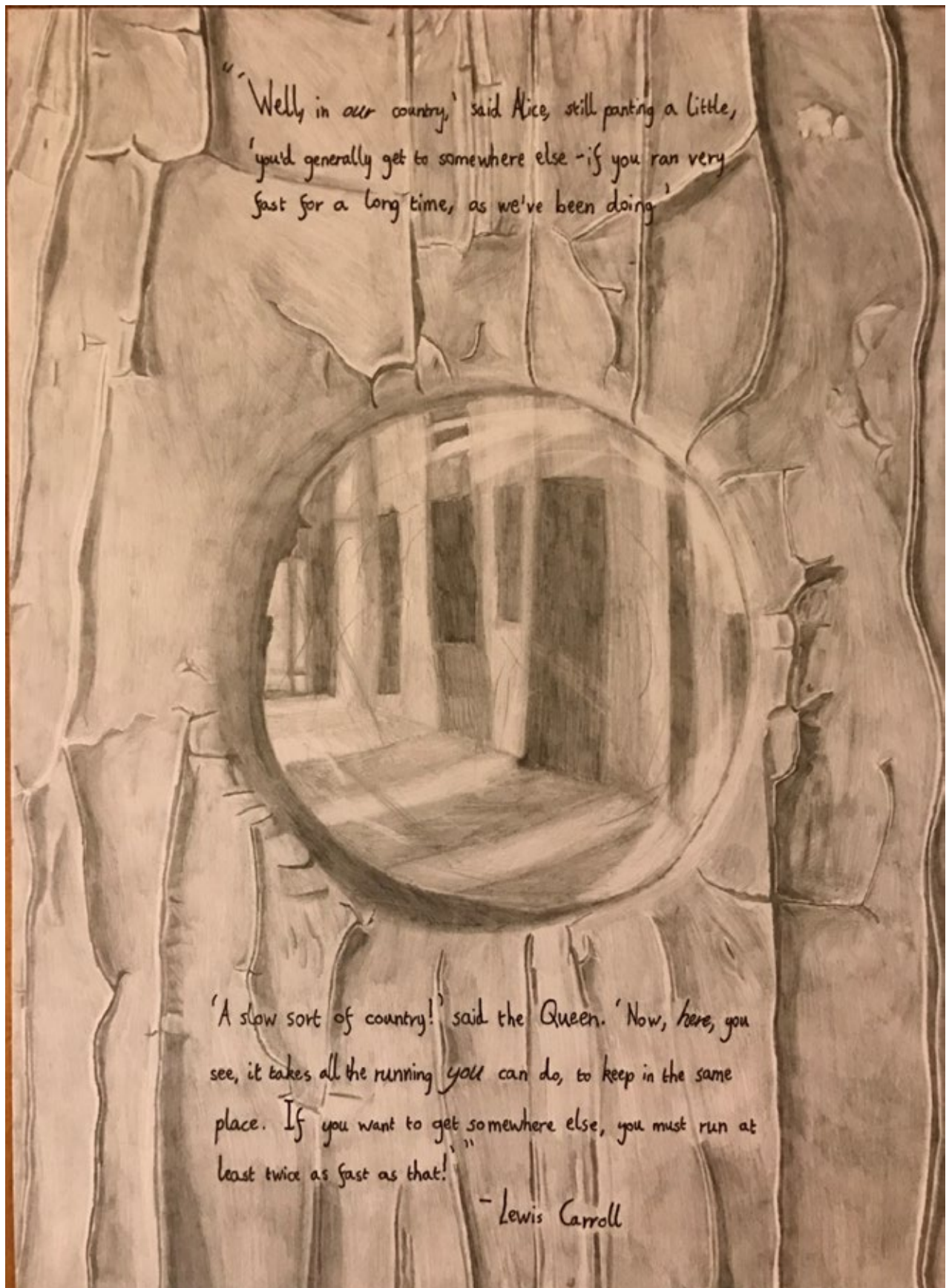


Experiences of Transitions to Adult Years and Adult Services

Health and Social Care Alliance Scotland

Scottish Government Directorate
for Children and Families

May 2017



Hannah Francis
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Foreword

Ministerial Foreword



The transition from childhood to adulthood is one of the most daunting phases in anyone's life; a period of huge change and adjustment. Crucially if we want to build a truly fair and inclusive Scotland, we must make sure that all young people are supported during this time of transition to ensure they reach their potential, irrespective of personal circumstance.

And yet, too often for disabled young people, that transition to adult years is a negative and detrimental experience. The support structures and relationships that have allowed them to develop and flourish as a child are left behind with little consideration for the ensuing impact. Such experiences are why the Scottish Government has commissioned this report; and it is why we will be considering in detail how to take forward the recommendations.

Working with young people and their families, as well as service providers, this research report considers whether carrying over some of the principles of *Getting It Right For Every Child* into adult services has potential to aid this transition process. As the report demonstrates, concepts such as the wellbeing indicators and person centred planning can help to continue placing the rights and wellbeing of the young person at the heart of the services that support them, irrespective of age, helping bridge the gap between child and adult services.

It is on that note that I wish to express a heartfelt thanks to the young people, and their families and carers, who have been the primary focus of this study. Their poignant and thought-provoking reflections, captured in the case studies, demonstrate a real desire to see positive and practical change.

I echo that sentiment. Truly effective solutions to the problems and barriers faced by disabled young people in the transition to adult services must be drawn from the lived experience of disabled people themselves. It is our responsibility as public servants to make sure that such conversations do not stop, and that we actively reach out to those who use our services. Whilst this report leaves little doubt that substantial improvements need to be made, it is clear that progress is possible and achievable, and I am pleased to see many examples of good practice highlighted in the report. In particular, the *Principles of Good Transitions 3*, recently published by ARC -Transitions Forum, demonstrates the excellent practice which should become the standard for all transitions services in Scotland.

The Scottish Government is committed to working together with local authorities, education, health and social care providers, and employers, to improve points of transition. Only by working together in this way can we ever hope to provide support that is fully aligned and responsive to the needs of disabled young people.

Of course, such a desired outcome will have important ramifications well beyond periods of transition. That is why the Scottish Government is currently developing a *Framework to Support Disabled Children, Young People and their Families*; so they can receive the right support, at the right time, and in the right way, from birth through to adulthood.

Just as with the transition to adult services, we want to work together to develop policies and approaches that can solve problems and dismantle barriers. We may have high ambitions for the changes we want to see, but disabled children and young people, and their families, have the right to no less. A fairer Scotland can only be realised when we secure equal rights for everyone.

Mark McDonald MSP, Minister for Childcare and Early Years

Foreword by Ian Welsh



The future is unknown for all. However, this report is about anticipating change, forward thinking and listening to what helps young people with additional support needs move on to adult years and adult services in a wide range of circumstances.

Even while making progress, some young people, parents and indeed professionals may feel they are going ‘up the down escalator’ and running very hard simply to stay still. This was the sensation of one young adult participant who has made huge strides even during the period of this study. Participant Hannah Francis drew the picture on the inside cover to convey her experience. Looking ahead, there are dark openings to unknown rooms. There may be new doors to open but support, guidance and understanding are likely to be necessary with each exploration. She and her family have wanted help to be practical.

The ALLIANCE is delighted to have worked in partnership with the Scottish Government, local authority, health and third sector professionals to produce this report. We are deeply indebted to the young people and families whose voices have contributed to the learning and recommendations. I commend this report to all who have an interest in ensuring that disabled young people and those living with long term conditions have successful transitions to adult years and adult services.

Ian Welsh OBE, Chief Executive, Health and Social Care Alliance Scotland (the ALLIANCE)

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations with a network of over 1,900 members including large, national support providers as well as small, local volunteer led groups and people who are disabled, living with long term conditions or providing unpaid care.

The ALLIANCE vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

1. Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
2. Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self-management, co-production and independent living.
3. Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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1. Executive Summary

- This qualitative study about transitions to adult years and services was commissioned by Scottish Government and completed by the Health and Social Care Alliance between July 2016 and March 2017.
- The study is primarily based upon the experience of some 30 individuals and families for whom the transition paths to adult years and services has been impacted by a broad spectrum of complex and interacting disabilities.
- The geographical study area covers East Lothian, Midlothian, West Lothian, the Scottish Borders and the City of Edinburgh. The age span of most participants is 15-24 although younger siblings and older participants have contributed, alongside parents, family members and carers.
- The participant spread includes diverse family structure; home base; economic opportunity; rural/urban location; legal situation and stage in transition.
- The views of professionals and managers from a wide range of statutory and third sector agencies have been taken in to account.
- There is a central interest in the experience of application of core components of the Getting it Right for Every Child approach. There is a specific interest, where applicable, in the experience of a co-ordinating lead professional; and in the experience of planning for each person that is based on a holistic consideration of wellbeing. There is an interest in the extent to which these core components are experienced in service transitions.
- The study is not an inspection or an audit but does seek to recognise aspects of professional systems and approaches that have contributed to successful bridging, support and inclusion during a life phase that is unavoidably affected by loss and change in service and relationship.
- Conversely there is a reflection on generic themes in approach and systems that appear to have increased a sense of isolation, confusion and anxiety about practical cliffs to be negotiated.
- The ALLIANCE seeks to bring the voice of contributors to bear on widespread efforts at improving transition pathways. The aims of the study are to make a practical difference.
- Publication of the study is intended to complement the Scottish Government commissioned national mapping of transitions processes for individuals with additional support needs (1); and correlates in time and theme with Principles of Good Transitions(3).

Effective transitional support has depended upon:

- An understanding of family and of the interaction of relationships that are part of each young person's growth and development through transitional stages
- Sufficient continuity of a co-ordinating key professional during transitional phases
- Approachability and pro-activity of key professionals
- Practicality and expertise of key professionals offering guidance during loss, separation and service change
- Early, guided accessibility to information about processes, resources and timelines
- Adequacy/inadequacy of budget allocation in relation to all wellbeing needs
- Creative bridging of gaps for individuals through partnerships between family, third sector and statutory services
- Respect, honesty, encouragement and support for parents and carers who may find themselves in adversarial positions.

Recommendations

1. **Wellbeing:** Use of the Wellbeing Indicators should be supported in transitional planning processes across services.
2. **Principles of Good Transitions 3 (3):** This resource should be adopted as the standard approach to transitions across all statutory and voluntary sector transitions services. It clearly demonstrates how to ensure good transitions, and is the standard all services are expected to work towards attaining.
3. **Information:** There is a need for improvement in access to local information about resources and processes. Information about local pathways is needed to help individuals, parents and professionals navigate local systems and to signpost support. Local areas should consider the potential application of vehicles such as ALISS (2) as a platform for a locally self-generating directory.
4. **Training:** There is scope for a pre-qualifying and cross-service training module covering effective support for transition, for example in social work, nursing and housing. There is scope for development of introductory, interactive training materials online. The Scottish Government and other partners should consider the feasibility of developing such a resource.
5. **Outreach:** Consideration should be given by Scottish Government, local authorities and health boards to developing an outreach role. This would be designed to reach (a) those with additional support needs who may be at

significant risk and (b) those who have not been well known to services because they have not been at known risk but who may become isolated and exhausted without proactive contact, signposting, networking and support as needed.

6. **Coordination and Point of Contact:** A lead professional is very important when there are interlocking services in transition planning. The availability of a lead professional to coordinate services for families within statutory health and social care and through third sector services during transitional years, e.g. at least from 14-21, would offer a considerable improvement in the experience of many families. Ensuring processes are in place so that families going through transition have access to a lead professional should be considered by local authorities and other statutory services.
7. **Structures:** Some children's social work services in the study area are planning for potential continuity of service to age 26, taking service user feedback into account. Restructuring services in this way should be considered by relevant service providers and lessons learned from future evaluation of this structural initiative should be shared and acted upon.
8. **Planning in Partnership:** Family Group Decision Making is a model that could offer a range of benefits in family led, co-produced transition planning for families in which family members, statutory and third sector services have a part to play. This is a form of collaborative, practical and person-centred planning with individuals and family members or those most important to the wellbeing of the young person (4) (5) (6). The neutrality of the coordinator and the careful preparation of these processes are key to their success. Scottish Government and statutory partners should explore the feasibility of developing such a model.
9. **Resourcing:** Local authorities should give consideration to initiating a policy and practice review in relation to those respite or short break arrangements which are significantly cut because a young person turns 17 rather than because of change in need.

2. Introduction and Context

This report describes a qualitative study of transitions to adult years and adult services for disabled young people and young people living with long term or life limiting conditions.

Transition

For the purposes of this study, transition is taken to mean the period when young people move in to adult years and move on from school and the support of children's services.

Transition has a different meaning and emphasis depending on who is using the term and what their experience and responsibilities may be. Some services may focus upon transition as the leaving of one service and transfer to another, like handing on a baton. However, this study supports the concept of transition as a complex of interwoven emotional and developmental processes for an individual and their family rather than a single event. There may be shared themes, but the hopes, fears, memories and meanings of transition are unique for every contributor to this study.

The individual potential, wellbeing and future wellbeing of each person has a pattern arising through the past. The way we grow through change is shaped not only by our own strengths and challenges, but also by relationships with those who care for and about us.... and by the strengths and challenges facing *them*. Transitions are interactive and there are often repeat patterns in the way individuals and families manage stress and change that stretch back and forward across the lifespan. This might be described as the 'DNA' of transitions. This analogy conveys a sense of potentials and vulnerabilities combining and open to influence in the present, but unavoidably connected to our histories and our future opportunities.

This study is about the 'how'. It is about pragmatic help in the present, without delay. The least successful phases of service in this study are disjointed, impersonally procedural and disconnected from the stage, understanding and experience of individuals and families. There have been many successful phases. This study explores the tensions.



(image credit: <https://uk.pinterest.com/steven2181/dna/>)

Participants

The basis of the study is the lived experience of young people and their families. The young people or young adults in this study are in the age range 15-24 with one aged 30, reflecting on transitions ongoing. Families and individuals have come forward from the whole study area, which encompasses East Lothian, Midlothian, West Lothian, Scottish Borders and City of Edinburgh. Thirty families offered to take part and 29 proceeded to participate in the period July 2016-March 2017.

Aim

The intention of the study is to inform improvements by outlining themes and suggestions arising from experiences of transitions. Conclusions and recommendations are intended to support practitioners and managers in their practices, services and strategic developments. This is not an inspection or an audit but rather a constructive reflection on processes and services that have worked well together; shared dilemmas; and practical suggestions drawn from emerging themes.

Focus

The study explores the extent to which key components of the Getting it Right for Every Child (GIRFEC) Practice Model appears to be evident or have value for families through transitional processes. GIRFEC is an overarching policy and practice approach that is underpinned by the United Nations Convention on Rights of the Child. (6)

The ethos of GIRFEC is realised in practice when:

- The child, young person or young adult is at the centre of all planning – and this means attention to their experience, their needs and their aspirations

- The team or services involved build on strengths as well as address risks within the young person and in the ecology of their relationships.*
- Partnership is promoted between those who care about and those who have responsibilities towards the child/young person

The core components of the GIRFEC model with which the study is specifically concerned include the concept of a single young person's plan co-ordinated by a lead professional; and a holistic consideration of the wellbeing of young people.

The indicators of wellbeing as defined within the GIRFEC approach are defined further below in this report. Their place within a Child or Young Person's Plan are now embedded within section 96 of the Children and Young People (Scotland) Act 2014 (7).

*'Ecology of relationship' refers to the way that relationships between an individual, their family, significant others and their wider environment all interact, evolve and affect individual development and transitions. (8)(9)

'Complex disability'

The study considers individual and family experiences in relation to a broad range of additional challenges. All the participants in this study are impacted by multiple and interacting conditions. At one end of the range there are young people described as 'high functioning' but affected by autism, anxiety and depression. There is scope in their future journeys for considerable fluctuations and development in their wellbeing and independence. By contrast there are those with profound and multiple disabilities, whose exceptional health care needs will involve long term and intricate dependency on families, carers and a regimen of specialist services. The range of conditions and situations encountered in the study is listed in below. However, in summary, interacting conditions have included:

- Learning disabilities – mild to profound
- Severe physical disabilities – a wide spectrum affecting sight, hearing, mobility, feeding, breathing, heart, circulation, digestion
- Autism – a wide range of severity and combinations with other conditions
- Epilepsy – a range of severity and combinations with other conditions
- Mental health crises and chronic mental ill health in combination with other conditions
- Complex separations and attachment difficulties with associated challenging behaviour and developmental delay
- Late onset conditions or chronic disabilities following traumatic event or debilitating illness

Timing

It has been a sensitive time to progress such a study and yet the timing of this report may be opportune. A number of families and some practitioners have suggested that

budget reductions, structural reform and legislative change are placing new stresses on services and families. A study based on the journeys of those involved may not be a welcome initiative in times when *'just keeping the lid on'* may be extremely stressful. However, if reviews of service, procedure and processes are in progress, the lived experience of young people and families should be a formative influence and this study, alongside other and more extensive research and national guidance, may assist in conveying that influence.

Parallel developments

The timing of this study also coincides with publication of ARC Scotland's Principles of Good Transitions 3 (POGT3), concerned with the transitions to adult life of young people with Additional Support Needs. This has been described by an experienced transitions service manager in the Alliance study as *"The go-to national guidance for those shaping transitions services"*. POGT3 is endorsed by Scottish Government and the National Disability Delivery Plan 2016-21 (10)

National mapping of transitions

In parallel with the Alliance qualitative study, the Scottish Government have also commissioned an overarching and quantitative analysis of transitional processes in Scotland. There is a plan for publication in summer 2017(1). Early findings are congruent with the themes and recommendations in the ALLIANCE study.

Policy Context - the Doran Review

Scottish Government's November 2012 response to the Doran Review *"Meeting the needs of Scotland's children and young people with complex additional support needs"* (11) was accepting of recommendation 11 that, *"Scottish Government should provide leadership and where appropriate direction to local authorities and health boards and consider the adequacy of existing legislation to ensure that the transition from children's to adult services for young people with complex additional support needs is properly coordinated, managed and delivered."*

The Doran Review was prompted in part by the Education (Additional Support for Learning) (Scotland) Act (2004). This legislation introduces duties relating to planning and co-ordinated provision of additional support on moving into, through and on from school. The Principles of Good Transitions³ (introduction p14-15) provides a flow chart (Appendix) (<https://scottishtransitions.org.uk/flowchart/>) outlining the web of inter-related public duties relating to: Additional Support for Learning, Self-Directed Support (12), wellbeing needs and planning in the Children and Young People (Scotland) Act 2014 (13), Guardianship (14) support for carer and young carers (15) and public sector duties under the Equalities Act (16).

The Doran Review found the GIRFEC approach to be a key to integrating improvement in many areas and Scottish Government accepted Recommendation 15 that, *“The Scottish Government working with local authority services, the health boards and the voluntary sector should provide detailed guidance and support for the application of the GIRFEC approach and specifically the practice model to meeting the changing needs of all children and young people and specifically those with complex additional support needs from the earliest stages to transition to adult life.”*

The Doran Review underlined the role of inspection agencies in supporting continuous improvement in this direction.

Policy Context – Integration - The Public Bodies (Joint Working) (Scotland) Act 2014.

Transitions policy, procedure, practice and funding is affected by required integration of health and social care, on all levels.

In Edinburgh an Integrated Joint Board became responsible for the delivery of integrated joint services from 1/4/16. Joint Partnerships are required to set out plans and intentions for joint provision of care services. Guidance on the Public Bodies (Joint Working) (Scotland) Act (2014)(17) affirms that service users should have a clear understanding of what they can expect from Health Boards and Local Authorities in relation to the 9 national Health and Wellbeing Outcomes which apply to integrated health and social care (section 3(2) of the Act).

Health and Social Care Standards

‘Standards’ is a collective term to describe both the outcomes and the descriptive statements which set out the standard of care a person can expect. Health and Social Care Standards in their draft form (18) have a focus on transition as a move between services (Revised draft Health and Social Care Standards, Scottish Government, November 2016 s2.9) *“If I need or want to move on and start using another service, I will be fully involved in this decision and helped to find a suitable alternative. If I am moving from a service for children to one for adults, I am helped with this transition.”*

The Standards have been prepared to support delivery of a range of legislation and Scottish Government policy that relates to health and social care, such as:

- Scotland Performs: National Performance Framework
- Getting it Right for Every Child and the wellbeing indicators
- The Public Bodies (Joint Working) (Scotland) Act 2014 and the National Health and Wellbeing Outcomes
- The Social Care (Self-directed Support) Act 2013
- The Carers (Scotland) Act 2016
- Social Services in Scotland: a shared vision and strategy 2015-2020
- A National Clinical Strategy for Scotland

The table below shows the connections between the National Health and Wellbeing Outcomes and the Principles of Good Transitions 3:

National Health and Wellbeing Outcomes	Principles of Good Transitions 3
1. People are able to look after and improve their own health and wellbeing and live in good health for longer	1. Planning and decision making should be carried out in a person-centred way
2. People, including those with disabilities or long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.	2. Support should be co-ordinated across all services
3. People, including those with disabilities or long term conditions, or who are frail, are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community.	3. Planning should start early and continue up to age 25.
4. People who use health and social care services have positive experiences of those services, and have their dignity respected.	4. Young people should get the support they need
5. Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.	5. Young people, parents and carers must have access to the information they need
6. Health and social care services are centred on helping to maintain or improve the quality of life of people who use those services.	6. Families and Carers need support
7. Health and social care services contribute to reducing health inequalities.	7. A continued focus on transitions across Scotland
8. People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and wellbeing.	

9. People who use health and social care services are safe from harm.	
10. People who work in health and social care services feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.	
11. Resources are used effectively and efficiently in the provision of health and social care services.	

National Disability Delivery Plan 2016-21

“We will work with schools, local authorities, health and social care partnerships, further and higher education institutions and employers to improve the lives of young disabled people. This includes points of transition into all levels of education – primary, secondary further and higher – education and employment.

We will be mindful of young people who have faced structural inequalities and complex barriers that result in lack of employment. We will ensure that supports are in place so that they can live a life of equal participation, with the support they need. We will embed the Principles of Good Transitions, and prioritise person-centred, coordinated support.”

From spring 2018, the new standards will provide a framework for registration and inspection of individually registered care and health services, and they will also be relevant to all care and health services including those not inspected by the Care Inspectorate or HealthCare Improvement Scotland. Services which are not currently required to register with or be inspected by these regulators will be encouraged to adopt and apply the Standards as a framework for high quality care. In short, this will be a reference point in relation to transitions of various types.

There are no Scottish transition-specific quality standards equivalent to the 2016 NICE transitions quality standards which apply in England, Wales and N. Ireland. Health Improvement Scotland contributed to their development and The Principles of Good Transitions 3 reference NICE Quality Standards (19). NICE Standards are a professional framework which link to English legislation and cover all young people (aged up to 25) using children’s health and social care services who are due to make the transition to adults’ services, including those with mental health problems; with disabilities; long-term, life-limiting or complex needs; or in local authority care. This covers the period before, during and after a young person moves from children’s to adults’ services, covering all settings in which transitions from children’s to adults’ health or social care services take place.

The national wellbeing outcomes provide overarching expectations in relation to transitions improvements. They are listed below in parallel with the Seven Principles of Good Transitions and National Disability Support Plan in order to show their congruence.

Integration Authorities must now set out in their strategic plans how arrangements for the delivery of the integrated health and social care services are intended to contribute to achieving the national health and wellbeing outcomes (section 29 (1) (b) of the Act). The national health and wellbeing outcomes must be taken into account when reviewing a strategic plan (section 37(2) of the Act).

A health board, local authority or Integration Joint Board must have regard to the national health and wellbeing outcomes and integration delivery principles when they are delivering integrated health and social care services (section 40 of the Act).

There are also opportunities for scrutiny bodies such as the HealthCare Improvement Scotland and Care Inspectorate to evaluate the extent to which integration principles are locally evident in transition policy, process and practice.

Integration authorities themselves must report annually on their performance against key measures and indicators in relation to the national health and wellbeing outcomes. There are opportunities for transitions service development and improvement within these required processes.

There may be difficulties implementing financial integration, despite statutory and regulatory support. If funds are successfully pooled, there is a separate challenge around budget holders' control over access to services. Costs may not go down but comparative research shows this is sometimes for positive reasons – in that areas of unmet need begin to be addressed. In relation to transitions, part of the key is likely to be having shared priorities and principles. There is a growing literature on integration including comparative international research (20).

