see them placed into college courses of limited interest or value to them, often centring on 'life-skills' rather than vocational qualifications.³³² This gave rise to a perception from some young people that these destinations were designed to keep them busy rather than to equip them with the skills and knowledge for a flourishing life. There were even reports of individuals feeling coerced into

³²⁰ (Stalker & Moscardini, 2012)

³²¹ (ARC Scotland, 2017)

³²² (ARC Scotland, 2017)

³²³ (Scottish Parliament, 2020)

³²⁴ (ARC Scotland, 2017)

³²⁵ (Fraser of Allander Institute, 2021)

³²⁶ (Scottish Parliament, 2020)

³²⁷ (Fraser of Allander Institute, 2021)

³²⁸ (Health and Social Care Alliance Scotland, 2017)

³²⁹ (Fraser of Allander Institute, 2021)

³³⁰ (Cross-Party Group on Autism, 2020)

³³¹ (ARC Scotland, 2017)

³³² (Scottish Parliament, 2020; DIVERgent INfluencers, 2021)

undertaking such courses,³³³ and there was evidence that parents can play a role in this if they believe that a college environment will provide the best support for their child.³³⁴

Other stressors for young people leaving school include uncertainty over their job prospects,³³⁵ and the administrative challenges associated with leaving school (such as exams, results and applications).³³⁶

Best practice

Much of the best practice associated with leaving school reflects good practice at large, such as concerted advance planning, and the promotion of self-efficacy and self-management. Without these, the shift from full-time support and supervision to very limited support can be very challenging.

The evidence on best practice within educational settings, however, appears more limited. It should, however, be noted that for the purposes of this review, best practice regarding transitions from school into employment, and personal development and relationships are covered in different sections.

While good transition planning should take proper account of the young person's aspirations and actively involve parents and teachers, there is evidence that this does not work in practice. For example, parents and teachers may underestimate young people's abilities and post-school opportunities which can ultimately negatively impact the options available to young people.³³⁷ There is also a clear appetite from young people for more person-centred planning; this was the most common answer when asked what would improve post-school transitions.³³⁸

Schools often take on a key role in transition planning. However, given the need for sustained support beyond school-ages, they may be better placed to feed into a transition plan rather than lead on coordination.³³⁹

The evidence points to the importance of extensive and tailored education and training, targeted at a specific end-goal, in securing a successful transition for young people with additional support needs.³⁴⁰ (This, in turn, will likely require person-centred and strengths-based planning to identify these goals and needs). The importance of both vocational and general education has also been highlighted by academic reviews with regards to a range of professional, educational and other outcomes.³⁴¹

³³³ (Scottish Parliament, 2020)

³³⁴ (Fraser of Allander Institute, 2021)

³³⁵ (ARC Scotland, 2017)

³³⁶ (DIVERgent INfluencers, 2021)

³³⁷ (ARC Scotland, 2017; Fraser of Allander Institute, 2021; Papay & Bambara, 2014)

³³⁸ (ARC Scotland, 2017)

³³⁹ (Fraser of Allander Institute, 2021)

³⁴⁰ (Scottish Government, 2017; SPICe, 2019)

³⁴¹ (Baer, et al., 2011; Miceli, 2008)

Young people may, however, not know what their exact end-goal is, and they have therefore emphasised the value of taster sessions, visits to colleges/universities, and work experience.³⁴²

A survey of young people in Scotland found that among 14–17-year-olds, information on leaving school was a priority.³⁴³ ARC Scotland have also noted that information provision on post-school opportunities is not always adequate, and have called for the publication and diffusion of accessible guides to this end.³⁴⁴

Employment

Common experiences

Disabled people's employment outcomes lag behind those of non-disabled people, both in Scotland and elsewhere. A recent Scottish Parliament consultation on transitions saw stakeholders express dissatisfaction at below-average employment rates,³⁴⁵ and young people report feeling excluded from employment and demoralised at a perceived lack of opportunities.³⁴⁶ It has also been observed that once in work, young disabled people are disproportionately likely to be working shorter hours.³⁴⁷