Policy context – Self-Directed Support and ‘co-production’

The Social Care (Self-Directed Support) (Scotland) Act 2013 has provided a potential vehicle by means of which individuals and families can make their own decisions about their own care and services. The ALLIANCE study does not attempt to evaluate implementation of Self-Directed Support, but diversity of practice is evident in the study and some contextual comment is necessary.

There has been considerable national and local investment in social work Self-Directed Support training. Implementation practice appears to vary across the country, across the study area and even within teams. The application of eligibility criteria and the scarcity or inaccessibility of some key resources in relation to day care and respite for those with the most complex needs does impinge on the realisation of true informed choice in some situations. The need for children and families social workers to develop awareness of Self-Directed Support is gradually being addressed across the country. Appreciation of the PANEL Principles,

(Participation; Accountability; Non-discrimination, Empowerment and Legality), reinforced by guidance on the 2013 Act, are crux to real partnership in transition.

By exploring transitional journeys for individuals and families, this study sheds light on the experience of partnership between participant services and families. The potential sea-change in social care practice that might be realised by Self-Directed Support depends on commitment to 'co-production'. This is a term promoted and explored in many social care settings in Scotland (21).

“Co-production describes a relationship between service provider and service user that draws on the knowledge, ability and resources of both to develop solutions to issues that are claimed to be successful, sustainable and cost-effective, changing the balance of power from the professional towards the service user.” (22)

The Christie Commission report on the future delivery of public services encourages a focus on the assets of both individuals and communities to create more effective services, where the people using it are equal partners. (23)

Young people have a direct contribution to make to service improvement. This was realised, for example in the early consultation about and development of the GIRFEC approach by Scottish Government, through a partnership with Young Scot; in the work of the Children's Commissioner; and in a range of projects since, such as *Agents of Change* (24). Begun in 2013, Agents of Change was a co-design project, supported by the Scottish Government, which aimed to empower disabled young people from across Scotland to explore ways in which they could influence, inform and participate in local service delivery and have their say on decision-making processes within their local area, particularly when making the transition to adulthood. During the period of the ALLIANCE study, the Scottish Health Council has commissioned a scoping exercise of the rationale, appeal and feasibility of the establishment of a pan-Scotland collaborative approach to young people's participation in the planning and delivery of health and social care services (22). At local partnership level strategic challenges relating to transitions between services present an opportunity to attend to the experience of those most affected – young people and their families. This study is a small strand of this intent.

Policy context - care for the carers

The Carers (Scotland) Act 2016 has deep implications for local partnership responsibilities towards those providing care to disabled young people and young adults. This includes parents and kinship carers, many of whom are already at full stretch as their young adult loses access to levels of respite and daytime support upon which they have relied.

The Bill for this Act of the Scottish Parliament was passed by the Parliament on 4 February 2016 and received Royal Assent on 9th March 2016. It will be commenced in 2017-18. The package of provisions in the Act is designed to support carers' health and wellbeing. These include, amongst other things: a duty on local authorities to provide support to carers, based on the carer's identified needs which

meet the local eligibility criteria. National matters which local authorities must have regard to when setting their local eligibility criteria will be set out in regulations. This will include a specific Adult Carer Support Plan; a Young Carer Statement to identify carers' needs and personal outcomes; and a requirement for each local authority to have its own information and advice service for carers. This must provide information and advice on, amongst other things, emergency and future care planning, advocacy, income maximisation and carers' rights.

The 2016 Act contributes to the Scottish Government's vision of a healthier and fairer Scotland, and sits within the wider policy landscape including: integration of Health and Social Care; GP contract; National Clinical Strategy; new social security powers; and Fair Work agenda. The '*personal outcomes approach*' proposed in the Act is developed in the comprehensive guide, *Talking Points: Personal Outcomes Approach* (25). This guidance underlines that personal outcomes should be identified through listening to people using services during assessment and support planning. Outcomes should be reviewed, to ensure the continued relevance of support planning and commissioning of services.

Policy context - bridging health transitions:

In this study there has generally been a highly positive family and individual experience of paediatric health services. There is often loss and fear around for families who feel as though they are losing part of an extended family within paediatric services.

Every professional consulted in this study has been sharply aware of the implications of structural and resource challenges within their own context; and awareness of instances when communication and handover has not worked well for individuals and families. There have also been multiple examples of persistently expert and person/patient centred planning and creative initiative.

There is also a variety of systematic research ongoing exploring potential improvement. For example, Professor Michael Brown, NHS Lothian/Edinburgh Napier University who has written extensively on improving general hospital care for people with learning disabilities, is leading a Scotland-wide Study in 2017. This research will examine health transitions from paediatric to adult health services for people with complex intellectual disabilities, focussing specifically on the role of the nurse. It aims to identify examples of good practice that will be used to develop an educational resource for NHS Education for Scotland (NES) (26)

The ALLIANCE study has offered opportunity to hear about a range of approaches and efforts to bridge structural divides between services and ease the path of the patient. It is beyond the scope of this study to detour in to mapping of these pathways or approaches, although some professional perspectives relevant to the study are presented later in this report.

Amongst the engines supporting standards and improvement, the role of the National Managed Clinical Network should be recognised (27). The Network for Children with Exceptional Healthcare Needs (28) defines the following transitional outcome:

“Outcome: All children with exceptional health care needs have an individual Child's Plan that includes plans for transition to adult services.

Measure: all children with exceptional health care needs have an individualised Child's Plan with actions, outcomes, timescales and responsibility recorded and allocated Named Person and Lead Professional. The Child's/young Person's Plan includes transition planning from 14 upwards”

This crucial network started in March 2009 with the aim of strengthening specialist services for children with complex and exceptional healthcare needs in Scotland. Parents, carers, voluntary sector organisations and professionals are invited to join the network and attend working group meetings and events. There are currently over 1500 people involved in the network.

The current and potential role of Healthcare Improvement Scotland (HIS) (29) in supporting positive transitions should also be recognised. HIS was set up by the Public Services Reform (Scotland) Act 2010 and took over the functions of NHS Quality Improvement Scotland and the regulatory functions of the Care Commission in relation to independent healthcare services. The HealthCare Improvement Scotland work programme supports Scottish Government priorities, in particular the HealthCare Quality Strategy for NHS Scotland. HIS develops evidence-based advice, guidance and standards for effective clinical practice; driving and supporting initiative and improvement in healthcare practice.

Some specific roles and initiatives have shown evidence of strong dividends within the ALLIANCE study. For example there has been extremely positive feedback on the role and practice of a NHS transitions coordinator for young people with exceptional health care needs, reflective of the requisite knowledge, skills and values in a well-constructed bridging role. There are implications arising from the apparent success of this role.

This study acknowledges the expertise and flexibility within the third sector in providing transitional bridges in health and social care services. There are many positive examples within this report. For example, the value of organisations such as PAMIS (30) and Kindred (31) have been highlighted during the ALLIANCE study. PAMIS provides training and support for family carers nationwide; a library of resources and publications (such as Bereavement and Loss Learning Resource Pack and DVDs) and links helpful in relation to those with Profound and Multiple Learning Disabilities. Parents and professionals within the ALLIANCE study area have been interested in their Innovative work on Digital Passports, a vehicle that fits the ethos of person centred and co-produced services and plans. Kindred's advocacy and support has been appreciated by many participants.

During the period of this study there has been a scoping exercise on behalf of the Disabled Children and Young People Advisory Group (DCYPAG) for education and training of those professionals working with children and young people with complex

needs and disabilities (32). There will be some suggestions about generic training about supporting good transitions, emerging from themes arising from this study.

Mental Health Strategy

The Scottish Government published its Mental Health Strategy 2017-2027 and this is of direct relevance to the needs of some individuals within this report (33). Action 21 is to *'Improve quality of anticipatory care planning approaches for children and young people leaving the mental health system entirely, and for children and young people transitioning from CAMHS to Adult Mental Health Services.'*

Context – Inequalities

The geographical area covered by the Alliance study is diverse but care has been taken to avoid pin pointing participant locations. Access and opportunity to support and resource is not equal. There are distinct patterns in the way local networks of support evolve and expectations of services evolve. By way of general context it should be acknowledged that poverty rates in Scotland are higher for households with a disabled adult, with 23% of families with a disabled adult in poverty in 2014/15, compared to 16% of those without (34,35). Disabled Citizens Advice Bureau clients have reported being forced to use disability benefits to 'plug gaps' due to low income from other sources.

Benefits reform brings risks for young people in transition at this juncture (36). For example, the Disability Benefits Consortium (DBC) (37), which is a coalition of 80 different disability charities working towards a fair benefits system, have flagged concerns that the Personal Independence Payment (PIP) criteria are already too strict, and that this has led to almost 50% of disabled people and people with long-term conditions losing access to some or all of their support when being reassessed from Disability Living Allowance. Scottish Government have committed to sustaining DLA at age 16 to age 18.

This study takes place against a backdrop of review of welfare benefits in Scotland. Those with whom the ALLIANCE study is concerned will be affected and concerned about the complexity of survival amid changing systems has been a feature. Those entitled to benefits and those supporting claimants require protection of rights, access to advocacy, accessible information and support through complex processes.

Policy intent addressing disabilities and equalities are set out by Scottish Government in *"A Fairer Scotland for Disabled People - Our Delivery Plan to 2021 for the United Nations Convention on the Rights of Persons with Disabilities"* and this includes supporting transitions. A national Framework to Support Children, Young People and their Families will be produced and implemented to improve the outcomes of young disabled people and ensure they are getting the best provision and support possible. The ALLIANCE study is one of many ways in which individual and family voices can influence the Scottish Government Framework for delivery on this plan.

3. Methods and Meanings

This section of the report outlines how the study was progressed; the ways in which participants contributed; and the meanings and uses of terms such as lead professional, wellbeing and mental wellbeing.

Primary sources:

The foundation of this report is direct discussion with participant families and with key professionals and managers of relevant services. Care has been taken not to identify specific persons and situations and some potentially identifying details are altered or removed from some summary extracts in this report.

Process of service support and monitoring

Initial support and agreement was given by the Lothian and Borders GIRFEC Implementation Group, chaired by the Associate Director & Child Health Commissioner, Strategic Planning, Performance Reporting & Information NHS Lothian.

Presentation of study parameters, intent and methods was made to the Edinburgh Children's Partnership. One suggestion arising from this presentation was that the study should be larger than the original intention taking in to account the diversity of experiences and challenges. Although academic advice was that meaningful data could be derived from the original sample in a study of this kind (8-12 families), Edinburgh Children's Partnership comment has been heeded and participant family numbers have been trebled (to 30) .

A detailed research access application was submitted and accepted by City of Edinburgh. Other areas required individual meetings with strategic managers or group of managers before proceeding. Access to local authority staff was supported in 4 of 5 local authority areas. However participant families have come forward from throughout the study area and information about practice issues, procedures and policies have been provided by all 5 local authority areas. Parents and kinship carers from beyond the study area have heard about this study and offered comparative information about themes arising in their own networks.

Following outline of the study parameters, methods and intentions, Lothian NHS Ethics Scientific Officer advised that the study could proceed without presentation at NHS Ethics Committee in that participant sampling has not proceeded through NHS routes. Health practitioner views about generic themes in transitional processes has been invaluable throughout the study but their perspectives on specific patient pathways has not been sought.

Regular feedback on all aspects of process and progress, from initiation to conclusion has been provided to the accountable officers within the Health and Social Care Alliance and to Scottish Government. A formal half way monitoring report was presented to both. The Lothian and Borders GIRFEC Implementation Group has been informed of progress and advice and support provided by the national GIRFEC Third Sector Advisory Group, ARC Scotland/Scottish Transitions Forum, and academic and professional critical advisors as listed in the Appendix.

Within City of Edinburgh a structured meeting was convened with senior staff across sectors in December 2016 to review and comment upon a report on study progress and relevance to systems and practice issues in Edinburgh and similar meetings have been offered in other areas.

In February 2017 a half day Transitions Seminar was set up under the auspices of University of Edinburgh School of Social and Political Science to allow a sharing of emerging themes with parents, practitioners, senior managers and academics. The Seminar offered opportunity for debate on connections between the Alliance Transitions study, Principles of Good Transitions 3, the National Transitions Mapping study and comparative research in 3 European countries focussing on the experience of parents and families supporting post school transitions for young people with Asperger's, ADHD and Tourette's syndrome. In short the process of agreement, support, consultation and advisory feedback has been continuous and incremental.

Participation by individuals and families

Participant individuals and families are self-selecting, having had information about the study from professionals – primarily specialist transitions social workers, third sector key workers, and transitions co-ordinators. Some families heard about the study within their own networks and felt encouraged to take part. There was a positive response from a carer bulletin in one zone of the study area.

When social workers or key workers have let potential participant families know about the study verbally rather than by an email, this has often led to a positive interest.

Consent was sought in writing from individuals, parents, carers and where relevant, local authority welfare guardians in each case. In some situations, there have been limitations about what individuals have wanted shared in the report, relative to what they shared with the researcher in account of their journeys. This has been respected by means of summarising generic themes that the individuals have been content to convey.

Self-selection may lead to a slant away from those who are not well engaged with services; or who feel too strained by circumstances to contribute. It might also lead to a slant towards those that are highly concerned about services and who are able to be articulate and assertive in relation to their concerns. This does not reduce the value of their message. However the views of professionals from a variety of housing support and homelessness support agencies have underlined an awareness that the data in this study derives from those who are able to engage. There are many who

need persistent support in transitional phases who find services less accessible or comprehensible. Some of the suggestions arising from the study relate to these people.

Dimensions of transition

Family experiences of transitions are “layered”. The moves to adult services are just one aspect of transitions to adult years. There are other health, social, psychological and relational changes occurring (38). These strands of change continue to interact in peaks and troughs, long after transitions to adult services have taken place. The needs of adult children may become more complex. Energies of key family carers on whom their lives depend may wane. Professional definitions of transition to adult services and adult life are inadequate if they do not take in to account the evolving connections between an individual and those to whom they are closest. In this study for example, carers and family members have had their own changing support needs, other responsibilities, other stresses and losses impacting on their potential to provide care. The needs of siblings and the development of their relationships and involvement with each individual have also been diverse and significant.

Motivation of participating families

Transition is a term covering a broad landscape. There are a thousand windows on to that landscape and each participant and professional comes forward to give their view from their own vantage point, with their own focus. There is inevitably a lens through which the transitions landscape is seen by each of us. This is affected by what we have seen and experienced already and also by what we may be ‘looking for’. The table below provides indication of the emotional context of participant narratives.

The table summarises feelings and motivations commonly expressed by parents and carers coming forward to take part in the study. There has often been a fine balance between generosity and stress; between a wish to share experiences that will help others in future and a wish to share what transitional processes have meant to them in the past.

The summary is an introduction to some of the specific themes identified by each participant in section 4 of this report. A similar summary is provided in relation to the subjectivity of professional perspectives.

Balance and range of motivations and contextual stresses from contributing parents and carers:

Attitudes and motivations in contributing to study	Stresses and experiences preceding participation in study
Dignity and balance	Anger and frustration
Love and commitment within family	Too disturbed about transition to relate detail
Endurance and courage	Afraid for child's future, for own health
Creativity, originality and humour	Exhaustion and isolation
Wish to take part for sake of others	Grief and anticipated loss
Determination to work together	Uncertainty and isolation
Expertise in their situation	All relationships stressed

Home base and circumstances

Participants have come from a wide range of home base and circumstance including:

- History of foster care
- History of residential care or currently in residential care
- Adopted
- Experience of being Looked After and Accommodated
- Low income v well resourced
- Kinship care
- Supported accommodation
- One parent families, two parents, no siblings, multiple siblings
- Isolated v socially integrated

The participants include parents who are single and socially isolated or in partnerships and equally isolated; or single or in partnership and seeming socially well supported, and yet in many ways isolated within transitional experiences.

Processes

After initial meetings, in most situations follow-up contact is offered with participants. Depending on each situation there may be multiple meetings within the network of each participant and in other situations, due to circumstances including ill health and bereavement, just one meeting.

There are a variety of ways in which views may be expressed and shared. Where individuals are able to talk about their feelings about transitions their impressions are gathered in semi-structured conversation. There have been options to use questionnaires and charts, pictures and talking mats and all these have been used at some point when individuals have been capable and interested to do so.

Some young people/young adults have preferred to speak alone and others have chosen to be accompanied by carers or parents. Some parents have preferred to give their perspective alone in a neutral setting and others have offered to meet in stages – as individuals, as a couple and with the whole family together to give a comprehensive impression and discussion. In some situations due to illness or choice, meetings have been with parents alone.

Summaries have been sent after each home visit to allow participants to correct or supplement the account. It has been reassuring that this process has led to detailed additions and corrections, suggestions and comments in many cases. Key themes from each process have been summarised at the end of the study period and these are being relayed back to participants (April 2017) with opportunity for confirmation, change, further discussion or withdrawal.

The study has been reliant on parents and carers perspectives for those whose disabilities leave them unable to voice their views on change although when permissions have been given, individuals have been met with their families. Views from siblings have been gathered from brothers and sisters between ages 7-25. A range of relevant professionals and agencies have been consulted in relation to the transitions of participants, when consent has been received to do so.

Consultation with professionals

The views and analysis of a wide range of services, professionals, managers and groups have also been sought and their most recent procedures, policy documents and practice guidance have been reviewed. The range of professionals and services consulted is listed in the appendix but in summary, this has included

- Personal carers
- Day services
- Social work strategic leads, team managers, specialist social workers
- Special schools
- Residential schools
- Networking services, Advocacy services, Advisory services
- Third sector providers of care packages

- Community learning disability nurses
- Hospital based specialist nursing staff – paediatric, transitions co-ordinators, adult specialists for epilepsy, spina bifida, hydrocephalus and cystic fibrosis
- CAMHS, paediatric and adult mental health services, toxicology and acute health care
- Children's disability team social workers; adult health and social care transitions social workers; social work managers
- Supported accommodation, Homeless services
- Academics and policy leads in relation to children's services and transitions

Motivations of participating professionals

Professionals have also expressed a combination of feeling and motivations in their engagement with the study. The table below provides indication of the balance of themes within these expressions of concerns and motivations.

Constructive approach to study	Stress in engagement
Deep personal commitment to support individuals and families through change	Frustration at being asked to reflect on well-known issues and doubts about timing and practical purpose of research
Determination to improve systems and improve pathways both from the front line or strategic leadership positions	Awareness of family stress and distress; and concern that research is an avoidable stress
Demonstration of person centred, effective, creative work and long developed expertise in disabilities and transitions	Tensions between outcomes based/person centred ethos and budget limitations
Resilience supported by good teamwork and inter agency communication	Awareness of inequities
Wish to take part for sake of others	Personal impact of family and individual losses
Determination to work together with other agencies	Anxiety at time of structural change and rising expectations

A learning attitude	Overload reducing capacity to adapt beyond core tasks
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Exploration of GIRFEC principles and core components:

Section 4 below summarises experiences of individuals and families. They have all been asked about their experience of co-ordination of planning; about their awareness of the lead professional approach; and of their experience of planning that relates to all aspects of wellbeing.

Lead Professional

Lead Professional has a variety of connotations to professionals and families. Scottish Government guidance (39) states that when it has been agreed that a Child's Plan should be prepared there should be a Lead Professional to make sure that the Plan is co-ordinated. They should make sure that the child and their parent(s) understand what is happening at each point so that they can be involved in the decisions that affect them and ensure the Plan is accurate, up-to-date, implemented and reviewed regularly. The Lead Professional should be a practitioner who is chosen because they have the right skills and experience to ensure the Plan is managed properly, and who can work with all those who support the young person. The ALLIANCE have produced an Easy-Read description of the Lead Professional Role. (40)

Wellbeing needs and outcomes

The meaning and use of the term 'wellbeing' is significant for the purposes of this study. The GIRFEC approach has the potential to ensure that the needs and rights of each child are central to assessment and planning. The approach promotes consideration of planning by families and services that is holistic and integrated. The wellbeing ('SHANARRI') indicators are interdependent. This is recognised in assessment and planning frameworks and meetings that support exploration, not only of needs in relation to safety, health and nurture but also connected needs and aspirations in relation to activity, achievement, respect, responsibility and inclusion. The indicators are more likely to be useful in practice if they have meaning to young people, young adults and their families.

For this reason an example of a set of outcomes associated with each indicator is provided below, using wording that has formed part of conversations with some participants in this study. This table has been adapted from Professors Bob Stradling and Morag McNeil's evaluation of the GIRFEC Highland Pathfinder. (41) Wellbeing outcomes will vary for each individual according to complexity of need age, stage and level of comprehension. The wellbeing headings can support professionals to

think about needs, experience and aspirations for each individual from each individual's perspective.

Transitions are not just about change in services. They are about adaptation to change, not only in services, but also in the evolving individual, in the context of their world and relationships.

SHANARRI Indicator	Examples
SAFE	<ul style="list-style-type: none"> • I feel safe at home/where I live • I know who to turn to for help if I need it • I feel safe with wider family and friends • I know how some people or activities may be a risk to me, including on the internet • I have had help if I needed it about my own behaviour – for example if I am putting myself or others at risk • I feel safe from bullying
HEALTHY	<ul style="list-style-type: none"> • I feel positive/good about myself • I have the support I need to manage my health conditions from family/carer • I know who I can talk to about my health and feelings • I have a healthy lifestyle and have guidance/information I need about this • I have good advice about health risks for me • I have the support I need to manage my health conditions from services
ACHIEVING	<ul style="list-style-type: none"> • I have help to learn to be as independent as I can be • If I need help with communication or other skills, I know who to ask • I am encouraged to achieve my own aims • I have ways of managing my own challenges and have help when needed • I am gaining confidence in relationships outside my close family and friends • I feel able to try new activities and explore new places with help if needed
NURTURED	<ul style="list-style-type: none"> • I experience warmth from those closest to me • I can keep in good touch with those who are important to me but don't live with me • I have the care in a home base where I feel comfortable • I usually feel safe at home/where I live • I have privacy/quiet space if need it and can be with people who are close to me if I need to be • I have food that I like and that is good for me
ACTIVE	<ul style="list-style-type: none"> • I have physical active interests and help to enjoy them if needed • I have chances to try new activities with extra help if needed • I have guidance and help so I can take part in activities safely • I am growing in my skills with my activities

	<ul style="list-style-type: none"> • I am making friendships through activities
RESPECTED	<ul style="list-style-type: none"> • I am listened to about my needs and feelings • I am supported in coming to my own decisions • I take a leading part in making my own plans • I can help others around me • My thoughts and experience are valued by others • I am treated as a person – as me. People respect what I am able to be
RESPONSIBLE	<ul style="list-style-type: none"> • I usually know right from wrong • I try to 'keep to the rules' and have help if I struggle with this at home or in the community • I am caring towards others and try to understand how they feel • I have support learning to manage situations that could be risky for me or for others • I can take part in helping others at home or beyond home • If I have done something wrong or upsetting to others I try to learn from this
INCLUDED	<ul style="list-style-type: none"> • I feel an accepted part of my close family • I feel accepted and involved with my friends • I feel accepted and a part of my work/college/club • I have support to take a part in activities, work and study • I have help I need to manage/overcome any challenges in taking part in community activities • I enjoy taking part in activities and groups with others

Mental health and wellbeing

The GIRFEC Model is congruent with and potentially supportive of national policy development in mental health. This was explicit at the launch of the Mental Health Indicators for Children and Young People 2011 NHS (Scotland) (42) (43). These Mental Health Indicators were developed to assist in tracking changes in mental health and wellbeing of children and young people in Scotland. The Indicators cover dimensions of mental wellbeing as well as mental health problems. The measureable, contributing influences upon mental wellbeing and mental health problems are identified as shown in the table below, headed 'contextual constructs'. The development of the indicators (44) included independent study of young people's views. This development followed a similarly comprehensive process to that for an adult mental health indicator set. This is useful background for studies of transitions in Scotland, not only because of the connections between mental health policy and mental health trends in Scotland, but also because of explicit recognition of the multi-dimensional personal and environmental relationships that contribute to mental wellbeing and mental health problems.

High-level Constructs				
Mental Wellbeing			Mental Health Problems	
Contextual Constructs				
Individual	Family	Learning Environment	Community	Structural
Learning and development	Family relations	Engagement with Learning	Participation	Equality
Healthy Living	Family structure	Peer and friend relationships	Social Networks	Social Inclusion
General Health	Parental healthy living	Educational Environment	Social Support	Discrimination
Spirituality	Parental Health	Pressures and expectations	Trust	Physical environment
Emotional Intelligence			Safety	Violence
Life Events				Culture

The Mental Health Indicator sets can provide bird's eye information about 'what is going on' in the population. The GIRFEC approach and wellbeing indicators have the potential to bring a holistic understanding to bear on the ground in a practical way in each situation. The need to take account of the multi-dimensional influences on wellbeing is common to both frameworks. Both frameworks prompt an ecological understanding of the wellbeing and transition of each individual, meaning an understanding that recognises different levels of environmental influence and relationship upon good outcomes for the individual.

This is sharply relevant to phases of transition to adult years and services. These connections become apparent in the examples below in section 4 of this report; and prompts suggestions in section 6 and the concluding section of this report about pre-qualifying training for professionals e.g. in social work, nursing and housing that could connect dimensions of health and wellbeing with principles of inter-agency work and development of community support for good transition.

4. Introduction to Examples

Families often talk in terms of 'bridges' and 'cliffs', although the experience of the journey is distinct from each perspective. The balance of anxiety and excitement may be very different for the young person and for parents. This next section attempts to reduce aspects of these journeys to headline themes and tensions in terms of what has been helpful or unhelpful for individuals and their families – 'bridges' and 'cliffs'. The cliffs relating to loss of school, health and other childhood services are clearly described. However, sometimes the hardest changes are in terms of family adjustment. There is always more than one river to cross and more than one way to reach the other side. Teamwork or partnership is usually essential. Names, initials, location and other identifiers have been removed or changed to preserve anonymity and many of the twist and turns in transitional processes have been subtracted to sidestep possible identification. However it seems necessary to retain the distinctive themes in each case because there have been significant variations in pathway, focus and aspiration.

The summaries identify the extent to which families have experienced co-ordination in transition planning.



(image credit: google images)

EXAMPLE A

This transitional process belongs to a young adult who is blind, quadriplegic, and profoundly brain damaged. Home base is with parents with and a supporting rota of personal support workers. The young adult has frequent painful muscle spasms and is non-verbal, depending on gastric tube for nourishment. However he is very expressive and responsive to emotional atmosphere (affection, sadness, excitement) and the environment – sensitive to sound, demonstrates ability in music. He is responsive to light, birdsong, familiar voices and touch. A comprehensive and sustainable plan of care has been negotiated and co-ordinated by parents, addressing all aspects of this health and well-being. It has taken a prolonged and conflicted journey over several years to achieve this. If it had not been for their forward planning, networking, expertise about specific needs, endurance and commitment to achieving the best possible plan, it is likely that the quality of the young adult's activities and relationships would have been compromised or at least, very different.

To an outsider's perspective it appears that a consistent, co-ordinating professional before, during and after key transitions could have reduced many anxieties in these processes. However it is not possible to do justice to the many ups and downs and perspectives here.

Bridges	Cliffs
Family endurance and determination that son lives as safe, secure, stimulating, happy and healthy life as possible	Apparently disintegrated professional understanding of care and support to fulfil activities timetable. Lack of recognition of two staff needed for total package.
High quality of co-ordinated services at special school	Obscurity and dispute about budget calculation. Family experience gaps in understanding of care implications of complex interacting conditions.
Parental co-ordination of services and daily activities, resources and recruitment of personal support workers	Lack of single point of contact once at home and understanding in long term future– “He’s transitioned – case closed.” Lack of follow-up integrated within plan.
Young man’s nature- expressive, engaging, sensitive, creative	Uncertainty, Fear of future – “ will have to fight all over again when package is due for review”
Self-Directed Support budget granted, negotiation eventually took place	Self-Directed Support funding still does not meet all assessed outcomes. Stress affecting parental health
Good NHS handover to adult services “a very strong NHS transition locally - really a complete success”	Communication with local authority tense about school leaving and funding, respite, assessment, budget rationale, forward planning. Phases of non-response

EXAMPLE B

This summary belongs to an engaging, spontaneous, biddable and articulate young person aged 19 years who is physically fit, mobile and able and lives at home with parent and siblings. Young person is affected by Asperger's and late onset epilepsy. Family have had a positive experience of professional communication, co-ordination, advice and support leading up to and beyond the transition from school and sustained, personable and knowledgeable involvement from a social worker in adult services.

Bridges	Cliffs
Secure and affectionate family support and home relationships	<i>"A long road but not necessarily a cliff. Promotion of transition as a time of threat can sometimes raise anxieties and cloud the resourcefulness of families."</i>
Good support, relationships and skills of staff at school to age 17. Work experience arranged from school.	<i>"Bubble of personal relationship with school and health services collapses". Realistic about pressures in adult services. Await transition to adult specialist epilepsy services</i>
Good range of daytime activities for now through Autism Network Scotland (1) Number 6: One-Stop Shop (providing free social opportunities and 1-1 advice and support on a range of issues); Outreach (funded packages of 1-1 support); and Housing. (2)	College underestimated support needed Developmental progress slow and many key boundaries and guidance need to be patiently and consistently repeated. Difficulty responding to young person's enthusiasm with realism.
Opportunities for information sharing and information sessions from e.g. Kindred about Transition. Timely information on Guardianship	Need for future plan to include support in learning about personal boundaries and relationships
Sustained and sufficient involvement from adult services social worker, with timely advice, co-ordination if needed and understanding of whole family	Long road ahead – many transitions to adult life, work, relationship and supported independence are only just beginning. <i>I want support to get a volunteer job!</i>

EXAMPLE C

This transitional process belongs to B, a young man aged 20, living with parents and siblings. He is affected by severe autism and learning disabilities. He has additional neurological problems affecting mobility. The thresholds for initial involvement from social work felt very high to the family. The co-ordination of care and services has been led by parents.

Bridges	Cliffs
Affectionate, stable home life with 'well' siblings and parents; and some extended family support	Late recognition of autism interacting with mental health conditions.
Intensive Behaviour Support Service -practical, skilled, short term assessment support and guidance at home	Instability in school – frequent class changes added to anxiety. Would have benefited from longer in school Sudden and prolonged deterioration aged 15 – aggression, anxiety, depression
Transitions social worker was pragmatic and detailed talking through plan. Parents have been able to co-ordinate the plan. SDS budget adjusted – adequate	Delayed social work response. Repeated calls to social work during crises – no reaction till there was a physical accident in the home Lack of continuity with social worker
Extended commitment of psychiatrist and psychologist from paediatric services – delayed transition to adult services	Hunt for information: Internet hunt for suitable resources and carers – lack of guidance and advice – no single integrated plan
Consistent team of 6 personal carers and driver found by parents	Complexity of managing personal care team under SDS – “needs the skills of running a small business”
Flexible college skills programme followed by creative tailored day programme	Other family members needing close support

EXAMPLE D

This summary of themes belongs to a young adult with severe autism and learning disabilities. He is living with parents and has a structured daytime programme in 2 services. The family have pieced together their own plan over the last 12 years and continue to do so.

Bridges	Cliffs
Stable and reliable core family relationships with practical resource e.g. flexible working hours of one parent	Lack of information. Family have been invisible to social work services between ages 5-17
Informal parent network provides ideas about comparative resources Young adult beginning to branch out in new social activities and have ideas about work activity	Lack of advice till age 17 on complex benefits, funding paperwork, guardianship
Transitions social worker allocated briefly to young person at age 17.5. Ceased involvement age 18. Social worker was helpful - outlines SDS processes and some resource options.	No holistic assessment during school years and ongoing lack of appreciation of complexity of care needs. <i>'We would have valued a single plan and lead professional approach'</i>
Local resources – choices available for young person : Accessible and suitable range of day programme options	Respite provision ceases as budget allocated absorbed by cost of day services and transport

Parent's comment on second meeting:

"If we had not been assertive we might have gone along with the post school option which was first presented. This would not have worked well for our son. Some parents might want advocacy or guidance in such processes. Thistle were helpful for us in one stage by offering a mediating and advisory role at times. Other parents encouraged us to explore the options; and we tried different services which have worked well for our son. This has been funded with a Self-Directed Support budget and hopefully similar funding will be available after annual review "

"If my employers had not allowed me to work flexible hours, the plan would not work. There is an assessment going on now by a new social worker because we are seeking Guardianship. Essentially we have managed alone throughout school years. It would have been good to have a known point of contact, even for a yearly discussion about options, but perhaps this is unrealistic if families are just about coping."

“Local information and guidance for parents could be improved – and someone to talk through what different services do... and help with planning or networking of needed. It would be helpful to have a sort of Tripadvisor website for families.

At this stage we are beginning to think ahead to supported accommodation when there comes a time that we cannot care for our son. We don't know what's possible. There is no hurry but it is not sufficient to be given a leaflet or a website. Ideally we need someone who could be alongside in crucial stages and knows our family as we find out about possibilities and work towards them. It is not enough that our son is occupied and has somewhere to do during the day. We want him to be well, happy and able to fulfil his potential. That means thinking beyond safety, care and the immediate 'package'. We need to think about what he could learn to do in future”

EXAMPLE E

These transitional themes belong to a young woman living at home with her parents. She is 18, has a severe form of epilepsy; some difficulties with speech, comprehension, mobility and self-care. There has been a positive experience of a lead professional in terms of co-ordination, communication, advice appreciation of family and individual wellbeing.

Bridges	Cliffs
Family stability: love, reliability and resilience + young person's positive, open appreciative nature	Fears for loss of transitions worker Fears for loss of paediatric health services
Transitions social worker – good advice, communication, teamwork	Paperwork , delay and frustration with benefits paperwork (ESA)(3)
Neurologist and consultant nurse specialist at RHSC -praise for expertise and communication	Need to plan well ahead: e.g. for review of guardianship
Personal carers team recruited in partnership by Thistle (4) within budget – college skills course, third sector day service and Community Network.	Support about personal relationships for young adult
Occasional one night respite for parents and opportunity for supported independent experience for young adult	
Neighbourhood Network (5) , developing independence and friendships	

EXAMPLE F

These transition themes belong to a young adult living at home with parents, affected by Asperger's and phases of high anxiety and withdrawal. There has not been experience of a lead professional approach.

As one parent summarised:

"I did not expect to have to develop the expertise to support such a wide range of professionals in the discharge of their respective roles. From accessing education to suggesting appropriate medication, the family has been virtually the only source of proactive, practical and aspirational support for my autistic teenager."

Bridges	Cliffs
Highly intelligent young woman with loving, reliable close family relationships	Delayed recognition of autism in secondary school. High anxiety, depression and withdrawal from school.
Creativity of family in finding appropriate schooling and exploring options beyond school, networking with other agencies	Lack of single known point of contact with social services. Brief assessment contact with social work
Brief support from specialist autism support worker – informative, helpful GP recognises impact of interacting conditions	Lack of advice on practical strategies when needed in relation to health (e.g. dietary), ongoing learning opportunities and social steps forward. Delay in GP recognising short term treatment opportunities. Scope for greater awareness of treatment and therapies available

Feedback from young adult and parents on the summary above: *"It does not capture the IMPACT of the "cliffs" very well.....cliffs contribute to educational and social exclusion. In practice there was loss of educational entitlement because formal education ended at age 15 without qualifications."*

EXAMPLE G

These transitional themes belong to a young man with previously life threatening epilepsy. He is highly motivated and independent of spirit. He is likely to remain living with support of parents with siblings in his foreseeable future. There has not been experience of a lead professional, single plan approach.

Bridges	Cliffs
Close family support , grandparents also strong role model	Managing mood swings - anger and low mood
Courage and determination of young man – active lifestyle and work aspirations – volunteer work in progress	Adjustment in peer relationships and losses of some relationships
Skill of surgeon 8 years ago and positive continuous follow up from neurology in children's services	No prospect of follow up from adult mental health services after discharge from CAMHS , no transition support
achievement in sporting activity and lessons through sporting discipline, coaching, goals, positive thinking	No single point of contact for information and advice/ no social work involvement
combined support from family, education , health services and third sector for self-awareness and self-management	18 months in hospital aged 13-14 – continuing emotional adjustment to near loss of life
guidance teacher - Memories of positive support	Continuing adjustment to future expectations
Contribution to youth group at Epilepsy Scotland – proactive youth worker (6) adult specialist epilepsy nurse - proactive engagement and advice	

EXAMPLE H

R is now 21. She speaks with great clarity about how epilepsy shook her life and confidence just as life was opening out in college years. Transitional processes are ongoing as she rebuilds a sense of her own potential and learns to manage the anxieties accelerated by the condition.

There has not been a lead professional approach in this situation. Those who do not have the need for complex packages of co-ordinated care may never the less be severely handicapped and isolated by their conditions during transitional phases. Third sector organisations sometimes meet the need for connection, information and encouragement. From a professional / services point of view in this case, there was no co-ordinated plan about Transitional processes for R. Essentially the family found their own way through, sought the services they needed and thoroughly appreciated the personal engagement, knowledge and understanding of Epilepsy Scotland who were for a while a necessary light in a dark time.

Bridges	Cliffs
Family stability , calmness and understanding. Energetic and positive attitude to problems, interests and possibilities	Shock and loss from onset of condition; compounded by practical loss of work, college place, friendships, normal opportunities
Expert support from health professionals, psychologists in paediatric services	Loss of confidence, sense of isolation , overwhelming anxiety about going out. Prolonged period of isolation
Practical family strategies. Gran came in to keep her company when mum and dad were at work; extended family are good listeners. Alarm system installed reassures R that help could be quickly on hand if she was alone.	Parents also feel isolated in transitional gap in services “ <i>We were left struggling to cope</i> ”.
Young person’s nature is open, direct, curious, with ideas and hopes that take her imagination beyond the house	Interaction between mental and emotional health and other conditions. R feels high anxiety (or high excitement or unusual tiredness) can trigger to fitting.
Parents and young adult praise Epilepsy Scotland for bridging the gap for outreach, acceptance, development of friendships, information. R is in turn supportive of others.	Some friends faded away (but the key friendships have remained)
Re-evaluation of medical treatment has made a crucial difference. Due to a new medication she has managed the last 11 months without a fit. She is thinking again about having the confidence to apply for work.	Family wish follow up and review after leaving paediatric services could have been quicker

EXAMPLE I

This summary belongs to an 18 year old, who lives at home with his mother, stepfather and younger sisters. He has cerebral palsy, which mainly affects his lower body. He has some degree of learning disability, autism and ADHD. He is quite mobile now but this could get more difficult.

"I knew something was not right when he was a baby but it was not till he was 2 ½ that he was diagnosed with the cerebral palsy. At 8 years old he was diagnosed with ADHD. At 13 he was diagnosed with autistic spectrum disorder. I had to press for answers and explanations at each stage. At each stage doctors were reluctant to give a diagnosis and they refused to test him for ADHD for years. They each said that his difficulties, "were just his way of communicating". I knew that there was something long term that was not right.

He needs pills for his ADHD and he knows they make a difference and knows to take them. They are necessary. I had no information about benefits from professionals. I heard about (eg) Disability Living Allowance from another parent when he was 10 years old. I have not had a benefits assessment from any professional. I do now get Carers Allowance.

I have managed without social workers for the first 16 years of his life. I had a visit from one at that stage because at school he made up a story about not being given breakfast, so I had a social worker out to check my fridge. They were shocked that I had not had assessments and support and since that time I have had great help from the council Transitions Team. I have Guardianship but it was late on that I heard about this – probably when he was 16." Parent

Bridges	Cliffs
Lively and chatty nature, responsive to encouragement	Delayed recognition of autism and of ADHD. Absence of assessment or support from health or social work in early school years
Close family, protective siblings, some extended family support	There was no assessment of what he needed or what mother needed as his carer when he was younger No 'transition plan' (until past school leaving age, when a transitions social worker was allocated).
<i>"The (local additional needs) school were great with him and they were great about communicating with me" – Parent. They let the young person stay on a year</i>	Young man's fear of change eg at school, of being away from home Needs a constant care worker for his own safety. No idea of danger - he cannot cross the road alone.

The day service have been great for friendships, tailored activities at Teens+ (7). Flexible and encouraging life skills course at Edinburgh College	<i>"GP does not really know him. His health was always dealt with through the RHSC, including prescriptions for his ADHD pills; and now we are about to have a first appointment with a doctor at the Astley Ainslie Hospital "</i>
Learning disability nurse has been helpful with repeat sessions on sex education, communication, relationships	Family anxieties about close friendships/relationships in future
	Anxious dependency on mother: <i>"I cannot see him every being able to live independently. He will remain at home with me. That is where he wants to be and that is where he belongs and that is fine with me while I am able to do it."</i>

EXAMPLE J (a)

This summary belongs to B, who is 16 years old and lives at home with parents and siblings. This is an example of well co-ordinated planning and early thinking about transitions to adult services; yet with some serious practical concerns ahead.

B has cerebral palsy affecting all four limbs and is fed by gastric tube. She has some visual impairment. The biggest challenge in terms of safe care is that she has needed to be ventilated since she was 9 years old. She needs a complex regimen of medication.

There are cycles in her physical status in that for weeks on end she will be very sleepy and then for weeks she may be sleepless, giggly and hyper.

Before the age of 9 she had many infections and became seriously ill frequently, fighting to breathe. Eventually during one emergency episode she was given a tracheostomy and following this surgery she was 18 months in hospital. 10 years ago young patients needing this procedure would have remained in hospital. Now is possible for children to be discharged home when there are caring family (and professional carers) trained not only in safe care with tracheostomy but trained specifically in relation to each child's needs.

The upside of the procedure has been that infections and emergency episodes have been very much reduced. The down side is that she needs 24 / 7 care and so to assist her parents there are 2 shifts of carers, between 7.30 and 4.45, dealing with school when school is open and between 8pm to 8am. Nobody comes in on weekends or between 4.45 and 8pm.

The changeover in staff can be problematic because handover processes at night when family are tired can be prolonged every time there is a change. Also there are times when new staff are not tuned in to something not being right. Tracheal granulation is an example of something that can cause serious obstruction to breathing and her mother knows instantly when this appears to be occurring. Someone new to her may not pick this up.

This means that family rarely have the home to themselves. It is an essential part of the balance that they have some time to themselves – not so much apart from B as to themselves 'as a family'. No professional carer can be left alone with B because of the complexities of caring for her. This means that even for a short visit to the shops, she would have to be dressed and fitted in to a wheelchair and taken with her mother. The option of two professional carers at home would not be funded.

The biggest concern about transition to adult services is that the formula for calculating respite will change and the number of nights that they get to themselves is likely to be 40-42 per year.

Even a small reduction makes a significant difference to the emotional and practical sustainability of this complex care at home equation. The standard advice is apparently that if the ecology of care for a young adult cannot sustained on 40 nights per year then the alternative is full time nursing care. Leaving on one side the comparative detriment to the emotional health and wellbeing of each patient, the financial cost of full time nursing or hospital care is clearly many times the cost of

maintaining the level of respite on offer to the patient as a child. Her health and care needs will not get any simpler as he gets older and as his parents get older. The allowances are NHS determined.

The choice available for respite is also unclear at this point. The place that has been available is shortly closing. This service has provided respite as well as nursing and healthcare to those with profound and multiple health needs. This option will shortly be closing. Hamish's parents have guardianship for him and progressed this quickly when he turned 16. There are annual reviews at the school involving a range of professionals and there is a composite plan congruent with Getting it Right for Every Child framework expectations. Parental perspective on the inter agency reviews is that while an integrated plan may be useful on paper, it is not necessary for all professionals to be present.

In short transitions have begun and been considered early. By the time B needs respite in adult services and a daycare centre beyond school she will have some familiarity with care staff and setting so changes have been incremental. B's close family and his home will remain the foundation for all co-ordination and care.

Bridges	Cliffs
B's character. Lively sense of fun, alert and able to communicate quite clearly, non-verbally, with those that know her. Enjoys, cartoons music, outings, cinema and being with close family.	Constant precision, attunement and reliability needs to be sustained with all care and treatment needs
Stable, secure, affectionate family base. Close teamwork between parents. Employment has had to be adjusted for flexibility.	Health transitions are complex. Loss of consultants and staff who have known B since she was a baby
Transitions nurse co-ordinator – excellent support and information. Respiratory nurse - advice about "2 year transitions programme," for strands of handover to adult health services. Opportunity to meet adult consultants early - personable attitude.	Respite to be cut significantly in adult years – will threaten endurance of current equation. Keeping her well depends on sustaining a balance of respite, daycare and clinical input
Able to remain at school until 18 ½ Early follow up on all aspects of planning including Guardianship	One carer will not be permitted to drive her to adult day services. Would need two. Either a parent has to give up work or transport problem resolved.
Transition of at-home care staff to adult care-at-home services positive. manager is approachable, understanding, flexible	No immediate close family able to share care. If a parent becomes ill or unable to care as has happened for one phase – the complex schedule is very stretched for all.
Social worker identified-will 'track' and become involved for transitions 'package'	Additional care needs of another family member

Strong inter-parent support network for information and friendship.	
Social worker identified at Review, but does not yet know family – will 'track' and become involved for transitions 'package' not before.	

EXAMPLE J(b)

This summary belongs to J who is 19 and has exceptional health care needs. She has cerebral palsy, is non-verbal and registered blind. She cannot support herself in her chair and is completely dependent on her parents or carers at her daycentre for all care and movement. She has epilepsy but this well controlled by medication.

J is fed by gastric tube and requires a tube through her nasal passage to stop her tongue falling back and keep her airways clear. She is a light sleeper and needs oxygen at night. 6/7 medications are needed to keep her well daily and overall managing her care will continue to need a highly alert, attuned and energetic parent.

When J is on Respite her mother often just has to catch up on sleep. *"It is like having a baby in the house. You are constantly aware in the night, even when half asleep."*

Bridges	Cliffs
Affectionate, secure, reliable home base and family bonds. One parent able to manage all at home personal care J's nature: she is aware, sociable and sensitive to those around her. She loves music, outings and being out in the fresh air. She is appreciative and uncomplaining and will show her feelings by facial expression Appreciation of and by J: There is never a day that she does not bring a smile to my face."	She does not like to be left alone when anxious. Almost exclusive dependence on mother's health and ability to carry out all care at home tasks and make all arrangements. Would be helpful to have occasional help e.g. with showering No outreach care at home Impact of care arrangements on family – one parent gives up work.
NHS Nurse Transitions Co-ordinator – "a lifesaver - excellent advice, links and communication"	Loss of excellent treatment, attention and advice from paediatric doctors and nurses. <i>"In the past when J needed to have a night in hospital I could stay overnight. Cannot do that now"</i> Disconnected transitions between different facets of adult hospital based specialist
Positive experience of activities and staff at daycentre on part-week schedule	<i>"Lack of preparation for what comes next after school"</i> <i>"Would be great to have a directory of resource options and transitions guidance"</i>
Brief practical help at age 17 from transitions social worker in relation to assessment for SDS budget and daycentre services.	Future respite source unknown. Respite levels cut by more than 50% age 17, unrelated to any change in need or circumstances
Community Learning Disability Nurse helpful – in NHS Lothian this service can continue in to adult years	Reduced options for hydrotherapy after leaving school. Difficulty of mother

	managing this safely in any facility without a hoist
Information from other parents – led to early seeking of Guardianship. Would like to find a befriender who could drive and take J out in Motability car.	<i>“Would be helpful to have some continuity of involvement co-ordinating and advising and having a detailed knowledge of the family situation and potentially helpful resources”</i>

EXAMPLE K

T is 15 years old and he lives at home with parents and younger brother. T has cerebral palsy, severe learning disabilities and no speech but can express how he feels by smiling, crying, squealing with pleasure and making sounds that can mean he wants or agrees to something or does not like something. T tracks what people are doing with his eyes but has some cerebral visual impairment. His senses of hearing and smell are sharp. Those who know and care about him also know the subtle signs for how he is feeling and this is always a worry – that those carers who do not really know him will not be attuned to her needs. He is usually quiet and uncomplaining, with an apparently high tolerance of pain or discomfort so it is crucial for those who care for him to get to know him. His younger brother is talented at sports and music and was able to depict what transitions may mean for himself and T using Talking Mats.

Respite and planning

Within children's services, levels of respite can be high for children with complex needs who may be at risk of becoming accommodated. For these young adults, although their needs have not changed and may become more complex, the levels of respite are likely to drop, to the considerable stress of parents and carers.

Daycare and respite provision for the most complex needs is so expensive and so sought after that one (daycare) or other (respite) has at times in this study been compromised in order to remain within the allocated individual budget ceiling

"Transitions meetings" held in schools begin at different pupil ages across the study area. When they occur at age 16 or beyond, the degree of family anxiety and uncertainty is high because they do not know what resources will be "left" and be affordable within whatever budget they are allocated.