Employers often demonstrate a poor understanding of disabled people's abilities, and societal and parental expectations are similarly limited.³⁴⁸ There is evidence that this is especially pronounced with regards to people with learning and developmental disabilities.³⁴⁹ This can limit the employment opportunities available to young disabled people as their capabilities are routinely underestimated. To make matters worse, this can also apply within support services, with the consequence that employment opportunities are not planned or provided for.³⁵⁰

Low expectations contribute to young disabled people finding it difficult to enter the world of work and they are often reliant on third sector organisations to provide experience. However, such opportunities do not always ensure progression prospects.³⁵¹ It has also been suggested that young disabled people can often find themselves stuck in a cycle of voluntary work and/or work experience.³⁵²

Despite the well-documented importance of targeted and vocational training within the literature, disabled young people are under-represented in education and training,³⁵³ and stakeholders have observed a paucity of tailored, suitable training materials and packages.³⁵⁴

³⁴² (DIVERgent INfluencers, 2021)

³⁴³ (DIVERgent INfluencers, 2021)

³⁴⁴ (ARC Scotland, 2017b)

³⁴⁵ (Scottish Parliament, 2020)

³⁴⁶ (DIVERgent INfluencers, 2021)

³⁴⁷ (Scottish Government, 2013)

³⁴⁸ (Scottish Parliament, 2020; ARC Scotland, 2017)

³⁴⁹ (Francis, 2006; Fraser of Allander Institute, 2021)

³⁵⁰ (Stalker & Moscardini, 2012)

³⁵¹ (ARC Scotland, 2017b; Scottish Parliament, 2020)

³⁵² (Scottish Parliament, 2020)

³⁵³ (ARC Scotland, 2017b)

³⁵⁴ (Scottish Parliament, 2020)

Best practice

The importance of early planning again surfaced repeatedly with regards to young disabled people's transitions into employment, with the suggestion that it should begin from the age of 14, and that more tailored career planning should begin from 16.³⁵⁵ As part of this, personalised indicative budgets were seen as a means of clarifying and planning for available and accessible opportunities, especially given the complex service and funding landscapes.³⁵⁶ There is, however, evidence that information and support to enter work is lacking, with disabled 14-17 year olds in Scotland reporting a shortage of guidance.³⁵⁷

There is some evidence that low parental expectations of post-school employment opportunities are limited, however, and there is further evidence that these are highly predictive of outcomes.³⁵⁸

The importance and effectiveness of vocational training and preparation is widely noted in the existing literature, and especially so for people with learning and developmental disabilities.³⁵⁹ The Fraser of Allander Institute points to the effectiveness of tailored training programmes delivered in partnership between businesses, third sector organisations and/or educational establishments. These allow young disabled people to gain skills as well as practical experience. However, stakeholders and young people themselves have reported a shortage of such opportunities in Scotland.³⁶⁰

For young people with complex needs, to provide sufficient support for engaging and sustaining them into paid employment, a holistic approach is necessary where multiple stakeholders work collaboratively with them, tackling issues across multiple life domains including knowledge, skills, attitudes and wellbeing.³⁶¹

There is also evidence that young people can struggle with application and interview processes,³⁶² and mock interviews have been deemed valuable by young people themselves.³⁶³ Training packages may wish to take these into account.