"Transition is a huge thing for families, it is very hard to think of your child being with you at home forever! You need support to make sure all the system performs. You need equipment, medication, support workers, medical support. It is a huge team to hold and bring and co-ordinate together. This is what we as parents have achieved. Including managing a team of 6 and working with an agency." Parent of young adult with exceptional health care needs.

Bridges	Cliffs
T has a close, secure, attuned immediate family and some supportively involved relatives.	Other family members with deteriorating health. Parental fear that their employment will have to change.
T responds well to parental affection, cheery small cousins if not too loud, some	Service and staff changes in respite. Impending reductions in respite care from age 16. Absence of respite choice – difficult

music, sunshine, warm water, repeat activities that can be anticipated	to find somewhere that meets health and care needs.
Sustained GP knowledge of T and family	Lack of social work involvement, except for duty phone call. Need for holistic social assessment and transitions co-ordination that sees T through sequence of changes. Likelihood that assessment which may follow from a Transitions social worker will be completed by someone who does not know T or the family and will be involved briefly.
Guidance about transitions processes and resources from other parents; Kindred; and school information evenings	Impending loss of school routine, relationships and support at age 18, along with associated loss of physio, OT, school nurse and speech and language therapist Impending loss of paediatric health relationships, which have been excellent. Lack of information about health transitions pathways or about resources and processes post school age.
Response to pets and small children	Extra sensitivity to loud noise, busy situations, changes to routine, changes to staff, goodbyes.

EXAMPLE L

This summary belongs to S, a 19 years old who has exceptional health care needs. She lives at home with parents and younger siblings. One parent is usually the main carer due to demanding work commitment of the other. S has had multiple disabilities since birth, compounded by an acute illness aged 3 which caused brain damage. She had to be in hospital for 3 months. She has little movement, is fed by gastric tube, has a tracheostomy, no speech and has epileptic seizures. At night she needs oxygen. Vision is impaired.

In this situation the family would have found it helpful if there had been a description of choices open to them as regards day care, respite, financial issues and other relevant matters. There has been a pilgrimage process of search, rumour, investigation, application and appeal and this has been draining and anxiety provoking. The greatest stress relates to reduction of and uncertainty about future residential respite provision, the need for which is assessed, taking in to account the ecology of demands at home.

There has been helpful co-ordination and communication on clinical issues and services from the NHS Transitions Co-ordinator. There has not been a lead professional approach to bringing an overall plan together in relation to wellbeing of young adult and family.

Bridges	Cliffs
Character of S: Appreciative, responsive, good natured, easy going, loving of music and individual attention. Communicates happiness, excitement and distress clearly Secure, affectionate, stable home base	Loss of connection with hospital staff who have known her since infancy. Loss of approachable Paediatric Community Nurse
NHS nurse transitions co-ordinator very helpful for advice and support over past 2 years + GP Palliative Care Team offers continuity Expertise of adult VENT Team	Cannot be left with any single person at home other than either parent. No close relatives that can assist.
Effective transition of care at home services to "Complex Care" adult services - solo care workers 20 hours per week between 5.30 and 9.30 pm and on weekends between 2-9 pm	Cannot be left with any single person at home other than either parent. No close relatives that can assist.
One parent able to co-ordinate complex routine and arrangements as regards, health, respite, activities	Reduction of respite. Reduction in adult services from 8 days a month and 2 weeks holiday to 40 days. Could be reduced to 35 days a year. A small reduction has significant effect on family resilience. Uncertainty about location of respite next year. Unavailability of hospice respite after 21.

Remained at school till 18.5 Transport company remains same in adult services- trained escort needed SIGNPOST (8) information session gave good advice about Guardianship	Overnight care at home services do not equate to respite.
Positive experience of day service Positive experience of Music Therapy	Loss of connection with school. No day care provision lined up until just before leaving.
Parents network for advice, friendship and support	No close/sustained involvement of social worker. Allocated adult social worker at age 17.
	Protracted process accessing adequate level and location of day service. No clear prior statement about entitlement.
	Demanding work schedule of one parent. Additional care needs of some other family members

EXAMPLE M

This summary belongs to L who is 19 years old. He lives in supported accommodation. He left school one year ago and until last year lived at home with his parents. L has profound physical disabilities relating to cerebral palsy but he does not have diagnosed learning disabilities.

Bridges	Cliffs
Personal wishes about developing independence are heard. Parents take initiative in exploring options and co-ordinating of plan. Positive determination of young person	Multi-disciplinary meetings strong on information sharing, weak on decisions. Mainstream secondary school not set up for integrated schooling. Lack of information on post school options
Emotional and practical support from parents (who have power of attorney) and from adult siblings Creativity about daytime activities/volunteering needed	Gaps in daytime structure and activity schedule which had been developed over years – new developments will depend on support for personal motivation
Adequate SDS funding package from local authority when combined with benefits	Emotional adjustment to separation – honeymoon period in new care relationships and new anxieties about uncertainties ahead
Flexibility of supported housing services in planning transfer. Expertise of transitions care team. Responsive, positive relationships with small care assistant team	Complexity of funding applications and sources between local authority and benefits. Funding delays.
Transfer to local GP, OT and physio well co-ordinated	Early days- emotional adjustment to increased choice, responsibility, shifting dependencies and 'independence' is just beginning

Parental supplement on sequences of transitions affecting transition to adult years:

"It was very difficult for L to be integrated into secondary school - he could not even access classrooms on the first floor because of concerns on the part of the school about what would happen if there was a fire. They could not manage his care needs and at times called us to go up to the school to help him with toileting. They did not think he could achieve anything academically. He was transferred to a special school which was a good experience, though we and he were keen that if possible he should have been integrated into mainstream. He would probably not have achieved the same academic success if he had not moved. On leaving secondary school we were surprised not to have more support and had to do our own research about options for L. Other families might also struggle with this. We were frustrated that many services are geared towards young people with learning disabilities. As I did not have that label it made it harder to find appropriate supports".

Most young people with complex disabilities have already had a sequence of transitional phases in relation to their conditions; their development; home life and services provided by the time they approach adult years and adult services. Each phase and impacts on the next and every phase has multiple, interacting strands.

The age and physical and mental health of family carers are a fundamental consideration in transition plans. L is not able to weight bear and is completely dependent on help with toileting, bathing and mobility both in and outside the home. His parents have always been the primary hands on carers. He requires 24/7 availability of hands on care. His mother and father are in their mid-60s. They are fit and well but recognise that there comes a time when the direct physical demands of caring for L at home would become a risk for them and for L.

At each stage of transition, L's family have tried to ensure that plans focus on what is positive and potentially fulfilling for L, rather than on a pre-determined set of transition options. L has many enthusiasms and abilities, about which he can speak clearly with passion and humour. When he had the right help at school he did well, gaining standard grades with credits. He has a talent for music and can play an adapted guitar. He enjoys singing. He loves being in water and used to be able to swim widths unaided before spinal surgery.

Transitional support and planning is more likely to be successful if it is attuned to the developmental stage of the young person, taking into account the young person's maturity, cognitive abilities, mental health, needs in respect of long-term conditions, social and personal circumstances and communication needs. L had some big changes in his early life. He has at times been prone to intensely angry phases. He can be pre-occupied by some things that make him anxious, refusing to do some things and insisting on doing others. L and his parents both say that he has needed a lot of patience, help and understanding during such phases. The move to supported accommodation was a big shift in relationship for him and for his parents. He and his mother have been very closely bound.

The ecology of the young person's key relationships have been taken in to account in transitional planning. L continues to have close family support from parents, siblings and some long term family friends. Those involved in his daily care work in partnership with L's family. His parents hold power of attorney.

Although there may be clusters of professionals involved and aware within planning processes, the energy and consistent drive to bring plans together has until now depended on parents. His parents have a good understanding of local and national policy and care service issues. They talk with insight and empathy about the limitations of professional systems and roles, while remaining objectively assertive about how some gaps have impacted on good transitions for L. The intended principles and core components of GIRFEC are well understood by them. In reality they have found themselves acting as parents, carers and lead professionals, researching and co-ordinating transitional plans.

A good source of support and information has been Sense Scotland (9) this was originally founded by a small group of families pressing for services for their children, who were affected by deaf-blindness, many because of maternal rubella. Since then,

the organisation has more broadly supported thousands of disabled people and their families, in thousands of projects and services, throughout Scotland. Family friends, some of whom have professional expertise in social care have also been a strong resource.

Multi-disciplinary meetings do not necessarily lead to integrated planning. The 'information sharing' function of meetings is not always well balanced with pro-active solution finding and forward planning. Despite the number of professionals involved at various stages and despite the frequency of multi-disciplinary meetings throughout his life, L's parents have experienced a lack of integration in planning and at times a lack of clear information about options.

When complex needs are well known at an early age, each transitional stage takes planning that is co-ordinated, implemented and monitored. For L, there has been a need for concerted thinking about transitions at a very early stage before primary, from primary to secondary, from secondary to specialist and then on to adult life beyond school. Despite the frequency of professional meetings and individual expertise and positive attitude of some professionals, this has not generally been the case. There has been a need to explain L's needs "over and over again to every new professional, because his needs are complicated".

Prior to leaving primary school there were monthly meetings. However, contrary to preparatory discussions and family hopes and despite a dedicated secondary school key worker, the local mainstream school was not geared up to cope inclusively with his needs on a very basic care level; or in terms of institutional attitude to his potential. His abilities and academic and otherwise were not recognised or developed.

There were 3/4 meetings over an 18 month period prior to leaving secondary school. The bridge to planning beyond school was not there and school anticipated the local authority would fill the gap. This did not occur. There was a need for central co-ordination. L's parents coordinated and formed the plan and contacted an advisor from Skills Development Scotland recommended by the local authority children's services social worker. The Skills Development Scotland (11) worker was helpful and organised a placement with Momentum (10). This is a work skills and placement programme funded by Scottish Government

Self-directed support systems were not clearly laid out in pre and post school transition planning. The financial package for Housing Association involves combining SDS allocation from the local authority with DLA, Housing Benefit and ESA. The paperwork and communication processes have been '*complicated and endless*'.

L has till now benefited from his parents' persistent and energetic exploration of options for his care, health, learning, mobility, and access to opportunities for activity and relationship beyond the family, legal options and financial support. Most of the significant options have come from his parents own searches and suggestions or from close family and friends, except that quarterly respite weekends were arranged with a third sector agency through local authority children's social work services. (L

became ineligible as an adult.) Information about the housing association to which L moved came from another third sector agency - Sense Scotland.

Continuing dependency in some respects can create a tension with a young person's urge to be more independent. Although L lives some distance from his parents now, they retain frequent contact and maintain a protective and guiding role.

Freedom in the water: As with so many people whose mobility is limited, L's health and well-being is hugely benefited by hydrotherapy and resources are very scarce now he is an adult.

Example N

This summary belongs to a young adult who has recently moved to supported accommodation from temporary residential care. He has complex health needs, limited speech, learning disabilities and severe autism. He requires a gastrostomy tube and attuned, predictable, understanding carers.

Bridges	Cliffs
Previous Kinship Carers remain core relationships, providing continuing love and protective commitment	Isolation: Long period when kinship carers were managing in isolation, facing own losses and health problems
Continuity of oversight, involvement and understanding from social work disability team manager	Changes in social workers, various
Flexibility of interim respite resource Flexibility of youth club – extended involvement	Loss of school relationships, impending, unavoidable. Also loss of youth club relationships.
Person centred plan for transfer to supported accommodation and subsequent plan of support	Transfer to adult health services - uncertainties
Co-ordinated LAAC and school planning meetings	Fragility – relationships with new carer team in supported accommodation – many changes and challenges ahead
Guardianship held by local authority MHO –sensitive to needs of this young adult for protection and independence issues	Caution – careful planning with other family contact

P has now just turned 18. Changes in his routine and environment can also cause him great stress but close co-operation between family and professionals have eased the experience of big changes in his life in the last few months. He was born with disabilities which were compounded by further traumatic health episodes. The sequence of events in the last 18 years have been one long sequence of lightning strikes and transitional adjustments.

His grandparents were closely involved in his life since he was born and he came to live with them aged 5. He experienced a variety of disruptions and absences in care before this time. P is much loved and was gladly cared for with little assistance till age 15. Variability in the quality of bought in agency assistance led to grandparents shouldering almost all direct care themselves.

Continuity of affectionate care and excellent local medical attention contributed to him becoming much more settled emotionally. Close co-operation was needed day

by day with his school and his grandparents found that those senior staff that listened to what P needed were good to work with. Occasionally less experienced individuals struggled to understand P's outbursts and needed guidance to understand his reactions under stress. There have been other stresses and losses for P's grandparents while caring for him.

His grandparents were involved in a series of planning meetings with health, social work and education professionals in recent years. They found it unsettling dealing with a sequence of different social workers. Until he was approaching 16 their perception was that they were the leading parties in the care plan themselves. They have now ceded this responsibility to the local authority. They believe there has been a change in the way in which services work together as a team. They attribute co-ordination of P's plan to the current local authority social worker and have trust in the planning. They feel that planning does take in to account B's wishes and feelings and considers his well-being - including progress that he could make and things he could yet learn to do.

His grandparents finally became unable to manage him full time as he got older, stronger and more challenging. He has had a double transition from temporary residential care to supported accommodation. His grandparents grew to know everyone who has been involved in his care; and previously took part in interviews of residential staff.

Planning encompasses all aspects of health and well-being. P is mobile and energetic and likes swimming. He is interested in football and likes music and dancing. He is very perceptive and watchful about people around him and has got on well with some of his key workers. He hates noise and crowds. Current planning has a variety of oversight from school reviews, co-ordination from children's social work services, newly involved adult social work services; a Mental Health Officer with responsibilities in relation to local authority Guardianship; and the Third sector organisation providing supported accommodation. This is a potentially fragile time and there are some unavoidable losses and changes ahead, including the move from school when he turns 18; the phased ending of his involvement with a youth club; and the transition to adult health services. Changes have to be managed very thoughtfully for him. His plan will continue to be reviewed within the LAAC system till he is 21

Some aspects of his life, potential and choices have opened out in the last year in ways that may not have been anticipated before. When he has had people alongside that have understood him and been confident in helpful response, he has been able to manage a range of situations including going on a bus, visiting a cinema, being involved in an interview for Universal Credit, beginning to hold his own bank details. Grandparents feel no need or desire to get involved in the care planning meetings in the same way anymore and this is partly due to their age and exhaustion with the process. Their love for P has not changed but they cannot any longer lead on plans for his care.

EXAMPLE O

E is 19 and has lived in supported accommodation for a year, returning on weekends to his parent's home. E is a strong, mobile young man with severe learning disabilities and autism. He is not verbal and when frustrated or anxious, in trying to communicate he can become challenging and experimental

Describing what his family have been fighting for, his mother drew their hopes for his well-being in a bubble as follows:

- *“Safety*
- *Calm environment; space without noise; solitude*
- *Continuity of care*
- *Opportunity to develop*
- *Parents and family involved*
- *Specialist care and support;*
- *Cared for*
- *Security”*

Until a year ago, the family describe experiencing a lack of joined up thinking between health and social care in the move to adult life and services; a lack of integrated decision making; and there has been a big impact on the emotional climate in the family and ability to work. They are not critical of individuals involved but believe services are some way from integrated thinking and joined up decision making. There are some excellent skills and committed individuals and they acknowledge those services and actions that have made a difference. However with a young man who can be so difficult to look after, some continuity of support and understanding of the person and for the family feels crucial.

Self-Directed Support gives individuals four different options for managing care and support. These are: Direct payment; Individual Service Fund; Social Work Managed support; or a mix of the above options. The eventual care package for E was developed with an Individual Service Fund under which the individual budget is paid to a chosen provider. Individual/Guardians and the provider agree how the support will work best for the person.

<u>Bridges</u>	<u>Cliffs</u>
Ongoing close involvement of family in plans and weekend care Emotionally supportive persons in extended family	Extreme difficulty adjusting to any change. School teenage years were a period of increasing disturbance, anxiety, isolation, risk.
Partnership between third sector organisations providing care and daytime activities under an Individual Service Fund is eventually well co-ordinated by main	Deep impact of other physical pain and illness on E's behaviour – he cannot understand and explain

provider	
Willingness of family and partner agencies to 'think again', retrain staff, re-plan when initial transition phase did not work well.	Delayed provision and then withdrawal by CAMHS of (very good) intensive behavioural support at home No social work involvement till age 15; and case closed to social work 'when package agreed'.
LD nurse in hospital – 'beautiful co-ordination' of processes when admission needed Attentive school doctor, sharp to underlying physical issues	Absence of respite resources that could manage E. Tensions between services over payment boundaries Housing/accommodation options offered not realistic for E's needs
Advocate from VOCAL helpful while funding available	Parental ill health and employment pressures
Early application for Guardianship	Retraction on budget levels – cause of tension and amendment of transition plan
	Complications in GP transfer

EXAMPLE P

This example belongs to a 16 year old with profound learning disabilities and autism. His family offered a series of contributions throughout the study period both by direct discussion and correspondence.

<u>Bridges</u>	<u>Cliffs</u>
<i>"Policy talk about positive destinations for all children should be as determined for young people with such profound disabilities. My son is not a 'case' needing a 'package'"</i>	<i>"How will families barely coping in school years cope with reduced services in adult years?" "We get funding for respite through SDS but this is for just 12 hours respite per month. If you adjust such limited opportunities for a break downwards, a small change can be the difference between surviving and not"</i>
<i>"It would be helpful if there was a timeline that began early"</i>	<i>"Services for those with profound and multiple learning disabilities are oversubscribed"</i>
<i>"Many forms of disability are 'lumped together' in strategic discussion about resourcing. We should recognise that the needs and implications for individuals are disparate"</i>	<i>"Social workers involvement in co-ordination of planning should not boil down to whether the parents are coping or are in crisis"</i>
<i>a GIRFEC approach continuing through the transitional period would be helpful –it is all very fragmented so far</i>	<i>"Why there is no apparent linkage between co-ordinated support plans and the impending needs for transitions planning?"</i>
<i>"Give us a directory of resources and processes. We have no time to run around doing research. Even getting to an information evening is a logistical exercise</i>	<i>"I am just trying to piece things together from snippets. I don't know what services are out there. I want this to be better in future for others"</i>
<i>Citywide special schools group is a potentially useful vehicle for passing on information between services and parents and could be a way to influence change</i>	

EXAMPLE Q

This summary belongs to a 16 year old, V, who lives at home with parents and younger siblings and will attend an additional needs school for another year. Some of the detail of his disabilities are summarised below to give an indication of the continuity of intensive care that will be needed following the radical loss of multi-disciplinary attention and access to resources at his specialised school.

He has complex care needs relating to cerebral palsy caused by lack of oxygen at birth. All four limbs are affected, which means he is lying or sitting all the time. V has epileptic seizures. He has very limited impressionistic visual perception within 20cm or so of his eyes although he is sensitive to sound. He is unable to speak but communicates to those that understand him well by noises which express contentment, beyond which he has almost no vocalisation. He will cry briefly if he is in pain or strong tensing of his limbs and hyperventilation if he is anxious. V's health and well-being will continue to depend on a degree of sensitivity by his parents and other carers that is akin to attunement to a large, unusually quiet infant. That is unlikely to change through transitional years. His needs may get more complex. *There is a risk in his quietness if carers assume this means everything is ok.* Any changes in V's care and routine should be gradual or he tenses up and it takes a long time to calm him and relax him. It is serious when he tenses because it limits his breathing and previous illness and surgery has affected his lung capacity and strength. Despite his lack of outward comprehension, changes and actions should be accompanied by simple explanation.

V loves cuddles, the feel of warm water and tastes of treats like crisps and chocolate and these feelings will bring a brief smile to his face. He is substantially nourished by way of percutaneous endoscopic gastrostomy feeding tube. V is responsive to music and is alert to different voices and different rooms in ways that those who do not know him might not notice. He likes to feel the sun on his face. He loves the hydrotherapy pool. The family have a Labrador who is also very affectionate towards V having been with him since he was a puppy. He had a very problematic hip replacement procedure, which has left him with some lung problems and he is very prone to infection. However, he does not need ventilation or oxygen.

His parents have managed to take him away abroad on a couple of holidays where he has enjoyed some warmth... something which requires almost military preparation, but which they have managed to achieve with success for V and all the family.

There is great family anxiety in this situation about securing what is a very low level of respite that is adequate for V's health and care needs. The role of the NHS nurse transitions co-ordinator has again been crucial and in general communications and planning from health, education and social work have been well co-ordinated, with due consideration of all aspects of well-being. In this situation, good transitions planning entails a very slow burning look at the evolving life stages and ageing of family around V.

<u>Bridges</u>	<u>Cliffs</u>
Stable, loving home base with one parent able to focus on daily care needs and arrangements – a full time job.	Loss of multi-disciplinary team at school impending
NHS nurse transitions co-ordinator informative, advisory, helpful liaison as needed, accompanying to evaluate day-resource suitability.	Change of health services impending
Positive long term involvement of social worker from children's disabilities team . Reliable communication and advice. Then recent allocation of transitions social worker.	Change of long term social worker at transitional stage who will assess and assist in planning of practical change of services
Helpful school information session for parents on transitions with information on Guardianship and elements of GIRFEC approach (lead professional etc.).	There is a risk in V quietness ... if carers assume this means everything is 'ok'. The complexity of his needs requires a fine degree of attunement to his communication.
Transitions meeting/review at school was pragmatic about different aspects of his care and well-being beyond school care and transport – such as various sorts of therapy	SDS budget levels will not allow for continuity of respite in the resource with which young person is familiar. (Current level is up to 18 nights per year). Change of respite and day resource is likely to be necessary. Likelihood of either day provision or respite provision being compromised by budget level. Budget calculation is obscure to parents who are anxious that V's needs in future could be compromised by agreement to low level of respite
One care worker from a previous respite resource can be employed for sudden needs for overnight care at home	Extended family emotionally supportive but not able to offer practical care. Reliance on primary carer's health and well-being for whole equation.

EXAMPLE R

This summary belongs to R, who is 18 and lives at home with her parents, younger sibling, and significant cat. R has a severe form of epilepsy that led to more than 100 fits a day before she had surgery 4 years ago.

<u>Bridges</u>	<u>Cliffs</u>
Commitment, love and protection from parents an sibling. Family expertise, patience, determination, and work flexibility for one parent. Family communication and coordination skills.	School transitions meeting sounded reasonable but does not lead to a practical plan. Gap in ongoing professional co-ordination of transitions. Delayed appointment of adult services social worker.
R's courage and character: engaging, witty, imaginative with a funky take on life music and colour, (including hair colour), interest in art and possibilities of travel, work, greater independence. Family positive attitude supports R's aspirations e.g. opportunity for supported travel abroad.	Side effects of surgery include impaired movement on right side of her body, struggles with speech and impaired cognitive function Loss of abilities leaves a deep and prolonged emotional transition including waves of depression, frustration, anger, sense of worthlessness at times.
Excellent support from head of guidance at school before leaving. Paediatric services which have been 'extended family for 10 years'. Still a source of advice. Operation was probably a life saver.	Changes to abilities have left real and experienced sense of social isolation Bereavement: loss of closest friend with similar condition School friends are missed
Positive involvement with Epilepsy Scotland , both youth group and befriending. Early information from ES about Guardianship Hospital nursing team flagged correct benefits.	Loss of paediatric services which have been 'extended family for 10 years'. Loss is in relationship and sense of security as well as of expertise
Some hours voluntary work in local nursing home where elderly residents are appreciative and fond of R	One parent's work opportunities have had to adjust to prioritise care and availability
Longs to be able to read; enjoys listening; has aspirations to work and to live more independently.	Disappointment in adult OT budget's ability to support low cost high benefit items

EXAMPLE S

This summary belongs to T who is in his last year of school. He is affected by severe autism; interacting physical and mental health conditions. He lives at home with parents and siblings Transitional planning for post school is beginning and this feels quite a late stage to parents, who have a developed understanding of the systems involved.

The journey described by parents and siblings even to this point absorbed many pages of notes and as in many situations, reducing their experiences to bullet points feels diminishing of the transitional processes, cliffs and bridges already negotiated.

One of the strongest concern of younger siblings thinking about their brother was that other people involved in his care in adult years “might *just do their job without really caring about him*”.