A range of effective possible routes into employment have been identified within the literature, including:³⁶⁴

- Internships
- Voluntary work
- Work experience (especially with local employers)

³⁵⁵ (NDTI, 2011)

³⁵⁶ (NDTI, 2011)

³⁵⁷ (DIVERgent INfluencers, 2021)

³⁵⁸ (Carter, et al., 2012; Papay & Bambara, 2014)

³⁵⁹ (Flexer & Baer, 2008; Greene, 2009; Papay & Bambara, 2014; Bambara, et al., 2007; Wehman, 2006)

³⁶⁰ (Scottish Parliament, 2020; DIVERgent INfluencers, 2021)

³⁶¹ (Hart et al., 2020)

³⁶² (Fraser of Allander Institute, 2021)

³⁶³ (DIVERgent INfluencers, 2021)

³⁶⁴ (NDTI, 2011; Di Rezze, et al., 2016; Papay & Bambara, 2014)

- Supported apprenticeships and supported employment
- Blended study at college
- Self-employment

The Fraser of Allander Institute has noted that employment in the third sector can be an effective first step as the sector can “offer the empathy and flexibility to allow for young people to find their feet and build confidence in the workplace.”³⁶⁵ As noted above, however, it has been noted that people can often struggle to move out of/beyond this introductory step.³⁶⁶

A number of (meta-)reviews stress the effectiveness of supported employment and placements, which are associated with improved professional and personal outcomes.³⁶⁷ Young people themselves have validated this approach, highlighting the value of work experience.³⁶⁸

However, a review of the landscape in Scotland suggested that routes into employment for disabled people are geographically inconsistent, and that eligibility and referral can be a question of luck.³⁶⁹

Independent Living

Common experiences

Independent living is central to the transition to adulthood but can often be fraught with practical obstacles.³⁷⁰

Independent living does not refer to complete self-sufficiency (or living alone), but rather the extent to which “independent living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives”.³⁷¹ However, once again there is evidence that many young people struggle to access and coordinate the supports necessary to achieve independent living.³⁷²

Within the literature, independent living is associated with a number of key factors including self-management as well as practical issues of housing, transport and finance.

Self-management of the young person’s disability and clinical needs is seen as an important aspect of adulthood, both by researchers³⁷³ and young people themselves.³⁷⁴ Young disabled people closely associated self-management of their

³⁶⁵ (Fraser of Allander Institute, 2021, p. 10)

³⁶⁶ (Scottish Parliament, 2020)

³⁶⁷ (Di Rezze, et al., 2016)

³⁶⁸ (DIVERgent INfluencers, 2021)

³⁶⁹ (Fraser of Allander Institute, 2021)

³⁷⁰ E.g., (SCLD, 2017; SCIE, 2017)

³⁷¹ (European Network on Independent Living, n.d.)

³⁷² (SCLD, 2017)

³⁷³ (Zhou, et al., 2016; Lindsay, et al., 2014)

³⁷⁴ (DIVERgent INfluencers, 2021)

diagnosis with gaining and asserting independence.³⁷⁵ However, it has also been suggested that in the UK, training and support for self-management is routinely lacking in transitions services and planning.³⁷⁶ Some young people may also want their parents to maintain a stake in their decision-making and the support they receive,³⁷⁷ and over-protective parents may struggle to cede control.³⁷⁸

There is evidence that housing is often an afterthought and that options for disabled young people, and especially those with learning/developmental disabilities, are limited.³⁷⁹ A large proportion of people with learning disabilities appear to live with family or in residential care.³⁸⁰ Many have typically ended up in residential care homes alongside much older people, with adverse impacts on their wellbeing and social lives, though there is evidence that housing provision for this group is improving.³⁸¹

Stakeholders report that among those who secure their own housing, the default is often single tenancy accommodation, depriving young people of the social experiences of communal living enjoyed by their non-disabled peers.³⁸² This can compound common issues of isolation and limited support networks.

A number of common difficulties securing appropriate housing have been identified, including a limited supply of housing, a lack of clear information on housing availability and options, inadequately signposted advice (which is often of a high standard but inadequately incorporated into planning), complicated funding of housing support, and difficulties accessing and coordinating support.³⁸³

Best practice

Independence and self-efficacy are seen as important both in their own right, and with regards to successful transitions in other domains, including health, education and employment.³⁸⁴ Gaining independence is widely seen as important to young people both in Scotland³⁸⁵ and internationally.³⁸⁶

A number of (meta-)reviews suggest that independent living requires concerted planning, and the provision of life-skills training and/or community-based instruction.³⁸⁷ These features were found to be predictive of post-school outcomes relating to general quality of life as well as education and employment.³⁸⁸ Early planning was again seen as vital to “ensure that the patient has the necessary

³⁷⁵ Ibid.

³⁷⁶ (Colver, et al., 2019)

³⁷⁷ (Young Minds, 2020)

³⁷⁸ (Lewis & Noyes, 2013)

³⁷⁹ (NDTI, 2011; SCLD, 2017)

³⁸⁰ (NDTI, 2011)

³⁸¹ (Lugasi, et al., 2011; SCLD, 2017)

³⁸² (Scottish Parliament, 2020)

³⁸³ (SCLD, 2017)

³⁸⁴ (Lugasi, et al., 2011; Baer, et al., 2011)

³⁸⁵ (ARC Scotland, 2017; DIVERgent INfluencers, 2021)

³⁸⁶ (Chaudhary, et al., 2013)

³⁸⁷ (Baer, et al., 2011; Papay & Bambara, 2014)

³⁸⁸ (Baer, et al., 2011)

knowledge and skills for autonomous behaviour at the time of transition and after”.³⁸⁹ Key features of life-skills provision and planning for these purposes identified in the literature include.³⁹⁰

- Self-management of conditions and treatment/support
- Housing
- Transport
- Finance

It has been suggested that these issues may be especially important for young people with learning and developmental disabilities.³⁹¹

Self-management is closely associated with the transition to adulthood,³⁹² and has evident benefits for both individuals (in terms of greater self-efficacy and independence) and for services (in terms of resourcing and cost).³⁹³ The ‘shared management model’ suggests that as children and young people mature, they should take on developmentally appropriate responsibility for self-management of their condition and clinical needs.³⁹⁴ The principle of promoting self-management is widely mentioned in the literature on best practice with regards to transitions to adulthood, though it has been suggested that it enjoys only limited attention in both research³⁹⁵ and practice.³⁹⁶

It has also been suggested that self-management has attracted growing academic attention, but that knowledge gaps persist with regards to the outcomes and mechanisms of supported self-management that are most valued and effective, and with only limited attention paid to people with disabilities.³⁹⁷

There is evidence that self-management should be built up gradually; young people have reported struggling to take greater control of their clinical care in tandem with managing other aspects of their transition.³⁹⁸

Reviews of interventions aimed at supporting self-management suggested that effective programmes are characterised by a range of features including: workshop-based/face-to-face delivery by trained practitioners; the assignment of homework; and parental involvement in self-management strategies. Typically, these were delivered in multiple sessions over a longer period of time (in most cases, at least 3 months), though there was evidence that shorter intensive workshops can also be effective.³⁹⁹ There are mixed findings with regards to parental involvement in self-

³⁸⁹ (Lugasi, Achille, & Stevenson, 2011)

³⁹⁰ (NDTI, 2011; Fisher & Elnitsky, 2012; Bambara, et al., 2007; Wehman, 2006; Flexer & Baer, 2008; Greene, 2009)

³⁹¹ (Papay & Bambara, 2014; Wehman, 2006)

³⁹² (Lindsay, et al., 2014)

³⁹³ (Grady & Gough, 2014; Lindsay, et al., 2014; Colver, et al., 2019)

³⁹⁴ (Lindsay, et al., 2014)

³⁹⁵ (Lindsay, et al., 2014)

³⁹⁶ (Colver, et al., 2019)

³⁹⁷ (Boger, et al., 2015; Lindsay, et al., 2014)

³⁹⁸ (Young Minds, 2020; Scottish Parliament, 2020)

³⁹⁹ (Lindsay, et al., 2014; Campbell, et al., 2016)

management, with some suggesting that over-protective parents can in fact be an impediment to self-management,⁴⁰⁰ and some young people may want their parents to remain involved in their support and decision-making.⁴⁰¹