<u>Bridges</u>	<u>Cliffs</u>
Parents Close, loving, calm and well informed parental anchor	Constant risk of self-injury without closely attuned care. Young person does not respond well to any changes and needs one to one or two to one attention depending on the setting.
Sibling group- strong, secure, loving relationships, all good with T in different ways	Information: Lack of accessible information on day services- very challenging to care for safely
GP supportive- practice knows him well	Inflexibility: Offer of further year at school retracted
Child psychiatrist - good communication and advice	Health transfers: Uncertainty about transfer to adult psychiatry and adult health services. No co-ordination of health transfer
Children’s disability social worker empathetic	Budget. No allowance for respite from home e.g. befriender. Respite likely to be cut by <u>more than half</u> when moves to adult services
Transitions social worker newly allocated- with good practical understanding	Guardianship: late advice and then only from another parent

EXAMPLE T

This summary belongs to a young person with Down's syndrome, aged 17, who is very happy in his family, school, community, friendships and activities. He lives with his parents and older sibling. There has not been a lead professional approach or co-ordinated plan relating to his wellbeing leading up to transitions.

His family wish that

"....for parents in future there could be straightforward information when you need it, e.g.:

- *This is the transition process;*
- *Here are the steps*
- *Here is the plan at this stage , on pdf*
- *This is the timeline*
- *Here are the choices at this stage*
- *A sequence of podcasts as guidance would be useful*
- *Talking through different stages and processes*
- *Such as how SDS works or how Guardianship works –*
- *No more than 5 minutes at a time*
- *Parents often don't have time to put an hour aside. Would save a lot of anxiety, research and phone calls and give us time to talk things through*
- *A directory of resources online would be useful*
- *Including some indication of waiting lists .*
- *We don't really know what is out there.*
- *A point of contact would be helpful*
- *Also providing some templates – forms*
- *Some parents are going to struggle if they get a lot of information at the last minute.*
- *They may need someone alongside and time to process the information in bite size chunks "*

<u>Bridges</u>	<u>Cliffs</u>
Stable, loving, close family base within supportive community and network	Co-ordinated support plan discontinued aged 13 – would have seemed a helpful basis for transitions planning Specific fears of young person to overcome and specific health needs Need to handle young person's expectations at every stage
Enthusiastic, appreciative, sociable character of young person	Requests for social work assessment – repeated- some delay – first visit now taken place No previous s23 assessment Tasked based engagement only – parent will have to self-refer again to time with

	college application
Background parental awareness of systems and organisations leads to some confidence in asking questions and putting requests on paper	Complexity of information about Self Directed Support at a late stage. Some parents will be overwhelmed
Transition year at school - familiarisation with aspects of the community – visits to college, accompanied shopping and use of public transport; 'lifeskills'; outdoor education and sports; taster work experience. 6 week programme includes 'show/tell'/ 'all about me' and 4 weeks activities. 'All about me' session with Carer Adviser	Uncertainty about resources and options and practicalities e.g. how transport would work. Decision for college will be made in April – not long if college place not offered – emotional time if separated from long term school friends some of whom will be at college
Approachable, caring, expert and passion of special school staff Detailed printed updated transition policy which goes back to early years and primary transitions	Late and incomplete information about Guardianship, including costs of application
Third sector advisory organisation provides helpful booklet of information and 4 week intro to transition course for parents. Briefing session from solicitor re Guardianship	Feeling that son leaving school means that parent will become full time carer.

EXAMPLE U

This example belongs to W, an insightful and articulate woman aged 24 who lives at home with her mother, father and younger sibling. W has a form of epilepsy that was finally diagnosed when she was 14 years old.

Social work services have never been involved in this example. However a low key, low maintenance co-ordinated transition plan running before and after school leaving age would have been supportive. The impact of the condition has been challenging at times and family and young person have felt isolated and at a loss what to do at times.

<u>Bridges</u>	<u>Cliffs</u>
Secure home base and close family support	Bullying at school; underachievement relative to abilities; sense of being an outsider. No transitions plan or person centred plan relating to support for next steps beyond school years(from diagnosis onwards)
Helpful learning support strategies in school applied by one teacher, not by all. Absences relating to epilepsy not understood – treated as lack of focus by majority.	No handover between children's and adult services in terms of health ,educational support and developmental support
Support, encouragement, information from Epilepsy Scotland – reduces sense of isolation for young person and parents	Depression, isolation and low self-esteem during and following school. Tendency under stress to have difficulty making decisions, to freeze and panic
Educative approach and personal warmth of manner of the epilepsy nurse at RHSC who explained things well and diminished a sense of fear about epilepsy(– however this was lost when this service closes aged 17)	Lack of information about agencies and choices that might have been helpful – about health, activities, benefits and employment
W has been successful in finding and maintaining office work in business support	Would have liked initial individual interview with clinician in adult health services age 17 to be supported Anxieties for young person and family in relation to trying of different medication for epilepsy
W has been helpful as a mentor to others with epilepsy	Parents left feeling 'what could we have done differently'

EXAMPLE V

This summary belongs to C who 19. He lives at home with his parents and siblings. His parents hold guardianship. C is an intelligent, creative person with a vibrant imagination when he is well enough to share it through drawing, painting and music. When he is well enough he wants to learn; and retains close bonds with immediate family. These bonds are especially close with his mother, on whom he continues to depend. A variety of talents and aspirations have been paralysed by complications from illness which began when he was aged 10. A combination of auto-immune responses and inter-twined psychological impact has left him prone to extreme fluctuations in health and in his abilities to communicate, or do anything for himself. Family life has significantly revolved around these intense and prolonged crises for the past 9 years. C wants to know about plans for his own care and treatment. He worries about the future. He is prone to seizures, and has been unable to walk for 10 years. He is house bound and has extended periods (months/years) of being quadriplegic. When he is well enough he can communicate through restricted conversation but is otherwise completely withdrawn for prolonged phases.

<u>Bridges</u>	<u>Cliffs</u>
Creative potential of young adult: Outwardly immobilised, young person retains a vibrant inner life – musical appreciation and ability to draw and paint when well enough	Isolation and exhaustion for the whole family. Lack of respite with nursing care (other than call in home-care). Intermittent and unpredictable emergency hospital admissions necessary.
Parental reliability, flexibility and insight. Ability to co-ordinate care; understanding of professional systems	Loss in level of attention and understanding in adult health services. Need for co-ordinated physical and psychological assessment and treatment. Lack of understanding of interactive conditions contributes to lack of clear health pathway
Call-in home care assistants have progressively increased in past 5 years from 3 to 60 hours per week following review social work assessment of SDS budget	Delayed recognition of extent of care needs at home. Discontinuity in social work allocation and co-ordination of planning. No social work allocation or source of consistent consultation
GP: Helpful listening attitude and understanding of history and whole family by one GP.	Loss of years of schooling pre transition – will require creativity and commitment to redress
Planning . During one previous phase co-ordination of transition planning at home was helpful. Would <u>still</u> be helpful in adult years.	Loss of employment. One parent gives up all work to act as full time carer and care co-ordinator

Advocacy from Kindred helpful in a previous phase	Gap in co-ordination of ongoing transitions across health and social care. Separation of silos ('social care budget' and 'health services') Need for care for the family in the form of short breaks
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Family supplement to the reduced summary above:

"We think the headings under 'bridges' and 'cliffs' are all very appropriate. Respite is only possible with help in the house and we have not had any more than a few hours at a time. More nursing care will be needed for us to get any meaningful respite. "Despite this, C is an artistic, creative person (if C could be well enough). C likes to learn as much as health allows. A naturally positive personality and lively interest when able could be utilised as bridges if professionals could be interested enough to help. C's expressed wish is to be living at home with the family."

EXAMPLE W

W is a young adult years old and has been through a sequence of transitions since leaving school more than 8 years ago. She has moved from the family home to a supported flat. However she continues to value spending weekly overnight stays with her parents and sibling. W says she has '*two homes*'. W is a sociable, enthusiastic, courageous and determined young woman who needs 24/7 personal care due to multiple health challenges. She has global delay affecting comprehension; although the fact that she is sensory impaired leads some to underestimate her understanding and excellent recall. W is a wheel chair user and needs carers who are attuned to her communication and fragile health to enable her to meaningfully interact with her world.

Bridges	Cliffs
Loving and committed family base as the co-ordinating energy and anchor for a sequence of transitions	Loss of positive and forward thinking of a paediatrician who co-ordinated care and health planning through a long sequence of operations, procedures and developmental stages
Outgoing personality, affectionate nature and positive attitude of young person. Willingness to push on with opportunities so long as she can stay in close enough touch with family anchor	Premature loss of special school placement due to school reaction to health concerns
Understanding, assessment, challenge, encouragement and support from a third sector agency	Communication and partnership stresses within local authority services at senior level during transitional phase.
Flexibility, positive attitude and skill set of current supported accommodation services and care team, working in partnership with other disciplines Independent Living Fund applied effectively(12)	Protracted difficulties working in partnership with services locally which could meet needs for assessment, communication with young person, training opportunity or care arrangements; leading to a sequence of failed or curtailed arrangements. Young person becomes very frustrated, unhappy and ill.
Continuity of involvement from adult social work services in relation to assessment, review and administration of care plan, which by parental decision does not involve direct payments or Self Directed support. Social worker/care manager throughout worked in partnership with parents Sufficient communication and partnership between authorities involved. Local authority accept out of authority supported accommodation service choice	Fear of loss of services of committed personal carers. Fear of review of budgets which could compromise service levels, safety and well-being

Additional parental additions crucial to wellbeing and successful transition in all dimensions. *“W has a supported work placement for two hours a week and is proud to get small payment each week for this. She attends a social network group for young adults with additional support needs and participates in a drama and music group. W goes swimming weekly when she is well enough and has a friend whom she meets weekly. She goes to the cinema, bowling with friends at the weekends and loves to people watch. I think she has a more active social life than us!”*

W is at the centre of her yearly review which is a comprehensive exercise in partnership between third sector agencies, family and local authority. It is based on her wellbeing outcomes. The expectations of all partners in the plan are spelled out in relation to w’s wellbeing outcomes. Actions and activities are agreed with her. W made an illustrated booklet which is at the centre of her plan. This is about “what is important to me” under the following headings
It is important that

- *You listen to me*
- *That I see the people I want to see*
- *That the people who support me know how I communicate*
- *That I stay as well as I can, eating well, exercising, using my wheels and standing frame,*
- *That I have things to do, projects and drama and activities with friends, going to work and having massage*
- *W’s own plan showed what she needs and what has gone well this past year, what she would like to do next year and some of her projects and dreams*

EXAMPLE X

This summary belongs to G, aged 20 has learning disabilities, cerebral palsy and autism, who lives at home with his mother and younger sibling. There has been a positive and sufficiently sustained experience of co-ordinated and integrated assessment and planning over transitional phases. This has been lead by a transitions social worker who knows the whole family situation and individual young person well.

<u>Bridges</u>	<u>Cliffs</u>
G: <i>“Enthusiasm, amazing memory, listens to everything you say, loves animals, enjoys pottery, music and dancing”</i> G can say clearly how he feels to mother, social worker, key workers	G: no sense of danger – need for constant accompaniment and supervision
Security at home in care of mother	Another family member has complex additional support needs
Continuity of social worker before and through transitional phases - 7 years. Good co-ordination of plan Fulfilling day programme and additional activities <i>“I don’t want to move from there. I like it much better than school.”</i>	Care depends completely on mother – sense of a long road ahead. Mother quite isolated and unable to have sufficient time to connect with work
Annual review of holistic plan takes place in day service. G takes part. Recent introduction of occasional respite for mother	Apparent confusion about both Self-Directed Support budgets and benefits – reliant on social work guidance Application for guardianship quite late, aged 19 years

EXAMPLE Y

This summary belongs to a young man aged 18 who is looked after in residential school. He is affected by learning disabilities and Aspergers. Since primary years those looking after him have been concerned by his angry, frustrated outbursts and mental health. However there has been remarkable improvement in a sustained maturation in the school setting and willingness of the local authority to spend a bit more to ensure transition to college and supported accommodation is achieved in granular steps that the young person can deal with. The current social worker has lead on co-ordination of assessment, services and planning.

Bridges	Cliffs
Residential school staff: listening skills, relationship skills, patience and firmness over 5 years	Fractured care history: 3 changes of residential school, history of anxious insecurity
Nature of young person: engaging, open, positive, sense of humour, willingness to learn, awareness that he has made great progress in calmness, relationship and achievements <i>"I wish my Dad could see me now"</i>	Vulnerability: open, unguarded nature also a vulnerability in the community. Sensitivity to early losses, about which he has clear memories
Nature of young person: engaging, open, positive, sense of humour, willingness to learn, awareness that he has made great progress in calmness, relationship and achievements <i>"I wish my Dad could see me now"</i>	Lack of continuity: history of changes in social worker.
Family contact : Interested and involved in all plans, affectionate, encouraging and protective in pre planned contact	Loss of relationships and structure: big move to supported accommodation – need for sustained encouragement and support
Flexibility of planning: extension of school leaving date to support transition to college	Risk of disengagement from college and relationships – retreat to computer, inactivity, social withdrawal beyond the screen.
Co-ordination: person centred social work, school health, college place lined up, supported work experience, attentive transitions social worker exploring supported accommodation	Need for continuity of social work co-ordinated attention beyond the next move to college and supported accommodation
Young person central: involved in all planning	

EXAMPLE Z

This summary of themes belongs to N - a courageous, intelligent and highly perceptive young man of 19 years old, with a wry sense of humour. He had a combination of health conditions affecting vital organs, his bones, his eyesight and mobility. His mother has always carried the knowledge and fears that these conditions were life limiting.

N learned the implications of the conditions when he turned 16. By the age of 19 he and his mother had struggled through multiple transitions and many emergency admissions to hospital, any one of which might have been the last. Speaking about his health in October 2016, there were things he was looking forward to, including a new council flat with adaptations for himself, his Mum and his dog. He was enjoying occasional drives out in to the countryside for the first time with a personal carer; and had hopes of a night out in town with friends, for the first time. He wanted to travel abroad. N and his mother's relationship, resilience and individual attitudes deeply impressed those who worked with them.

In the processes described below there was good co-ordination and communication between the two social workers involved from local authority and hospice services; with attention to the wishes of this young adult and his mother.

Bridges	Cliffs
Personal courage, optimism and outgoing nature. <i>"I do not feel isolated"</i>	Exceptional physical fragility relating to interacting health conditions. Anxiety/depression for both son and mother from living in constant suspense. Having to learn to 'self-limit' to avoid critical injury
Loving home base with a mum whose life has always revolved around his care Flexible contracting of a trusted support worker 10 hrs a week via Self-Directed Support	Happy move to specialist primary, though no transport provided. Integrated in mainstream secondary though much school missed through illness. Delay in local authority social work involvement till respite care needed age 12.
12 years of excellent respite relationship in children's respite provision but public transport struggle getting there GP knows mother and son well and provides excellent sustained service Frequent high quality emergency hospital care	Care depends on Mum's health and well-being. She has own health concerns and depression and needs own support in process of care No other relatives supportively involved. Respite care was coming to an end before age 21. Lack of any other suitably staffed respite
Joint planning by local authority social worker and hospice transitions worker. Focus on N's needs, choices, health and well-being	Long delay in getting all due benefits. Application for Disability Living Allowance was refused 5 times before N's mother went to a Tribunal. Benefit granted immediately.

Themes relating to mental health underlined by parents

The following themes have emerged from accounts of process from a range of families in which a young person has faced severe mental ill health alongside other challenges. There are families who have offered detailed accounts of their own processes to the author but prefer that the general views that arise from their experience are presented as below, 'in abstract.'

1. When one complex condition is complicated by interaction with another (as for instance when there is an interaction between an autistic condition and a form of mental illness), individuals and families within this study have faced severe additional risks and handicaps because of delays in diagnosis of one or both conditions. The treatment and management implications of interacting conditions are a crucial element in successful transition to adult life.
2. Early recognition of complex additional support needs; and early assessment and support planning in school is critical to prevent a deteriorating achievement, health and relationship. When there are severe and complex difficulties, there is a compelling case for continuity of a lead professional who knows the family strengths and stresses and can ensure the plan knits well in to adult years.
3. Families may not have clinical expertise in the categorisation of mental health conditions. However, all families are expert in relation to their own lived experience and this should be listened to. When parents have reason for concern about diagnosis and treatment, requests for a second opinion in urgent circumstances should be regarded positively as an opportunity for reassurance about optimal action.
4. While respecting areas of legitimate privacy and confidentiality for a young person, all health, education and social care professionals should seek to work in partnership with parents in their work with young people, especially approaching phases of transition (unless there are reasons why this is not safe or possible). Within this study there appear to be examples of parents being side-lined in planning and decision making, even when the stability of the young person depends on structured, negotiated partnership between parents and professionals; and even when parents are expected to be the rock on which forward planning is based. Such a decision-making process creates fracture zones on an already fragile path.
5. There can be dilemmas about capacity to make informed choices and about boundaries of confidentiality for young people approaching 16 years, especially when mental state is variable.
6. Transition is more than transfer of service(s). It is about a movement to another life stage and internal and external changes are involved to varying extent and at varying pace for each individual. In the complex situations explored within this study it has proved hazardous when services regard transition simply as discharge from one service; or the point of achievement of

a “package” of care and daytime occupation at school leaving age.

7. The process of transition should start while the young person is still in contact with children’s services and may, subject to the needs of the young person, continue for a number of years after the transfer to adult services. This will ensure that young people and parents know about the opportunities and choices available and the range of support they may need to access. It should not be the case that when a young person with chronic disabilities and acute mental health problems is age 17, parents are uncertain about ongoing transitional support.
8. The threshold for attention in terms of severity of illness may be higher in Adult Mental Health Services. The transfer to adult services should be negotiated and adequately supported. Within this study there is illustration of serious risk to an individual when moves took place from a situation of intensive supervision and structure to a new situation in which there was minimal supervision and structure, and where the individual had proven and urgent need of close supervision and structure.
9. Within several process examples parents have been distressed by risks resulting from gaps in realistic, step by step planning, gaps in contact with the family and gaps in forward thinking. They recognise with concern that safe and effective transitional processes can be compromised by changes in staff; lack of specialist expertise ; a lack of suitable care resource; shortage of funding; and disintegrated processes in which treatment is considered in isolation from nurture and core relationships.
10. By contrast there have been processes within this study when creative, committed, expert, co-operative and personable approaches to communication and planning and relevant expertise have come together, almost in spite of systems.
11. The whole family needs for support should be considered through complex transitions such as these. *“To us it is essential to define which health professional takes responsibility for the health of the family. This person should initiate and follow up on any outcome from such a process. This lack of ‘looking after the family’ has been a huge problem.”* (Parents of 19 year old with severe interacting physical and mental health problems.)

5. Local Area Developments

This section is about selected aspects of local authority processes - a significant part of the context for the individual and family experiences summarised in section 4 above. The table below indicates how areas are trying to respond address needs.

This study has involved looking at a jigsaw of policies, procedures and guidance produced over the past 8 years. There are structural, workforce and procedural shifts occurring during the period of the study that could not be represented, because they are not concluded. Rather than attempt to represent a patchwork of business processes, a selection of positive and developmental strategic and operational features are represented in the table below in relation primarily to social work and social care across the study area. The National Transitions Mapping Study (1) will provide a comparative position statement across Partnerships.

A selection of developments from Highland are also represented at the foot of the table below. This is an authority which has systematically applied the GIRFEC approach for longer than any other authority in Scotland. It has long had a strategic focus on transitions. Highland's population is dispersed across an area the size of Belgium. Some initiatives are a response to inequalities of service accessibility across rural, semi-rural and urban areas.

The tables below indicates positive present and developing features of local Partnerships. Principles of Good Transitions 3 are an accredited benchmark for future plans. This guidance is already a foundation reference in developing procedures in some areas.

City of Edinburgh

Strengths	Developmental
Edinburgh have begun to develop a website ' Edinburgh Transform ' (2). This will help to keep the public in touch with what Integration of Health and Social Care may mean. The GIRFEC well-being indicators are promoted as a foundation for children's services. (3)	'Transitions' are not yet overtly linked in through this portal
Edinburgh Integrated Joint Plan for Children and Young People (2015-2018) intends that " <i>our children and young people in need or with a disability have improved chances in life</i> ".(Strategic Outcome 3)	Revision to Policy, Procedures and Guidance in relation to Transition under review since March 2016. Opportunity to streamline assessment activities and support links to relevant (new) legislation policy, frameworks, guidance (like Principles of Good Transitions 3)

<p>'Improvement Themes' include the need "to develop <i>Transitions Policy</i>", alongside other actions related to autism, challenging behaviour and Additional Support for Learning.</p> <p>There is an action point to "<i>Improve knowledge and understanding of Getting it right core components; and evidence use of well-being indicators to consistently and holistically assess and meet needs across all children's service delivery.</i>"</p>	<p>Parents would value directory of services and resources and accessible guidance on processes relating to disabilities, assessment and budgets.</p> <p>Accessible guidance could include short video or podcast explanations of key processes</p> <p>To develop a single pathway for life for people with a learning disability</p>
<p>Like East and West Lothian, Edinburgh has long provided a strong specialist Children with Disabilities social work team. The specialist Transition Team created over 8 years ago achieved positive feedback from Special Schools, service users and from ARC Scotland's recognition of good practice (in 'Principles of Good Transitions 2').</p>	<p>After consultation, The Transition team will remain as the bridge between child and adult services</p> <p>Parents and carers rely on key professionals having the relevant knowledge, skills and sensitivities, whatever the structure.</p> <p>Structural and process uncertainties can cause anxieties or confusion for families and other professionals</p>
<p>New Edinburgh guidance on Additional Support Needs (December 2016) (4)</p> <p>Recording and categorisation of Additional Support Needs occurs via the SEEMiS system which applies to all sectors of the education system on a managed service basis.</p>	<p>Apparent difficulty capturing numbers of children with disabilities needing transitional support. (Although Transitions team track numbers of children with disabilities transitioning needing complex packages; or accommodation; or autism support)</p>
<p>Local Area Co-ordinators (6) have a role in providing advice and support for example to:</p> <ul style="list-style-type: none"> • Use transport independently • Provide signposting to support locally • Keep up with friends and get to know people locally • Maintain people's independence • Look into further education that May help find get work, full-time, part-time, paid or voluntary • Use leisure services • Provide support to family or carers • Encourage healthy lifestyles 	<p>Some young people's cases may be closed by social work when packages of care are agreed- until such time as a crisis prompts re-referral to Care Direct (5), which is a council gateway to assessment and support or referral to a local area co-ordinator - for a person with mild to moderate physical or learning disability or acquired brain injury.</p>

Midlothian

Strengths	Developmental
Midlothian Integrated Children and Young People's Plan for October 2016-17 and 2019-20 has action plans based on the <i>Getting it Right for Every Child</i> well-being framework and addresses transitions issues. Statistical data on need and service user consultation embedded in the Plan. (7)	Decision to develop single service to ensure more joined-up working during transition to adult services Midlothian Council are c updating transition procedures around POGT3 for greater transparency and clarity of expectations, beginning information sharing earlier. Schools lead on organising a transition planning meeting 'at least 2 years' before the earliest possible school leaving date.
Midlothian Transitions social workers in adult services work with identified young people with additional support needs aged 15-19 years to support progress into positive education, training or employment destinations. Highly valued by families	Families don't want to lose Transitions social workers after experience of their support, co-ordination and advice
Midlothian Transitions social workers - creative use of networking services such as Neighbourhood Networks	Accessibility of services and networks for those in rural areas

West Lothian

Strengths	Developmental
West Lothian Health and Social Care Partnership integrates West Lothian Council and NHS Lothian. A multi-agency Transition group comprises managers from adult services in relation to learning disability, physical disability and the group manager; the manager of the children's disability service; co-ordinators from community child health and Complex Care; education and educational psychology; and Through care and After Care.	West Lothian written procedures and transitions pathways are under review.
Special schools in West Lothian – examples of well detailed transitions policies, starting early, integrating GIRFEC framework West Lothian special schools run advice sessions for parents . Transition Course	West Lothian Council website information developing e.g. around self-directed support, learning disability services, and personal carers (8)(9) West Lothian have recruited a graduate to support development of processes which

<p>running over a period of 4 weeks run by Signpost offers comprehensive (November 2016) booklet about resources and processes.</p> <p>West Lothian Self-Management Pilot Project (10) with children up to 14 with chronic conditions and their parents or carers - exemplifies principles that also apply at leaving school age</p>	<p>improve transitions pathways, policy and practice in West Lothian.</p>
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East Lothian