These programmes were (overall) associated with improved self-management and/or improved health outcomes, though it was noted that the features and delivery of each programme varied too much to firmly identify best practice.⁴⁰² It has been observed that, more broadly, “while self-management interventions have the potential to improve health behaviors [sic], there were relatively few rigorously designed studies identified.”⁴⁰³

With regards to housing, advanced planning is again essential. Disabled young people were seen to value proximity to family, friends and amenities, as well as a safe and secure environment, all of which should be considered in such planning.⁴⁰⁴ Independent living and housing may also rely on adequate at-home care/support and assistive technology, so support and guidance arranging and funding these should be provided.⁴⁰⁵ This will likely require highly trained and knowledgeable practitioners being involved in transition planning.⁴⁰⁶

Information regarding housing was generally found to be lacking, however, though it has been suggested that high-quality advice is available but not adequately incorporated into transition planning.⁴⁰⁷

Calls have been made for a package of information relating to basic housing questions to be made available early in the planning process.⁴⁰⁸ This may gradually give way to more practical/technical information (such as how to apply to be on the local housing register, and information about receiving welfare/housing benefits).⁴⁰⁹

For young people with profound learning disabilities, it has been argued that information provision, educational preparation for families and systematic follow up are all important areas of best practice for effective transitions.⁴¹⁰

In addition to guidance and support to find a house, best practice in preparation for independent living should also equip the young person in question with the necessary financial and housekeeping skills to maintain their home.⁴¹¹ Young people themselves have flagged an appetite for greater instruction in life-skills, such as cooking, cleaning and personal finance, including related issues around benefits.⁴¹²

⁴⁰⁰ (Lewis & Noyes, 2013; Lindsay, et al., 2014)

⁴⁰¹ (Young Minds, 2020; Soanes & Timmons, 2004)

⁴⁰² (Lindsay, et al., 2014)

⁴⁰³ (Lindsay, Kingsnorth, Mcdougall, & Keating, 2014)

⁴⁰⁴ (Lugasi, et al., 2011)

⁴⁰⁵ (NDTI, 2011)

⁴⁰⁶ (Health and Social Care Alliance Scotland, 2017)

⁴⁰⁷ (SCLD, 2017)

⁴⁰⁸ (NDTI, 2011)

⁴⁰⁹ (Health and Social Care Alliance Scotland, 2017)

⁴¹⁰ (Roos and Søndena, 2020)

⁴¹¹ (NDTI, 2011)

⁴¹² (DIVERgent INfluencers, 2021)

Personal Relationships

Common experiences

It has been observed that disabled young people often have below-average outcomes with regards to personal relationships and active participation in their community.⁴¹³ Social isolation is commonplace among disabled young people,⁴¹⁴ and especially so among those with learning disabilities.⁴¹⁵ Disabled young people report that they lack confidence in everyday social situations,⁴¹⁶ and that they are not given opportunities to be active members of the community.⁴¹⁷ While the theme/term 'active citizenship' surfaces occasionally in the literature, there is very little evidence on its practical meaning.

Young people can often lose touch with friends and peers when leaving school or child services, and some have reflected that they lack opportunities to meet other disabled young people with similar experiences.⁴¹⁸

Research with disabled young people shows that many see friendships as a key part of the transition to adulthood, but also something that is lacking from their lives, from many support services, and from much of transition planning.⁴¹⁹ Young people in Scotland have reported that they see building their interpersonal skills and relationships as a central part of gaining independence through their transition to adulthood.⁴²⁰ This is especially an issue and priority for people later in their transition (aged 21-25), for whom feelings of isolation may compound other feelings of demoralisation with respect to employment.⁴²¹

⁴¹³ (Maslow, et al., 2011) (Maslow, et al., 2011)

⁴¹⁴ (DIVERgent INfluencers, 2021; Di Rezze, et al., 2016)