<u>Strengths</u>	<u>Developmental</u>
<p>East Lothian Integrated Children's Services Plan 2013-17 set within the Getting it Right for Every Child (GIRFEC) framework. (11) The plan covers children and young people from birth – 18years old (and beyond for some young people for whom there are statutory and transitional responsibilities</p> <p>East Lothian - strongly led specialist Children with Disabilities Team (13) - focal point for both assessment and signposting (14)</p>	<p>Health and Social Care restructuring in progress (12)</p>
<p>East Lothian Versions of Transition Passports in use. For young people with complex and enduring needs there is additional guidance for Children's Services and Adult Social Care For children with the most complex needs, primary schools complete an early flagging form for secondary school, which assists adult social care to predict what resource will be required in future.</p>	<p>Multi agency post-school transitions group review transition needs for young people who may require input from adult social care.</p>
<p>East Lothian Disability Youth Transitions Service for young people with disabilities (from aged 15 - 20) to support post school placement in employment, education, training or volunteering. DYTS.</p>	<p>Public events in 2012 and 2016 enlisted family and professional views about proposals for improvements in transitional processes and structures. Creative initiatives in the area which seek to address issues of accessibility, including Children Inc's work on Self-Directed Support, respite and opportunities (15)</p>

Scottish Borders

<p>Scottish Borders Council - strong focus on Learning Disabilities in their Transitions policy and practice developments. Multi-agency Learning Disabilities Transitions Steering Group which meets regularly.</p> <p>Detailed integrated transitions procedures for learning disabilities</p> <p>Encompass (16) -third sector Agency in the Borders that plays a crucial part in consultation and strategic influence besides offering direct service around Directed Support. Video link guidance and briefings on Self-Directed Support are simple and helpful. They have conducted local case studies of family perspectives on Transition.</p>	<p>Transitions Development Officer leads a transitions project about young people with learning disability 14-21. Development of accessible information and coordinated assessments</p>
<p>Scottish Borders (17) learning disability governance structure includes 5 <u>Local Citizens panels</u> - made up of people with learning disabilities and carers. Borders Council consult with the panels on policy, strategy and practice.</p>	<p>Transitions Steering group have developmental link with ARC Scotland Policy Officer</p>

Highland

<u>Strengths</u>	<u>Developmental</u>
<p>Partnership Agreement between Highland Council and NHS Highland commits to effective joint arrangements for transitions into adult services for young people who have additional care, health and support needs.</p> <p>Highland's Chief Executives Joint Transitions Group leads on policy developments</p>	<p>Performance Framework for Children's Services requires effective handover of planning and support arrangements for people with continuing needs. Adult Services Performance Framework targets increase in number of people with learning disabilities who are in further education and "in paid employment".</p>
<p>Highlands Council Transitions Co-ordinator leads on training and implementation of processes that start aged 14, also collates data which will allow schools to identify those in need of enhanced support at an early stage. Young people's needs and aspirations are identified early. and works with</p>	<p>NHS Highland appoint Project Manager (one year secondment) for Transitions - scoping need for health and social care Transitions team for 14-25 year olds across NHS Highland and Highland Council</p>

<p>'Opportunities for All' Co-ordinator who has responsibilities to ensure all YPs have an offer of training, education or employment post school. Particularly our at risk category.</p>	
<p>Hi-hope (18) is a Highland Council resource whose original concept was developed in partnership with CHIP+ and NHS Highland for young people 14 to 24. It offers local information, guidance, work experience and other opportunities. Skills for Life, Learning and Work Team and relevant partners contribute to the content of the site.</p>	<p>New transitions protocol and pathway guidance for Highland Council and NHS Highland will be accessible via Highland's website (listed on highland.gov and also on the transitions page of hi-hope)</p>
<p>Self-Directed Support peer advisors advise young people and their supporters on use of Self Directed Support based on real experience Transitions Network set up in Lochaber. Transitions Champions identified across Highland (practitioners in each area who are able to sign post others to the services best to support the young person). Appointment of a social worker specific to transition in Lochaber</p>	<p>CHAMPS board run by care experienced development assistants (employed by Highland Council) currently working towards the setup of a "one stop shop" to support care experienced young people in transition. (Supported by 'Who Cares' Scotland)</p>

The subsequent section of this report extracts observations from a wider cross-section of agencies and committed professionals from within the study area who are steeped in the experience and dilemmas of their own fields of expertise.

6. Supporting Good Transitions

The purpose of this section is to illustrate approaches and dilemmas in supporting transition across a spectrum of third sector and statutory services. These windows on to the transitional landscape each provide a distinctive perspective, lens and focus. This is not a comprehensive list but rather a selection of themes, stresses and creative developments that form this landscape. The themes cluster around

- Sufficient continuity of service
- Partnership and co-ordination
- Creative networking between services
- Innovative person-centred planning and service development
- Bridging dilemmas and ideas in specialist areas
- Individual crises and growth in transitional stages
- Risky disengagement and proactive support

The combined range of third sector and statutory provision in health and social care within the study area is probably more varied and comprehensive than most parts of the UK. Some families with children with profound disabilities have moved to the geographical area covered by the study for that reason.

Sufficient Continuity – Perspectives from a Special School (1)

The Royal Blind School (3) is a non-statutory foundation which provides education, care and support to pupils with visual impairment, including those who have additional support needs and complex multiple disabilities aged 5-19. There is also a pre-school playgroup. It has a holistic and individualised approach to the in-school curriculum. The high staff ratios allow for building of confidence and development of potential in each pupil. There are many examples of students who had seemed withdrawn and locked in themselves who begin to find their own voice and express their views and wishes. During this study there have been examples of highly successful work placements, found within a week of leaving school.

Individual attention and relationships in the school community

Many pupils have need of considerable 1-to-1 attention. The school is currently aware of numbers of pupils who have significant mental health problems. For those whose who were not born visually impaired or blind, there is a complex and individual process of adjusting to loss of sight and the meaning of this loss through each life stage and change. Each young person at the school is likely to need listening time besides specialist help from a range of disciplines. From this quality of attention, significant trusting relationships develop. The school becomes, in the words of one young person, “more than a school”. There is a further loss when

young people have to move on and in some cases it is optimal for this aspect of transition to be delayed a year.

Challenges in promoting good transition from school

School managers expressed a wish that there could be a transitions co-ordinator “from outside” who comes in and helps plan and co-ordinate next steps from an earlier stage. Their reality is that this lead professional role is not achievable with most local authority adult health and social care services. By default the school end up acting in the role of lead professional during school years. It can be difficult to hold this role while being the main service provider. However the school can help parents advocate for their child’s future needs as an adult. This role cannot be extended beyond the gates although telephone help may remain available.

The school is doing all it can to make the leaving-school aspect of transitions as well planned as possible. Pupils are gradually prepared, stage by stage, year by year. The school works with Skills Development Scotland. Opportunities are cultivated with local businesses and third sector organisations in relation to potential work placements.

Parents are supported and informed about options (e.g. such as Guardianship and Self Directed Support) by means of occasional group sessions.

The school tries to engage with the local authority adult health and social care social work teams who are responsible for post school support planning. It can be a great struggle to get social workers to planning meetings when young people are not Looked After and Accommodated and a very small proportion of children needing transitional planning are Looked After.

There are positive relationships with third sector specialist support agencies such as the RNIB Transitions Team. Unfortunately RNIB Transitions team cannot resolve all the communication gaps.

There is a limit to what can be achieved without local authority support e.g. with negotiating suitable accommodation; positive training, work placement, work or daytime activity and co-ordination with health services as appropriate.

Families

Families are anxious about drop in respite availability as their child moves in to adult years and their needs become more complex and their parents grow older and no less needing of a break. Families are anxious about the lack of information about daytime opportunities that may be available locally for their son or daughter. Families are distressed when e.g. college opportunities and courses are offered that do not fit with their young person’s needs. Families value continuity of help and advice from professionals and they need professionals to have sufficient specialist knowledge.

Transition plans need to be realistic and co-ordinated. A patchwork of dislocated resources that are not well matched and for which a young person is not well

prepared, will lead to a break-down. There is an impact not just on the young person but also on the close family network. The reverse is true. When plans are well supported, the whole family is positively affected. It really matters how these things are brought together.

Some families need encouragement to let go and allow their 'child' to grow beyond their dependence on parental relationships. This is a difficult challenge for all parts in the triangle and it is a sensitive and difficult matter reflecting on relationships that occasionally accentuate a child's impairments.

Inclusion

In the experience of many specialist education professionals there will always going to be some who need a higher level of care and attention to achieve their potential. Many children with visual impairment in mainstream school do not have access to specialist careers advice and support. (*"There are around 3000 children and young people in Scotland, 3-18 who are blind or partially sighted and many do not have access to specialist transition support".*)

Royal Blind School have had successful students at university level and many strong achievers with certificated courses. However in adult life, 70% of the 8,500 registered blind and partially sighted people in Scotland of working age cannot find employment (4). More able students are better supported e.g. through the Disabled Students' Allowance (5). However, the school is concerned at low aspirations for many young people who are less able and know that without sustained support and advice, most end up reliant on benefits.

Improvements

In common with the experience of other special schools and pupils known within this study, RBS have said it has generally made a critical difference when students have been given the flexibility to remain a year until they are ready for a next step.

On the other hand there are examples where the pressure to achieve a practical move has led pupils with significant additional support needs being offered accommodation options unsuited to their needs and emotional development.

Education staff comment that it would seem beneficial if local authorities/health and social care partnerships had more comprehensive sources of advice about resources and resource access relating to transitional processes in each geographical area. RNIB and other third sector organisations do an excellent job of sharing crucial information but cannot cover all areas.

In the view of RBS, positive transitions would be better supported if children's social work services could see their assessment and support role for those with complex needs through to age 26.

RBS can see value in exploring the concept of community based peripatetic co-ordinators who could support, network, mentor, advocate and advise families about options, support positive communication and planning. Where there are specialist transitions social workers they tend to be focussed on advice about packages of finance and care, just at the point of school leaving, rather than about ensuring continuity of access to support and help that may be needed for those with complex conditions and support needs that may change and get more complex at times.

Partnership and Coordination: Perspective of a Special School (2)

Another local authority managed special school, offered a perspective from another part of the study area. It provides day education for pupils with severe and complex learning, physical and sensory disabilities aged between 5 and 18 years of age. It also provides Early Years and Childcare provision. The needs of most pupils are profound and so the staff ratio is high. All pupils in the school have a level of need such that they require a Co-ordinated Support Plan. Service provision on site is comprehensive and well integrated.

The challenge comes when it comes to Transition planning. There is a clear and recent statement of process in a guidance document of August 2014 and a visual framework related to the GIRFEC practice model which puts the Child's Plan in accessible language for families. Transitions meetings are a 'person centred' planning meeting/transition meeting with family and young person and relevant professionals, including the child disability worker. This takes place in S4 when the young person is 15/16. This process is reviewed and repeated thereafter as needed, up to the time of moving on. There is an aspiration in local protocols that an adult social worker attend the meeting who can see the process through.

However the reality for this school is that there are long delays in getting allocation of the adult worker responsible for assessment and recommendation about budget and advice about services/assistance accessing services. As a result, planning transitions can be rushed and uncertain, even for those with the most complex needs. Education professionals are asked not to point families in the direction of specific day services in case budgets do not stretch to such provision.

A third sector organisation provides information and advice to parents and carers at the school parent sessions have been very positively received by families in this study.

Senior staff emphasise that the knowledge of the school team about each pupil should be applied to the assessment conducted by the adult social worker. They argue that it would be helpful if either the children's disability worker could see the transitional stage through; or if an adult services worker could become involved or aware at an earlier stage.

"There is a need for a lead professional throughout the process to ensure that there is continuity of attention to the needs of the young person as they move on to new daycare provision, new respite and other services. Sometimes young people lose

skills as they move on to college or other day activity programme because the skill set of the staff around are not attuned to the communication needs of the young person. This is a loss of a key independence skill and is the sort of thing that should be valued within the Transition Plan.” (Deputy Head Teacher)

The school provided illustration of the need for careful early planning of services. Placements can break down when major changes are not planned to fit known responses of pupils that get very anxious about minor changes. Some parents have to give up work when there is no suitable daytime programme investigated, budgeted and planned early. There are examples of some young people being stuck in the house for the same reason.

“It is a dilemma for some families that the budgets cover both respite and daytime activity in that most budgets do not have sufficient for both. When at school, the education / daytime costs were met by education. When they have left school, there is one funding stream for all needs, except for those children with Exceptional Health Care needs whose health related needs are covered by NHS budgets. There is a lack of transparency about how the intended outcomes for each young person are translated in to levels of budget.”

“At present it is rare for the family situation/carer needs to be a factor in budget setting. However it is possible that the preventative implications of the new Carer (Scotland) Act will have some influence when it is implemented later next year.”
(Headteacher)

As some pupils have been with the school since they were very young, moving on is a huge change for them and their family. The transition is for the whole family. The school has provided total daytime care for all these years and been a primary source of advice. There is concern for what happens to those young adults who may move on to college but have ongoing complex support needs beyond and during college and if college or other provision breaks down. For some, they are not ‘sufficiently disabled’ to gain the attention they need and others fall between categories of need. One of the features of this school is that it is clear from the outset that a high level of professional attention is going to be needed for the foreseeable future.

Partnership and cooperation, Services by the People for the People – People First

People first is an organisation that is run by and for people with learning difficulties. The work of this agency is flagged because they provide support for phases of transition that it has not been possible to address through case examples in this report. For example, People First have directly supported good transitions for young adults and young parents with learning difficulties; and people with learning difficulties in legal troubles. They have also contributed to policy development; and professional training for student social workers in Edinburgh. The People First homepage states *“our lives are often ruled and directed by laws and policies that we have had no say in. One of our mottos is “nothing about us without us” and we’re pleased to say that, these days, Government and local government usually tries hard*

to listen to our points of view” (1,2,).

Thistle - Big Plans and Person Centred Plans

Thistle Foundation is a health and wellbeing charity that supports people living with long-term conditions across Scotland to live the life they want (6) have had positive feedback from families in this study for personalised and creative approaches to transitional planning and effective partnership with education staff leading on transition. Thistle offer the ‘Big Plan’ as an optional process which is person centred and gets a number of family groups (8-12) together in a neutral place over a series of evenings (perhaps 5-6)before a plan is crystallised. Participants include those whom the young person sees as important in planning for their future. Each family group also has a group supporter who was not previously known to the family. This adds something to the usual family dynamic and adds some additional, principled and experienced perspectives to the discussions. The experience of being ‘labelled’ is challenged.

The aim is to encourage a young person to think ahead positively towards what they would like to be and like to do, without the constrictions of very limited statutory options.

Transitions within this process are considered as opportunities rather than as anxiety- provoking times when the familiar is lost. There is a strong emphasis on allowing the young person not only to feel at the centre of the planning but also to feel ‘in charge’.

One of the benefits of having a “Big Plan” or individual person centred plan preceding formal statutory planning meetings is that social workers taking on responsibilities are introduced immediately to the aspirational personal outcomes of the individual and their family. The focus is on what matters to the person before allocation of the budget; and identifies strengths and assets of the young person and their network. There is also a recognition that leaving school and what happens immediately after is not the end of the story or the ‘destination’, but rather a significant step along the way to adult life.

Individual Person Centred planning may also be offered through Thistle and the core principles of the approach are shared throughout all services within the Thistle Foundation. There are some similarities to the Family Group Decision Making/Family Group Conferencing approach.

Thistle’s ‘Interact Project’ helps young people explore feelings about the future and think about choice, change and possibilities. This part of the Interact project happens in school. There are also meet ups which keep the young person connected once they have left school and help them get out and about, try new things and discover new places in the city. There is a film about the work of the project at www.thistle.org.uk/youngpeople

Creative Bridging: Contributing, Being, Belonging, Sharing and Control

During the process of the study there was opportunity to visit Donaldson's School for the Deaf which was about to diversify and set up an individualised service for young people (16-25) who face barriers to sustained employment as a result of their social understanding and social skills – for instance when affected by Asperger's. This programme is now operational. The service provides tailored personal development and employability mentoring which supports work-based and/or further education placements. The range of options and pace of activity is flexible, geared for trainees who have the potential to be in sustained employment or self-employment, but who may be deterred by social awkwardness, misreading of situations, a lack of social awareness or high anxiety. Plans incorporate family and carers and professional supports and address underpinning 'ordinary needs' towards living a dignified life. These needs are defined as contributing; being someone; belonging; choice and control and sharing ordinary places. The service aims to improve self-esteem, experience of collaboration, respect for others and resilience. A network of placements and employers will be developed and some young people may be supported in their own enterprises. The programme is motivated by a sensitivity to the paralysing struggle some young people have to make sense of standard teaching, peer relationships and competitive expectations. The programme will be evaluated.

Homelessness and Transitions – Bridging Gaps and Disengagement

Streetwork (7) was one of a cluster of services consulted in this study in relation to young people with additional support needs, homelessness and transitions to a more stable, well and self-managed life. Streetwork catches many of those who are homeless and find it hard to engage with or be engaged by health, housing, social work and other social care services.

Some have already passed through statutory care systems. Streetwork provides a variety of outreach services to connect with those who are unlikely to come forward or keep in touch with services that could support them transition towards a safer, healthier and more stable phase in their lives and relationships. There is close partnership with social work, housing and health amongst other services around the needs of the most vulnerable individuals. It is often difficult to sustain the persistent support to homeless individuals that is necessary to achieve change and stability.

The GIRFEC practice model has been adapted and integrated within Streetwork's brief assessment framework. The indicators of wellbeing and concept of resilience are applied alongside some highly pragmatic goal-directed indicators specific to moving on from a life phase of homelessness and risk.

There are signs that many young people using services have difficulties in functioning to do with past trauma, mental ill health, undiagnosed or diagnosed learning difficulty or attention deficit condition, autism and other chronic challenges. Accessing assessment, support and treatment can be complicated by substance

misuse. Streetwork try to be flexible and continue to work with and reach out to those for whom this is a barrier to help. However, as indicated above, it is difficult to sustain the personal connections and resource the outreach and attention needs of this population.

Reference has been made to the risk reduction approach being trialled by Edinburgh Access Point and related programme 'Inclusive Edinburgh' (8), which applies GIRFEC concepts to planning around adults with multiple challenges. There is a close working relationship with Edinburgh Housing and Social Work services. In many cases the involvement of statutory services with persons needing sustained support is transitory, comprising initial assessment and planning.

There has been some partnership with Community Learning Disability Nursing staff but their resources are also stretched thin. The area of support for safe and healthy sexual development, behaviour and relationship is particularly difficult within a range of young people whose emotional needs, emotional state and living situations may be unstable, excluded, isolated and additionally confused if complicated by substance misuse or attention deficit, autism or learning disabilities.

Efforts are being made to develop Group Decision Making meetings, using Family Group Conferencing/Family Group Decision Making principles (9, 10, 11). The person's needs and wellbeing are central to a process that is prepared and facilitated by a neutral co-ordinator. A practical plan is formed in a group meeting in partnership between those who care about and have responsibilities towards the person. City of Edinburgh use the approach for children in many urgent circumstances; and this is an initiative to use it with adults at risk and in need of a support plan. Staff acknowledge that individuals may not have reliable family relationships around them but they may have supports and friendships that can be brought together to assist in forming a person centred and group directed plan that could mobilise the support needed to move to another phase of living.

Training modules found to be helpful for Streetwork staff helping young people move on include motivational interviewing; de-escalation and conflict resolution; psychologically informed practice; foundation knowledge of legislation relating to vulnerable adults and homelessness; and systematic use of support planning tools. There are also skills in approaching and engaging young people in the community in groups that are difficult to acquire by training but are demonstrated and developed with success by Streetwork staff in practice. Streetwork provides a range of services and their flexibility and ability to reach out to those who may be chronically disengaged. There is much to be learned from their approach to supporting good transitions, bridging the cracks between mainstream services.

Upward Mobility – Creative Person Centred Bridging and Personal Growth

Upward Mobility (12) is an Edinburgh-based charity providing support and opportunities for adults with learning difficulties and autism the project is running over 70 workshops a week in Creative Arts, Employability and Health and Wellbeing subjects for over 135 students. Young people and parents in the study participants

praised their approach. As well as providing tailored support services, UPMO have a growing reputation for our curriculum of creative workshops, educational activities and vocational programmes. Upward Mobility is also a registered support service provider accessible through with self-directed support. Tailored support can be provided 24 hours a day, 7 days a week and 52 weeks per year.

UPMO provide an extensive range of educational workshops structured around the Curriculum for Excellence. Workshops are designed to enable compatibility with colleges and other educational providers. Access courses, delivered through the SQA unit structure, can be accredited by educational partners. Collaborative learning promotes self-confidence and the development of personal skills and abilities through practical learning. A short break service called Outward Mobility offers a variety of experiences, encourage team work, greater independence and personal confidence.

Person Centred Services Bridging Sever Communication Needs

The study gave opportunity to visit a service, highly praised by parents, young persons and professionals in this study. TEENS+ is a service which provides further education, life and social skills, offer work placement support, transition to ownership of tenancies and lifelong learning, to young people who, due to their needs, would ordinarily be excluded from accessing any form of further education once they have left school. TEENS+ is an Edinburgh-based, full time, transitional education project for young adults aged 17 to their 20s, with complex and severe communication needs, such as autism, who have left school and are entering adulthood. The qualities that stood out were personal knowledge and relationship of staff with participants and respect and partnership with parents. There is a depth of experience and expertise in management that undoubtedly contributes to a shared ethos about patience, listening and inclusion.

Bridging Services and Policy Development – Advocacy for Parents

Kindred (14) is a third sector advocacy service for families with complex needs, originally based in RHSC in Edinburgh and now with an independent office in Edinburgh and team in Glasgow. They have achieved consistently positive feedback from families in this study for listening, expertise, and encouragement. Kindred support 800-900 families a year and are well attuned to the whole family perspective and offer individual and group support with transitional issues.

Networking and Partnership with Parents

All the successfully established third sector services in this study started small. 'Children Inc' is an East Lothian service based in Musselburgh. There are at least 500 children in East Lothian with Additional Support Needs and/or a disability. It is a

struggle for many to access local provision and activities. East Lothian has rural areas where families can be isolated and excluded from local and Edinburgh provision due to lack of affordability. The very few local providers tend to be oversubscribed. A project co-ordinator arranges to meet with children and families individually and in groups to explore their wishes and to design and facilitate short breaks using a person centred, asset based, outcome focussed approach. Each family will be offered an amount of support time from staff or volunteers sufficient to participate in their chosen activity and achieve their objectives. Children Inc support disabled young people to identify activities they enjoy, build on strengths and local connections and break down the barriers to accessing opportunities. Their aim is to increase access to resources within local communities, promote inclusion and demonstrate the effectiveness of co-productive work with families. Services supporting transitional planning with families have something to learn from this approach.

Also in East Lothian and with core funding from the council, “Dad’s Work” (15) have proved successful in developing a network of peer support, counselling, group work and a range of community activities. There is nothing disability specific in relation to the service but the service is about a form of transition and is open to men of all ages who have children under 3 years.

Networking between Young People

Several young people and families in this study have reported positively on Neighbourhood Networks (16) an organisation that has been successful promotes friendships and independent learning between young people with additional support needs, who live within reach of one another. The young people have set their own activity plans but these fit with goals that they agree in terms of e.g. travel, money management, life skills, confidence, health and wellbeing, volunteering and work. The success of the approach is about relationships but pragmatic progress is measureable and graphically shared by means of outcome descriptors and points. This is an example of an organisation that opens out the world and promotes wellbeing for those who may otherwise feel isolated and tied to family.

Multi-Disciplinary Teamwork – Community Learning Disability (CLD) Nursing

Participant parents within the study have spoken very positively about the skills and contribution of CLD Nurses. Children with a learning disability and behavioural difficulties are more likely to experience discrimination and exclusion. Their educational, social and employment opportunities are frequently constrained and limited. CLD Nurse skills can have a significant influence on good transition and inclusion across the lifespan. (17)(18)

NHS Lothian is the only place in the country in which the Community Learning Disability Nursing service is ‘cradle to grave’. There are apparent strengths in

existing practices. Team meetings in which CLD nurses are integral are multi-disciplinary with an established interface with the sector social work team and local GP surgeries and 8 teams across Lothian work collaboratively with other health care services, social work, voluntary services and others.

The main aim is provision of a specialist assessment, advice, treatment and support services for adults with a learning disability and their carers. Unlike other parts of the country, community nurses in the team also provide services for children with a learning disability. A consultant psychiatrist from outside the study area acknowledged the advantages of Lothian systems in this respect. Currently there is a possibility of continuity when continuity is needed.

One potential gap in transitional planning about wellbeing in adult years across the study group related to sexual and relationship development. Some parents and carers feel that emerging feelings and explorations which may be an expression of normal development are considered as a dangerous problem to be treated. However young people are growing up with feelings and choices and need support in relation to their own wellbeing, health and safety (19); as well as for the health and safety of others. CLD nurses have access to training materials which are applied when appropriate. STDs are also an area of focus. CLD nurses find that there is a need for persistent and consistent one to one support and education for young people with learning difficulty to maximize the chance of retention and comprehension of key elements.

Specialist Bridging Dilemmas and Ideas – Epilepsy – Nursing Perspectives

Lothian paediatric epilepsy nurses at RHSC are very hard pressed with a caseload of up to 1000. The extent to which follow-up and direct outreach is possible is limited. Nevertheless, through epilepsy teenage transition clinics there are regular and predictable mechanisms to ensure the offer of preparation for transition to adult services. The adult epilepsy specialist nurses are also stretched with much higher caseloads.

There is an expectation of provision of at least annual review. Usually 6 monthly appointments are offered. Take-up is uneven and after two failed clinic appointments the usual process is a letter sent to the family and GP with a further appointment. Referral back to GP for follow up may happen if a young person has failed to attend appointments offered over 1 year or failed to attend a handover clinic appointment within the adult service. The impact of this is variable. In a small minority of situations there is sufficient concern for Child Protection enquiries to be triggered in view of the risk. At transition there is a greater proportion of young adult men who to disengage and the risk of death for those with severe conditions is understood to be higher for young men within the high risk age group 16-24.

The Epilepsy Nurse Consultant and team at RHSC are conducting a survey of attitudes to services and transitional support amongst 100 young people from 12 years old and upwards and their parents. There is likely to be an attempt to develop means of engaging through 'cloud based' media/ and mobile apps (such as Hekkel)

that have been tested in other settings. Approx. 50% of the 100 young people involved in the RHSC Hekkel study mentioned above and being treated for epilepsy, also have learning disabilities.

“*Ready Steady Go*” is a set of simple materials designed for supported completion with patients

(<http://www.uhs.nhs.uk/OurServices/ChildHealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>). They can work well when they work as a passport and preparation for moving to new services. Not all young people engage with such materials. There is research evaluation ongoing in Southampton in relation to this approach.

It would be ideal for the purposes of transitions to adult health services if there was a database that allowed tracking of all patients across services. However this does not yet exist. There are many patients with multiple conditions and transfers of service to adult health specialisms may occur at different times rather than as a seamless and co-ordinated occurrence. There are currently 5 consultant neurologists at RHSC and all have young people with epilepsy on their caseload. Epilepsy may not be the primary concern. For those with profound and multiple difficulties it is likely that consultants might retain young patients a number of years in to adult life when it is critically in the patient’s interests to do so. It is a factor in this retention that many patients who had poor life expectancy within childhood have survived through excellent health care.

It is of comparative interest that some specialties (such as diabetes) within English Health boards deliver services from childhood through to age 26, which almost certainly eases the risk of transitional disengagement

Staff are aware that more might be done with a slightly enhanced staff team – for example if one nursing specialist post could be found through fundraising beyond the public sector. NHS Lothian could match this for 3 years. There could be a more proactive approach with young people which could have an immediate impact on follow-up and this becomes hugely significant for patients who find it a struggle to engage with clinics and professionals they do not know.

The concept of the GIRFEC lead professional and single plan core components do not seem to be apparent within the thinking about transitions between health services in epilepsy, unless a child is also subject to Child Protection or LAAC processes. For those with Exceptional Health Care Needs the Nurse Transitions Co-ordinator has a valuable role much appreciated by families. There is currently specialist nurse equivalent with Spina Bifida and Hydrocephalus Scotland, assisting with co-ordination of Transitions for those impacted by these conditions. For children with less severe conditions the opportunity for co-ordination, tracking and follow-up is constrained by resources.

The impact of integration of Health and Social Care has apparently not yet been felt in terms of the direct management of transitions.

There is some anecdotal concern that some local authority criteria for Self-Directed Support may prevent kinship carers and family members getting payments as personal carers, although Kinship Carers may well get Carers Allowance. Some

authorities will allow pay of extended family members as personal carers through SDS.)

Within *adult* epilepsy nurse specialist teams the register of potential patients is very large— perhaps 10,000. 3000 patients are newly diagnosed every year. 70% may “get better” in year 1 following diagnosis, leaving 30% with refractory conditions. A review clinic is offered every quarter. If the patient is not engaged early it is much more difficult to get them engaged at all – a comment made elsewhere by diabetes specialists. The task of tracking those that are moving from paediatric services is particularly difficult in the absence of a database that facilitates this. There are also many patients that will not use third sector supports.

Some young people with complex/multiple conditions have 6-8 sets of clinical notes and this is in some ways a safety net. Those whose conditions are less complex are less easy to keep engaged.

There are many that may fall through the net of annual reviews and Transitions clinics in paediatric services, for instance because they or their parents are not motivated to attend. Referral back to the GP may work for some but as the patient moves in to adult years their own choice is obviously a key factor.

The ideal would be to have a name and the names of the key contacts around each patient as they approach transition, allowing tracking and follow up as part of a care plan. There is some interest in the idea of outreach and support from para professionals who are not nurses, so long as such outreach support was properly defined, funded, supervised and supported, working closely with core health services.

Some health professionals were of the view that there is scope for a national forum in relation to this area of practice. Health professionals drew attention to the role of Managed Clinical Networks in relation to making guidelines accessible and supporting professionals across disciplines in good process and practice (20) (21). SIGN guidelines are a helpful guide to parents, carers and patients. SIGN produce booklets that are lay translations of clinical guidelines; and help to make patients aware of the tests and treatments they should expect to receive from the NHS. Some may be in process of revision or development. Some patients may struggle to access or understand current publications and there is scope for development of more accessible patient information in a variety of specialisms.

Specialist Bridging Dilemmas and Ideas – Cystic Fibrosis

Treatment of Cystic Fibrosis has changed dramatically in recent decades. One of the biggest changes has been towards support for more intensive treatment at home. Paediatric nursing staff explain that they more often supporting parents and carers in administration of I.V antibiotics to prevent hospital admission. The hospital team works with families, not just the patients, all the time.

Numbers of patients have steadily grown – RHSC specialist team is working with around 150 patients and families now and their geographical remit now stretches beyond the Lothian and Borders to Fife and Forth Valley. Resources are stretched.

Transitions are supported in part through parent information evenings. In the past, supportive networking was encouraged between young people with cystic fibrosis. This is no longer the case, because of recognition of increased risk of cross infection.

However, staff emphasise that personal relationship is key to preparation for transition. Gradually, perhaps from the age of 13 and 14, they will try to encourage children to begin to think about taking care of their own health, so that they realise the importance of being honest, of following treatment guidance and starting to take care of themselves. This is a form of early preparation for taking responsibility for themselves and talking with health practitioners in adult services.

In all cases where patients are likely to transfer to adult services the paediatric CF team have a practical year ahead view and will invite adult specialist staff to come over to a detailed transfer discussion in each case. Given the pressure on adult services it is difficult getting adequate transfer discussion time. However there is a Psychology Unit in adult services which is an asset at the time of transition. Staff work closely with diabetes services because of the relationship between CF and pancreatic function.

Nursing staff make connections between parents that may be mutually supportive and this can have benefits through transitional phases and beyond. This has been beneficial for example with a number of some ethnic minority families who might otherwise have been more isolated. Recruitment and support of a specific interpreter has helped with communication. In the past the use of multiple interpreters who have not had specialist awareness of terms being used has been problematic.

Third sector organisations are close partners, including the Butterfly Trust (22) . MECOPP (23) is a much valued third sector organisation in Edinburgh that supports minority ethnic carers in relation to cross cultural issues, especially with Asian and Gypsy/Traveller families.

These organisations have helped with advocacy, listening help, completion of complex DLA benefit and Self Directed Support forms and applications; understanding of specific cross-cultural issues; networking and signposting. Some patients have complex social histories and circumstances and this requires networking with teachers, family, psychiatric/psychology staff and making extra efforts in ensuring the young person engages and remains engaged with the services they urgently need and in some urgent situations accompanying and introducing patients to other crucial health services.

Nursing staff emphasise that listening is the key to supporting successful adjustment to diagnosis and children and parents adjust at different paces and in different ways. That takes time. Not all the information on the internet (which children will access) supports positive adjustment as some of the blunt presentation is traumatic. There is a concern about those that disengage beyond paediatric services and the young person and family may not always be pursued in adult services as quickly and persistently as they would be in paediatric services. It is very difficult within current resources to monitor and track and re-engage such individuals. This concern prompts thinking about the potential value about some form of peripatetic or outreach support especially during transitional years that might serve as a bridge for

individuals and parents for whom the jump to adult services is not easily made and for whom other forms of advocacy and networking are crucial.

General pressures to allocate child protection work have reduced the potential for specific social work liaison with specialist teams in the hospital setting. There is little discussion about transition in standard nursing training. There may be a case for a pre-qualifying module in support for positive transitions and related issues e.g. to do with working with patients within the ecology of their family relationships and working together with other agencies.

Specialist Bridging Dilemma and Ideas – Diabetes Nursing

The technology for monitoring and treatment of diabetes is evolving very rapidly. This is another area where a high degree of professional specialism is vital. The working relationship between the paediatric and adult diabetes nurse specialists in Edinburgh is necessarily close in transitional stages. This between age 14, when patients first come to the adult setting for regular clinics with paediatric health professionals and aged 17 when the adult team take over. There is a nurse specialist in the adult team that focusses on transitional years.

There is a detailed and holistic handover summary for each patient but time is very stretched in relation to those that do not engage well with existing systems. The consequences of non-engagement and compliance with treatment can be fatal or lead to lifelong chronic conditions with crippling consequences for individuals and escalating costs for services. The key to successful self-management is early engagement with adult services. Clinics are absolutely predictable and patient education is carefully structured and detailed.

Diabetes management is often complicated by social circumstances and complications for some are predictable in advance. Resources are so stretched that there is very limited opportunity for follow-up in situations where individuals struggle to engage and understand the consequences.

There are likely to be ways to promote connection with information and support. The idea of a young adult diabetes patient group, on-line, would need careful thought but is appealing to nursing staff.

Many young adults rely on social media to communicate. Letters will not work well for some patients. A more versatile and flexible communication strategy may save lives. This echoes comments made in other areas of specialism.

Some peer to peer support has been set up on an individual basis, with mixed success. There are some successful parallels in NHS Lothian, CAMHS, with online peer to peer support between patients affected by anorexia.

Diabetic patients have access to psychological services. Multi-disciplinary work with social work and other agencies does occur when risks are high. However this does not often address the need to reach out to those below the horizon of formal co-ordinated efforts or are unreached by them; so there is some interest in the concept

of a peripatetic outreach worker supporting patients in transitional stages. A worker in such a role need not be a health professional or social worker. They would need to have the skills, knowledge and support structure to offer advocacy, mentoring, networking, signposting and connecting with key family and service supports as needed in each case. They might liaise, with due permissions, with health or social care services without cutting across roles and responsibilities. The volume of patients attending clinics mean that specialist nursing staff have no time for these sorts of activities. Diabetes management appears to be one of many areas in which the interface of health and social care responsibilities may require some creative thinking about bridging critical transitional phases in terms of communication media, information format, outreach and some generic training in support of principles of good transitions.

There have been two instances in this study in which the liaison role of a nurse specialist in arranging the process of hospital treatment has been crucial to an inpatient procedure for a young adult patient with learning disabilities and autism. The nurse co-ordinating the admission worked closely in preparation with parents. There was a further instance in which the communication between clinicians did not occur as planned and the procedure for the young person could not go ahead.

Crises and Growth in Transitional Stages – Mental Health Services for Young Adults in General Hospital

Children and young people in this study who have had extended in-patient medical treatment will usually have been known on first name terms by specialist health staff. Now they are one of a larger sea of adult patients and the degree of personal attention is much reduced.

Some of those that come to the attention of psychiatric services in general hospital in relation to self-harm have previously been Looked After or known to social work services. They are often experiencing multiple losses and rejections, including the disappearance of professionals with whom they have been to some extent familiar. Some choose to disengage. Others may be seeking to re-engage with services in ways that put themselves at risk – for example through self-poisoning. Where there is a need for a plan involving multiple services and significant risk to individuals then a case conference is sometimes called, convened either by a social worker if the issues seem primarily social and behavioural; or by a consultant psychiatrist in other cases where psychosis or other need for psychiatric treatment is the driver. The thresholds for multi-disciplinary case conferences are high.

There is also a hospital team approach in NHS Lothian termed the 'Patient Experience and Anticipatory Care Team'. This may be extended to young patients in transitional age and stages who are assessed as being at risk of unplanned re-admission. A keyworker and the patient and key clinicians agree an individualised anticipatory care plan which is shared with patient, hospital and GP. In many cases this involves communication with services in the community. Early signs are that this preventative approach is yielding positive patient experience and efficiencies but full evaluation is in progress.

Self-harm may have a variety of causes. In this study professionals have had a view that it may often correlate with a sense of rejection and despair in the transition to adult years. It seems unavoidable that there are cut offs and categories in service provision. It is unfortunate when multiple fractures in school, social work, carer and health services and relationships occur over a phase which can be associated with developmental disturbance.

For young adults with ongoing treatment needs, families are routinely involved. Indeed there may be a prolonged period of dependency with some patients who have complex needs and extremely supportive parents. It might take a while to encourage some young patients to be able to have a conversation with a doctor independently. With patients who have self-harmed, family members are core to care and recovery and are routinely involved but may or may not be reliable. Every situation is different and social work and housing professionals may well be called upon.

The availability of social work staff embedded in the hospital setting is reducing in some settings and some clinical staff are unclear what the 'inreach' will be in future.

Bridging Dilemmas – Young Peoples Mental Health and Wellbeing in Adult Years

There has been opportunity within this study to hear the views of clinicians in leading and strategic roles about dilemmas and work in progress, some of which falls outside the scope of this report.

Family perspectives on specific processes filter through in case summaries elsewhere in this report. Of particular note has been high praise for the skills of intensive behavioural support team within Lothian CAMHS; and praise for similar work with an overlapping but distinct group affected by autism by the Barnardo's Intensive Behavioural Support Team (24).

There is a shortage of in-patient and intensive out-patient resources nationally that can provide for young people with learning disabilities and acute mental health problems or severe autism and acute mental health problems. Resource issues have impacted on the pathways of some individuals and families in this study; but sustained consultation with CAMHS has proved helpful for individuals, families and professionals in some prolonged crises. The transitional period when CAMHS and school and potentially children's social work services are closing or transferring responsibilities is a time of heightened risk for those impacted by an interaction of learning disability or autism and mental health problems. The need for continuity and integration of service planning over this phase is crucial not only for the health and safety of individuals but for that of families, carers and professionals. Scottish Government have been supporting research and strategic development in this area of mental health policy (25,26,27).

There is a significant difference in threshold between CAMHS and Adult Health Services and in the scope for a holistic and preventative approach. There has been

great pressure to reduce waiting times for access to CAMHS. Lead clinicians contributing to the study would like to move in future towards a transitions protocol in which there is normally a planned transfer when individuals need continuity of service.

There are examples of some flexibility of margin in the 'transition phase' in patient's urgent interests. Successful developments include peer-to-peer support for those affected by eating disorders and improvements in transmission of accessible information and guidance for patients in some areas of specialism.

There are very limited in-patient beds for children and young people needing acute treatment and an absence of local in-patient treatment available for young people affected by a combination of severe mental health problems and learning disability or autism. This is an area of strategic consideration by Scottish Government and health advisors. There will be individuals whose complex needs will require multi-disciplinary planning for the foreseeable future and planning of transitions well in advance is a predictable and essential duty of care for Partnerships.

For patients e.g. in ADHD services who have been familiar with a service over as much as 10 years, there is little chance of sustained ongoing service from adult clinicians unless there is a clear requirement to continue medication for ADHD in adult years. If patients are transferred, and disengage, there are no systems in place for follow up in the community until other crises and problems occur. A significant proportion of those with ADHD have mild learning disabilities and/or depression or anxiety. The combination of factors in the fracture zone between services create additional vulnerabilities.

There are no current prospects of services developing along the line of CAMHS in Republic of Ireland, which has a model stretching from 16-23 years. Consequently the question arises as to whether there might be some supportive, pro-active follow-up in this period for advice, information, connections with services, mentoring and networking with family and other professionals, with due permissions. This might be done by an OT or by some outreach para professional as suggested in other spheres of work in this report.

One long experienced clinician summed up the professional features associated across services with successful transitions. These included: approachability; encouragement; clear information about processes and resources; guidance repeated as necessary in personal contact rather than just letters; a non-blaming approach to supporting family; and a solution-focussed approach. There is often a gap in public information about adult services and processes for individuals and families – and this gap is sometimes a barrier for professionals who would like to support transitional processes.

Scottish Government have commissioned research on effective models of service delivery in Learning Disability/CAMHS since 2014 (28). The interaction of conditions has implications for skills and resourcing. Learning disability by definition will require extra attention at transition in that it involves a significant, life-long condition that leads to a reduced ability to understand new or complex information or to learn new skills; a reduced ability to cope independently; and a lasting effect on development from childhood through to adult years. Physical health problems are more common, communication skills and coping strategies reduced, there is higher prevalence of

autism, of sleep disorder and of other mental health problems. There are risks of learning disability overshadowing other needs and diagnoses and for individuals to fall between gaps in categories of service. The need for holistic, co-ordinated planning, focussed on wellbeing rather than isolated treatments, seems especially clear when there is co-morbidity of this sort but it seems particularly difficult to achieve given the age related fracture zones and differential resourcing of age related service structures.

Mindroom (29) was mentioned by several families and professionals in this study as a source of expertise, information and solution finding, particularly for those with conditions associated with learning difficulties such as ADHD, ADD, autism, Asperger syndrome, dyslexia, dyspraxia, Obsessive Compulsive Disorder and Tourette syndrome. The collective expertise in this organisation is of significance in policy formation and development of practice.

Health Practitioners – Group Insights on Transition

At the very end of the study there was an unexpected invitation to talk about the study with a group of 15 health professionals (predominantly from psychiatry). Their comments and questions, helpfully underlined themes arising elsewhere in the study, namely;

- The value of co-ordination in complex transitions. Comment on the radical increase in cost, distress and risk if complex transitions are not anticipated early
- Recognition of the higher threshold for accessing adult mental health services
- Concern about reductions in budgets affecting 'packages' of care; and recognition of the impact of reductions in respite for those with exceptional health care needs as they move in to adult years
- Recognition of the difficulty for families managing the recruitment and maintenance of a team of carers when this may be needed
- Appreciation of the value and the skillset in the LD CAMHS intensive behavioural support team – a scarce resource
- Recognition of the need for improved information systems for families and professionals
- Appreciation of the value of LD Community Nurses in a lifespan role that offers potential continuity before and after transitions and excellent communication potential with primary care, specialists and social care services
- Awareness of special schools need for support in transitional co-ordination so that they can support endings
- Awareness of the need to consider the family context and impact on parents of having carried years of intensive care and crises; and their need for support as they either begin to relinquish their part in this dependency or are unable to do so

- Recognition of the need to understand that it may be a choice and a cheaper option for those with profound and complex needs to be cared for at home but carers need to be sufficiently cared for and supported

Bridges in to Life and Home

During the course of this study a web of services have shared their approach to supporting positive transitions with additional support needs. This has included the including Dean and Cauvin Trust (30) which has developed comprehensive and practical, certificated programme to accompany the mentoring of young people preparing to move out of residential care or supported accommodation in to their own tenancies. The materials are adaptable and flexible and the key to successful delivery is mentor relationship and pacing attuned to each individual. The materials are being tested collaboratively in various contexts.

Bridge to Life and Work

Parents in this study have praised the small group work and flexible support on Edinburgh College 'Future Step' courses (31) which are intended to create a unique path for the future, whether this means employment, apprenticeship, college or whatever they decide is right for them. There are a variety of courses adjusted for levels of support need. Each student has an allocated worker for support and guidance.

Self-Directed Support

Some families find Self-Directed Support guidance overwhelming and those who opt to administrate complex packages of care themselves find they need the time and skills needed to run a small business. Family comments are congruent with the findings in *"It's no longer them and us –it's just us; Report of the Collaborative Practice in Assessment Program"* (32) This is an essential and brief guide based on research about early implementation of SDS in Scotland. Vital to the relationship between SDS assessor and families working well is:

- *"Seeing the supported person as the expert in their situation, and keeping their interests at the centre.*
- *Reassuring people. Assessment evokes a range of emotions*
- *Assessors being willing to say 'I don't know, but I'll find out', when they do not have the knowledge there and then*
- *Offering empathy, rather than sympathy.*
- *Continuity: relationships are built over time and repeated interaction."*

Bringing the Threads Together

There are identifiable and repeated threads in the pattern of those phases of transitional support that have been successful, including:

- **Enduring commitment and expertise** of individuals in specialist areas, despite overwhelming service stresses
- **User-led and peer support services**
- **Creative initiative** bridging gaps in statutory services
- **Partnerships between statutory and third sector**

7. Outreach and Training

A. The case for Health and Social Care Transitions Practitioners or Outreach Transitions Workers in specific areas of practice

1. Several themes emerging in sections 4, 5 and 6 of this report come together within this recommendation. Health and social care partnerships have collective responsibilities towards individuals impacted by complex additional support needs and potentially life limiting conditions, throughout the life span. There follows a short argument for a connective practitioner role in supporting good transitions, drawing on learning from specific roles, professional and family feedback during the process of this study.
2. Many of those with profound needs do get co-ordinated services proportionate to their needs. However, there is a helpful warning here, about those lost in transition - in predictable fracture zones such as the years during which individuals begin to be described as adults and services and connections to school, paediatric health and other support available to children in the community fall away. Health needs and young adult relationships may become more complex. The resilience or availability of those on whom they have depended may fade
3. Some with complex additional needs disengage from primary and specialist health care treatment and review that they need. Their ability to re-engage constructively, (rather than through self-destructive crisis), may be limited.
4. At the 'other end' of the need spectrum others are isolated by their abilities. They are sufficiently capable to remain isolated and almost invisible to health and social work services and yet their health and wellbeing may be profoundly impacted by their conditions.
5. Within this study there has been a repeated demand for accessible information about resources, services, processes, supports and networks. This has often been accompanied by a wish for personalised guidance, mentoring and advocacy in relation to choices, confusing processes, communications with professionals and others that may crucial to survival and future wellbeing. Within hospital settings the information, advice and advocacy provided by such services as Kindred has received glowing press from some families in this study and there is much to be learned from their success in listening and connecting needs to services.
6. There appears to be a shared need for connective activity and a connective role helping individuals and families make best use of what they can access.
7. Professionals in statutory health and social work services and in third sector social care services have acknowledged the gaps between existing structures. Complexity of core duties and volume of core demand reduces scope for flexibility and outreach. Accessibility of social work services within

hospital settings in general are being reduced and prioritised around child protection activity. Some individuals and families also get caught up in boundary tensions between services to do with finance. Some patients/service users 'go off the radar' and others become avoidant and avoided due to behaviours core services cannot tolerate or manage.

8. Within existing hospital based services the role of specialist nursing staff involved in transitional support e.g. in connection with exceptional health care needs has been very successful in the perception of families in relation to co-ordination, communication, advice, support and understanding of the ecology of each family situation. NHS Lothian have creative partnership with the Spina Bifida and Hydrocephalus Scotland Association in the form of a nurse seconded primarily involved to support transitions for those impacted by these conditions. This co-ordinating role is already making a difference within isolated specialist pockets and there are generic lessons to be learned from the knowledge skills and values they apply within transitional phases. In the examples above the core training and skill base is in nursing but it need not necessarily be so.
9. There are areas of need where a form of peripatetic 'outreach' at transitional stages may help reduce risks, promote wellbeing, independence and self-management and help individuals work with services and others with whom they are in relationship.
10. Within transitions apparent to professionals across hospital settings, this role could well be effective, for example, between paediatric and adult epilepsy services; between paediatric and adult cystic fibrosis services; in complex diabetic transitions; for young people with mental health problems recurrently presenting for emergency treatment due to self-harm; and adjusting to emotional and relational implications of transplants and other complex treatments.
11. Within community settings the multi-disciplinary approach of Community Learning Disability Nurses in NHS Lothian has good feedback from families and Lothian is apparently unusual in accepting referrals throughout the lifespan. There is much to be learned from their skills and approach.
12. There are lessons to be learned from some of the skills and impact of the GP Linkworker programme in Glasgow 'deep end' practices, managed by the Health and Social Care Alliance (33) General Practitioners at the Deep End work in general practices serving the 100 most deprived populations in Scotland, based on the proportion of patients on the practice list with postcodes in the most deprived 15% of Scottish data zones . This ranking, based on the Scottish Index of Multiple Deprivation (SIMD), is published on the website of the Information Services Division of NHS Scotland
13. The Linkworker activities benefiting a cross section of patients presenting within the GP setting include Listening, signposting, networking, advocacy, partnership, information sharing and practical, personalised guidance and outreach home visits. Those within the Linkworker role embedded in GP

practices are not social workers or nurses, although they are managed as part of the Primary Health Care Teams. The momentum behind the impact of this and other such initiatives has caught Scottish Government attention and support. However the thinking has not been explicitly connected to 'transitions' to adult years and services and there is potential to take the learning from this programme and consider the application for those individuals and families in transitional phases affected by additional support needs known but isolated and known but disengaged and at risk.