⁴¹⁵ (Cross-Party Group on Autism, 2020)

⁴¹⁶ (DIVERgent INfluencers, 2021)

⁴¹⁷ (ARC Scotland, 2017b)

⁴¹⁸ (Stalker & Moscardini, 2012) (Stalker & Moscardini, 2012)

⁴¹⁹ (Stalker & Moscardini, 2012) (Stalker & Moscardini, 2012)

⁴²⁰ (ARC Scotland, 2017)

⁴²¹ (DIVERgent INfluencers, 2021)

Best practice

It has been suggested by various stakeholders that transition planning should include personal development and a focus on friendships and relationships.⁴²² Holistic planning and support are seen to go beyond outcomes-based metrics relating to education and employment, “but also psychosocial development, including ability to consolidate identity, achieve independence and establish adult relationships.”⁴²³

However, despite longstanding calls to improve efforts to tackle social isolation,⁴²⁴ a number of researchers have suggested that limited attention has been given to personal relationships in research, practice and monitoring.⁴²⁵ Stakeholders have similarly reported that young people in Scotland routinely lack support and planning with regards to this issue.⁴²⁶ There is further evidence that this is especially true of sexual relationships, despite transitions typically occurring in tandem with sexual maturity.⁴²⁷

Without greater attention to personal and sexual relationships, it is difficult to identify best practice and there is very limited evidence on this issue.

⁴²² (NDTI, 2011; SCIE, 2017; Henninger & Taylor, 2014; Fisher & Elnitsky, 2012)

⁴²³ (Zhou, Roberts, Dhaliwal, & Della, 2016)

⁴²⁴ (Francis, 2006)

⁴²⁵ (Di Rezze, et al., 2016; Stewart, 2009; Scottish Parliament, 2020) (Di Rezze, et al., 2016; Stewart, 2009; Scottish Parliament, 2020)

⁴²⁶ (Scottish Parliament, 2020)

⁴²⁷ (Stalker & Moscardini, 2012; Di Rezze, et al., 2016) (Stalker & Moscardini, 2012; Di Rezze, et al., 2016)

Conclusions

This literature review has advanced a comprehensive and detailed summary and synthesis of the prevailing evidence on disabled young people's transition to adulthood. This section summarises and reflects on the key findings, while the following Gap Analysis outlines areas for further research.

We find a broad consensus within the literature in support of certain guiding principles, largely revolving around holistic, personalised and concerted planning, developed in collaboration with young people and their families, and underpinned by high-quality, well-resourced and well-staffed services, delivered in partnership.

The counterpoint to this consistency, however, is a high degree of duplication within the literature. A full gap analysis is outlined below, though we briefly point here to key knowledge-gaps.

Broadly speaking, there is a very consistent commitment to these guiding principles, with less granular detail on their practical realisation. This may be a result of insufficient research, the non-standardised nature of much service-delivery, and/or the multiplicity of possible outcomes and variables. There is a broad sense that existing monitoring and evaluation processes are inadequate for the purposes of identifying best practice. We, and other authors, also note that many of the established examples and lists of best practice have been developed on the basis of stakeholders' input and validation, and consensus among researchers and practitioners within the field, rather than more rigorous evaluation.

There is, however, variation within this. Institutional transitions appear to have enjoyed greater attention within the literature, and much of this is arguably of a higher standard. There appears to have been more progress within the field of healthcare to identify effective practice with regards to transitions.

With regards to life-course transitions, education and employment appear to have attracted significant attention, with well-documented experiences and shortcomings across the literature. However, there are a number of gaps within the evidence base on best practice in these fields.

Much less still has been written about independent living, personal relationships and 'active citizenship'. It is unclear if these are missing from practice as well as research, though there is some evidence that this may be the case.

Nevertheless, this literature review advances a cogent, accessible, yet detailed synthesis of the research to date on disabled young people's experiences and needs during the transition to adulthood. It is hoped that this document will provide an invaluable steer for practitioners and policymakers alike in devising and delivering effective supports.

Gap Analysis

This section reflects on areas of consensus within the literature, as well as highlighting areas where less is known or established and flagging areas for future research.

Summary

- We understand what the common transition experiences of children and families are; namely, disorientation, inadequate planning, and limited ‘wrap-around support’.
- We know what characterises a good transition in principle, but robust and granular evidence about what works in practice, including in specific institutional contexts is more limited.
- While there is a wealth of high-quality evidence relating to transitions within healthcare, much less is known about transitions into further and higher education and employment, and about personal issues (including self-management, independent living, and personal relationships).

Findings

This literature review has advanced a comprehensive and detailed summary and synthesis of the current evidence on disabled young people’s transitions to adulthood. We found a broad consensus within the literature in support of certain guiding principles, largely revolving around holistic, personalised and concerted planning, developed in collaboration with young people and their families, and underpinned by high-quality, well-resourced and well-staffed services, delivered in partnership.

The counterpoint to this consistency, however, is a high degree of duplication within the literature. There is a consistent commitment to these guiding principles, with less granular detail on their practical realisation. This may be a result of insufficient research, the non-standardised nature of service-delivery, and/or the multiplicity of possible outcomes and variables.

Our analysis has identified a number of gaps in the current knowledge-base, relating to both specific transitions and specific subgroups. These include:

- Particular institutional settings (e.g. social care, education, employment and housing)
- Particular life-course issues (e.g. independent living, relationships (social and sexual), and citizenship)
- Particular conditions (e.g. autism/Asperger’s, sensory impairments, profound/severe/complex, mental health)
- Protected characteristics (e.g. gender, race).

A further limitation is a lack of intersectional evidence in relation to the above (e.g. the social and relational aspects of employment or the effect of differential demographic characteristics). There is some evidence that young people with learning and developmental disabilities can face especial difficulties in a range of transitions (including employment and independent living), but there is limited evidence beyond this.

Methodological considerations

We have also identified a number of further limitations within the literature regarding the types of evidence available, namely:

- A lack of robust qualitative evidence
- A lack of longitudinal evidence (which is particularly important when thinking about outcomes)

There is also a broad sense that existing monitoring and evaluation processes are often inadequate for the purposes of identifying best practice. We, and other authors, note that many of the established principles and lists of best practice have been developed on the basis of stakeholders' input and validation, and consensus among researchers and practitioners within the field, rather than more rigorous evaluation (e.g. clinical RCTs).

Broader reflections

A further and broader conceptual issue is the relationship between a good transition to adult services and a good transition to adulthood. There is an evidence base beyond the scope of this study about what makes a 'good life' for disabled people (though this varies across conditions, demographic characteristics and other contexts) but this agenda should be underpinned by the fundamental question of what the relationship is between a 'good transition' and a 'good life' and the contribution one can make to the other.

While this is not a sole focus of the materials that we have produced, it would be anticipated that the primary materials developed would feed into this broader question.

Future Research

A considerable amount of research has already focused on general principles underlying effective transitions overall. Given the high degree of duplication in this vein, we would suggest a more targeted and in-depth approach focusing on specific transitions, with the aim of identifying effective practices/processes in greater practical detail.

When transitions relate to particular institutions or fields (e.g. within healthcare, education or employment), we would propose a targeted approach to research, characterised by in-depth discussion of disabled young people's experiences and needs, and the identification of effective interventions within this particular

field/setting. Greater clarity and understanding could be sought on young disabled people's experiences and needs with regards to social care, education, and employment.

The exploration of more personal issues within transitions would likely benefit from a more free-form approach. This line of enquiry would be underpinned by the issue of what constitutes a 'good life' as well as a good transition for disabled young people, with the flexibility necessary to explore issues of independence and independent living, relationships, and active citizenship. Given the imprecise nature of some of these terms, we would propose asking respondents how they characterise and define such issues, before exploring these topics in greater depth.

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