14. There are young adults with acute and chronic impairments to their functioning and ability to engage who have never been diagnosed and referred. Some may be impacted by, e.g., autistic conditions, learning difficulty, emotional trauma, ADHD, untreated mental illness, repeated rejection and disintegrated social circumstances. Presentation to services may be to do with contact with police, homelessness and substance misuse. Creative networking and multi-disciplinary networking are apparent in the work of Edinburgh City Council's Access Point and Inclusive Edinburgh programme development (8).
15. The costs of being lost in transition are high within this group, for individuals, families and the community. Prisons, hospitals, primary health care, police and social work services are all strained in containment, treatment, control and protection activities relating to their needs. Within this group the case is made again for a peripatetic outreach role, offering sufficiently proactive and sustained contact with those needing support, information, guidance, networking, advocacy, acceptance following relapse, listening and reconnection.
16. Within the process of this study, social workers and other professionals have acknowledged that other pressures reduce direct contact time with individuals and families. . This is not always so. One of the secondary effects of this connective role – the health and social care practitioner (transitions) could be to diminish de-personalisation of services and sense of splits between services that arise in phases of anxiety and overload.
17. There are some parallels with the development of the social care worker role in statutory children and families social work teams. Skilled work is done by many social care workers in promoting relationship and contact between Looked After and Accommodated children and their siblings or parents. For decades this area of practice was given insufficient attention, with consequence for the overall trajectory of some care plans. It would be reasonable to consider whether there could be a social care role within statutory children and families sector teams that could major upon supporting positive transitions, reaching out to those individuals and families that need help in bridging the worlds of children and families social work and adult health and social care.
18. In short, the case is being made for the shaping of a recognised health and social care practitioner role supporting good transitions to adult years and

adult services

19. The base for such a role could be various – hospital, housing, primary care , social care or third sector advocacy service.
20. The funding for such a role should be derived from mainstream integrated health and social care budgets, corresponding to shared responsibilities and strategic priorities.
21. There would be generic skills, knowledge and values involved in such work and within specific areas of practice there would be a requirement for some specialist knowledge base. Section 7b below makes an outline case for relevant training, including a pre-qualifying module in transitions which might be offered jointly to professionals training in nursing, social work and housing; and interactive introductory training accessible online.
22. The Health and Social Care (Transitions) Practitioner might assist families with paperwork if so requested but would not encroach on the social work role of assessment of risk and need. A neutrality of stance in relation to resource provision and allocation is likely to be essential to such a role
23. Alongside skills in counselling, advocacy, mediation, networking there would be a need for development of skills in working with individuals in the context of their families and close relationships. It would be advantageous if this included knowledge and skills in family or group decision making because there are times in which it can be helpful to offer a specific vehicle for partnership planning at time of transition.
24. The supervisory structure for such a role would be dependent on the base location and service user focus. However the integrated line management and support of the role would be essential to safe, coherent and improving operation of such a service. This would not preclude valuable peer support, networking and training between those attempting to support transitions in other specialist settings.
25. The remuneration for such a post would relate to the specification for the post and essential qualifications, experience and responsibilities. It should not be essential to be a qualified nurse or social worker in all settings. There may be some settings in which it may be advantageous to be so. If that were so, this may be the sort of post that lends itself to the possibility of secondment and career development for those whose motivation and skills relate to developing aspects of front line practice in relationship, in the community.
26. It is potentially a highly challenging context and role and may suit those who may not immediately find a doorway in to health and social care through a degree course yet seek a well-structured and supported, yet creative opportunity to make a difference.
27. It would be advantageous if the strategic thinking and developmental and monitoring advice around such an initiative deliberately opened steering

groups/ committees to parents and service users with the time and expertise to give.

28. There are opportunities for practice learning placements attached to such post holders for practice learning in social work, nursing and some other professions. Such arrangements require careful preparation but the opportunities for learning across a variety of contexts are immediately apparent. This study has had a focus on transitions to adult years and services but there are strong parallels for needs to support re-integration of those leaving prison and older people leaving hospital.

7 B. Introduction to Transitions to Adult Life and Services – Interagency Modular Training

Sections 4, 5 and 6 of this report have shown some shared dilemmas as well as specific challenges in some areas of transition work. As young people move in to adult life and services there is a tendency towards higher thresholds for access to service and less integrated or connected service planning and provision. Just as there is an inter-agency need for awareness of GIRFEC principles, child protection and adult protection processes, there would be value in a shared awareness of support for good transitions.

It is suggested that an introduction to good transitions could form a component of pre-qualifying training across professions in health and social care. The materials could provide a basis for induction in a range of role, especially in social work, housing, nursing and third sector advocacy and service provision. There could be advantages for multi-agency training, as there has been in some child protection training.

Development and delivery should include involvement from service users, parents and carers as well as professionals with co-ordinating responsibilities. Podcasts, video-clips and interactive exercises could be created for online training.

The components suggested below interconnect:

‘Principles of Good Transitions 3 and the GIRFEC practice model’ would provide a congruent foundation in values, rights and underpinning legislation.

‘Leaving, moving and learning’ would provide an appreciation of practical pathways and emotional implications for all involved, for moves from school; from home base; towards college, work, daycentres, new explorations - whatever follows.

‘Health pathways’ could provide an introductory awareness of optimal bridging and co-ordination of changes, with realistic examples relating to structures and systems

‘Nurture and relationship’ could provide a recognition that the emotional security of each person depends on appreciation and support for the ecology of their close relationships. This should include consideration of safety, health and well-being in sexual relationship.

‘Skills in transition’ could provide an introduction to listening, planning, partnership and co-ordination skills with individuals and families; and inter-agency.

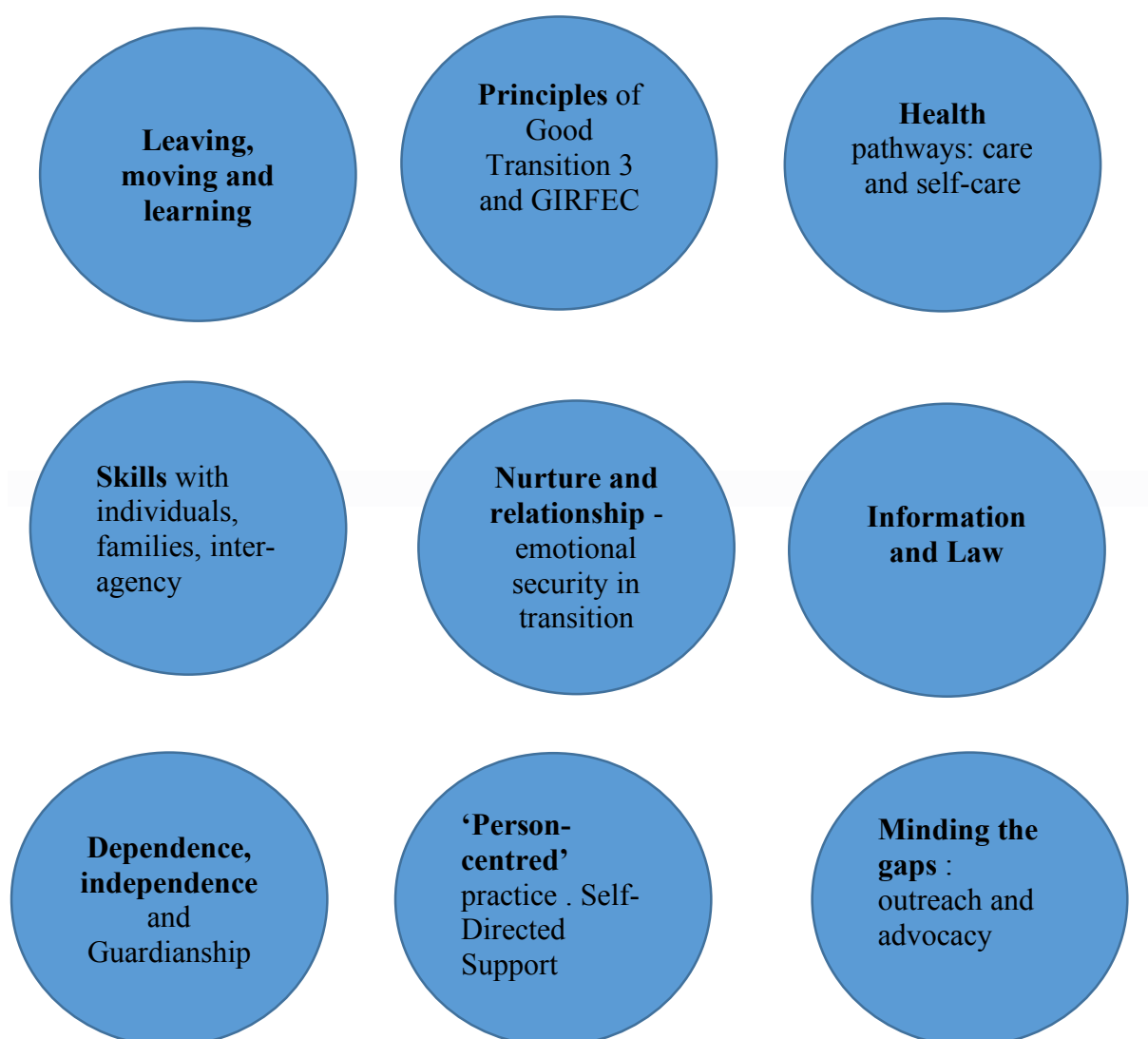
‘Information and the law’ could consider information networks, accessibility of public information about processes; resources; benefits and competent practice in sharing personal information.

‘Dependence, independence and Guardianship’ would introduce professional family and legal processes protecting individuals, their rights and well-being

‘Person-centred – from philosophy to practice’ would illustrate what works in person-centred planning, with specific reference to *Self-Directed Support options*

‘Minding the gaps’ would address inequalities relating to disengagement or inaccessibility of services, with specific examples of how gaps can be bridged by outreach and pro-active identification of risks and isolation.

There could be scope for packaging individual components for separate or local or on-line delivery.



8. Conclusions

1. Ecology of transition

This report began by suggesting an analogy – that there is a ‘DNA’ of transition – consisting of interweaving strands of need, relationship, risk and potential. There are interlocked patterns in the way individuals and those on whom they depend manage change. This has been apparent in some of the creativities, resilience and tensions encountered within this study

Experience of transition to adult years and services begins at different times and places in the experience of individuals and their families. Effective support for transition takes in to account the:

- Ecology of the young person’s past life and relationships
- Present impact of, for example, impending move from school and known health services upon young person and their family
- Likely ecology of their future relationships

2. Sufficient continuity

Where support is disintegrated and amounts to impersonal administration of a segment of change, then families impacted by sustained and additional difficulties feel isolated and vulnerable.

Effective support for transition for those with complex needs:

- starts early – at least at age 14
- involves sufficient continuity from those who assess and plan care during a period of multiple fractures in service

3. Consistency of approach and language

Many families express a familiarity with the language and understanding of the intentions behind the GIRFEC approach. Within this study, exploration has focussed on the concept of a lead professional, a single plan and co-ordinated transition planning that has holistic on focus on wellbeing rather than one element of health or care.

Most families believe that these ideas make sense when they are realised. They believe that these practice components would also make sense in adult years because the approach to assessment and planning is not consistent between children and adults services.

The language of GIRFEC is often used in Looked After Child Reviews and School Reviews by children and families social workers; and by some transitions social workers. Some third sector and statutory adult services

apply the language of the wellbeing indicators as part of assessment and planning processes.

The aspiration of a common language about principles of effective support for good transitions across services is 'work in progress'. The publication of Principles of Good Transitions 3 was welcomed across a range of social care practitioners and managers who were aware of it. There is not yet an equivalent awareness amongst health care practitioners.

4. Co-ordination or point of contact

A lead professional is usually needed when there are complex interlocking services in transition planning. Families do not always know who has a responsibility for co-ordination and linking of communication. Across the spectrum of needs in this study there are usually multiple points of professional contact for distinct purposes. Those families who have not had experience of externally co-ordinated planning wish for:

- a key contact for information about processes, pathways and resources
- an identified professional who has some familiarity with the young person and their home life over the transitional phase, e.g. 14 –21, who could be approached or who would visit on an agreed basis and "at least once a year..."

5. Practicality and expert guidance

Many families in this study have the experience of acting as co-ordinators of complex schedules, purchasing decisions, transport, health, activity and care arrangements. Understanding benefits and finances and making applications and re-applications is an extended minefield for many families, through which most would like guidance. They value the opportunity to talk through the 'nitty gritty' practicalities of choices, costs, aspirations and impact and need real expertise from those involved. Handing out a leaflet about a resource is not sufficient. Options need informed discussion. Providing an intense burst of information about Self-Directed Support can be overwhelming unless options and implications are talked through.

6. Personal engagement in transitional role

Health transitions are often seen as a completely separate process unless the combined health and social risks are high and case conferences or sustained joint work is needed. Within this study, experience of service provision is often segmented as school leaving age approaches and those that know the young person and the family best in school and health services, even if 'an extra year' is achieved, have to draw a line under their involvement.

Transitions work well:

- When a transitions social worker or adult services social worker is appointed early enough to get to know the family and young person

- When the learning from school and previous services, (e.g. about how a young person communicates and deals with change) is integrated in transitional assessment and planning
- When there is a personal and planned transfer between key health practitioners
- When key professionals are reliable, approachable and attuned to the whole picture

In health care transitions, the nurse transitions facilitators have been critical for those with highly complex needs, not only for their specialist knowledge of systems and conditions but also for their understanding of the family context.

Systems of health care transitions, for example, in epilepsy, cystic fibrosis and diabetes show great care and skill going in to early preparation and handover to adult services. The extent to which practitioners can reach out to those that become disconnected from systems during transition phases is severely limited by overwhelming workload and urgent attention to core tasks.

7. Information, public and personal

Patchy access to crucial information about resources, standard processes, choices and financial criteria is an anxiety for all families. They have limited time and varying capacity to access and debate choices and piece together a jigsaw that will support their young person's safety, health and wellbeing in to the future. Word of mouth through parent networks has been vital to many transitional opportunities. The most expert suggestions often come from others who have already struggled through similar systems and choices. Third sector agencies and health and social care workers can and have provided bridges to the web of information that has to be assimilated. However families wish for simple access to:

- A directory of resources
- A timeline for local pathways and responsibilities
- Explanations of process and decision making that are accessible, including e.g. podcasts and video clips
- Transparent criteria for budgets

Families and individuals struggle when they have to repeat complex information about to many professionals, time and again and some individuals need considerable support or advocacy to represent their needs and feelings accurately. Various information passports that help individuals and families pass information to carers and professionals are in use, such as 'All About Me'). The comprehensive but accessible PAMIS digital passport (34) is used in other areas of Scotland, but there has been no evidence of usage in this study.

8. Impact of resource thresholds and inequalities

There can be resource 'cliffs' for those that have had high levels of respite care in childhood. Some families are making choices between day service and respite come school leaving age because they cannot afford adequate levels of both. For those with the most complex and profound disabilities, levels of respite care in this study have been significantly reduced, by up to 50%, in adult years. There are situations in this study where parents have been confused and concerned about this resource divide unrelated to any change in the needs. Sometimes individual's needs become more complex in adult life and family carers conversely become less resilient with age. Families would like consistent criteria applied to the assessment and provision of respite. There was a general absence of awareness of the approaching implementation of the Carers (Scotland) Act 2016, which should influence how respite is considered.

The difference in thresholds for access to CAMHS and adult mental health services was generally acknowledged by professionals and there are equivalent threshold differentials in all sectors. Families were appreciative of those extensions to service in early adult years for some young people with complex and interacting conditions. For some young people moving on from paediatric services, the loss of a sense of relationship and care in the move was a shock. Considerable efforts have been made by health professionals in some spheres to provide a guided and supported transfer. This is not always possible. Individual service users will not always engage.

Resources are not equally dispersed across the geographical study area, with relatively intense clustering of services in Edinburgh. This can lead to increased isolation for some individuals and families in rural areas, unless extra efforts have been made to connect with them and connect them to services and opportunities. Some professionals observe that informal community support does seem to evolve strongly in some rural networks and that there can be pockets of difference in expectations of services when faced with a shortage of local opportunity and shortage of information about how choices might be made and horizons extended. Amongst the participant families have been a number of examples who have moved in to the study area (specifically 3 of the 5 local authority areas) from other parts of the UK, both because of the perception of systems of support from core services; and because of the wide range of specialist third sector resources.

9. Third sector partnerships

The word 'creativity' has cropped up frequently in participant summaries, in relation to the knitting together of plans for young people by families. There is also extraordinary creativity in third sector provision of care, training, supported accommodation, employment, activity, befriending, advice and advocacy. These services have sprung up in response to specific needs and gaps and time and again have made successful transitions possible. It is no accident because the expertise of those leading these services frequently

derives from personal as well as professional experiences. Their success has been as much to do with the manner as the content of their provision in terms of:

- Person centred communication
- Partnership in making plans with and for young people
- Understanding and advocacy for families in crisis
- Expertise in specific areas of need
- Encouragement of potential
- Promoting links to other people and services

10. Fight for wellbeing and inclusion

There were a few instances of tension and disparity between the experiences and aspirations of young people, parents and carers, unsurprisingly. Transitional relationships and opportunities have varied widely with levels of disability and capacity. Parents and young people are crossing different bridges during transition.

Every parent and carer in this study has demonstrated enduring, protective commitment, over very different pathways. Some processes have been recounted since birth of the young person and have required extraordinary endurance. The struggles to promote the wellbeing of their children have often been described by them as “a fight” with systems. Many statutory services have systems which focus upon safety, proportionate cost and evidenced outcome; and these priorities cannot always be reconciled with person centred planning. However, not all tensions are inevitable and some additional ‘bridging’ recommendations are suggested below, in tune with themes in this report. Effective transition means real inclusion. Real inclusion means demonstrated attention to potential and all indicators wellbeing, whatever the level of need, so that no individual is isolated by their additional needs.

9. Recommendations

1. **Wellbeing:** Use of the Wellbeing Indicators should be supported in transitional planning processes across services.
2. **Principles of Good Transitions 3 :** This resource should be adopted as the standard approach to transitions across all statutory and voluntary sector transitions services. It clearly demonstrates how to ensure good transitions, and is the standard all services are expected to work towards attaining.
3. **Information:** There is a need for improvement in access to local information about resources and processes. Information about local pathways is needed to help individuals, parents and professionals navigate local systems and to signpost support. Local areas should consider the potential application of vehicles such as ALISS as a platform for a locally self-generating directory.
4. **Training:** There is scope for a pre-qualifying and cross-service training module covering effective support for transition, for example in social work, nursing and housing. There is scope for development of introductory, interactive training materials online. The Scottish Government and other partners should consider the feasibility of developing such a resource.
5. **Outreach:** Consideration should be given by Scottish Government, local authorities and health boards to developing an outreach role. This would be designed to reach (a) those with additional support needs who may be at significant risk and (b) those who have not been well known to services because they have not been at known risk but who may become isolated and exhausted without proactive contact, signposting, networking and support as needed.
6. **Coordination and Point of Contact:** A lead professional is very important when there are interlocking services in transition planning. The availability of a lead professional to coordinate services for families within statutory health and social care and through third sector services during transitional years, e.g. at least from 14-21, would offer a considerable improvement in the experience of many families. Ensuring processes are in place so that families going through transition have access to a lead professional should be considered by local authorities and other statutory services.
7. **Structures:** Some children's social work services in the study area are planning for potential continuity of service to age 26, taking service user feedback into account. Restructuring services in this way should be considered by relevant service providers and lessons learned from future evaluation of this structural initiative should be shared and acted upon.
8. **Planning in Partnership:** Family Group Decision Making is a model that could offer a range of benefits in family led, co-produced transition planning for families in which family members, statutory and third sector services have a part to play. This is a form of collaborative, practical and person-centred planning with

individuals and family members or those most important to the wellbeing of the young person. The neutrality of the coordinator and the careful preparation of these processes are key to their success. Scottish Government and statutory partners should explore the feasibility of developing such a model.

9. **Resourcing:** Local authorities should give consideration to initiating a policy and practice review in relation to those respite or short break arrangements which are significantly cut because a young person turns 17 rather than because of change in need.

10. Acknowledgements, Professionals and Agencies

Dedication

This study is dedicated to Rhys, who knew his time was limited but kept looking forward; and to his mother. He sadly passed away before the report was completed. Rhys said that he wanted to take part in the study for the sake of others. With thanks and condolences to his mother who took part with him and who says she knows he would have liked his own name in this dedication.

Transitions study

This study was undertaken and written on behalf of the ALLIANCE by James Cox, Consultant, ALLIANCE Transitions Study

Transitions Study Monitoring, Supervision and Review

- Ronnie Hill, Associate Director, Health and Social Care Alliance
- Ruth Christie, Scottish Government, Children and Families Directorate, Children and Families with Disability

Participants

- Participant parents and young people
- Scott Read, Rebecca Williams, ARC Scotland/Scottish Transitions Forum
- Tracey Francis – independent researcher, Churchill Fellow
- Simon Jacquet, independent research consultant
- Marion Wood, Independent Social Worker and Service Manager, retired
- Alison Robertson and Lindsay Cunningham-McLeish
- Dr Arvind Veiraiah, Consultant, toxicology/acute medicine
- Divya Jindal-Snape Professor of Education, Inclusion and Life Transitions, Dundee University
- Paula Jacobs University of Edinburgh
- Jane Aldgate OBE Professor Emerita, The OU, Honorary Professorial Research Fellow, University of Edinburgh
- Dr Fiona Forbes, Consultant psychiatrist

Professionals and Agencies Consulted about Transitions

- Scottish Government leads on children and young people with disabilities
- Scottish Government LAAC Team
- Positive Realities SCIO
- The Getting to Know GIRFEC Advisory group, co-ordinated by Health and Social Care Alliance

- Lothian and Borders GIRFEC implementation group
- West Lothian Children with Disabilities Team Manager
- East Lothian Children with Disabilities Team Manager
- CEC Family Based Care
- CEC Adult protection officer
- East Lothian Group Service Manager Long term Care and Support
- Edinburgh Managers for Children's Disability,
- CEC Transitions Team
- RHSC Practice Teams. Specific social workers in relation to young people within the Study
- Edinburgh Head of Support for Children and Families;
- Edinburgh Children's Partnership
- Lothian Child Health Commissioner
- CAMHS & Hospital C&F Teams
- Midlothian Service Manager responsible for Transitions,
- Midlothian Head of Children's Services,
- Midlothian Transitions social workers;
- Midlothian consultant beginning revision of Midlothian policies and procedures for Transition
- Borders NHS Manager responsible for Transitions;
- Borders Council Steering Group for Transitions (Learning Disabilities); Encompass (Borders)
- Barnardo's Caern Project
- Kindred
- Epilepsy Scotland
- Thistle Foundation/ service managers / transitions co-ordinator
- Children's Hospice Association Scotland/Transitions co-ordinator
- Spina Bifida and Hydrocephalus Association /NHS Transitions Co-ordinator for SBHAS
- Carers of East Lothian; East Lothian Community Care Forum
- Children Inc, East Lothian
- Dean and Cauvin Trust, Y People, Dad's Work , Neighbourhood Networks, Forth Sector
- Freespace Housing
- MECOPP
- Sense Scotland
- Edinburgh College
- Upward Mobility
- Lothian Centre for Inclusive Living
- Pamis Headquarters Team
- Epilepsy Nurse Specialist Team, (Adults)
- Epilepsy Nurse Consultant, (Paediatric)
- Cystic Fibrosis Team (paediatric)
- Neurology Consultant (paediatric)
- Diabetes specialist nurse (adults)
- Consultant, acute medicine and toxicology
- Lead Clinician/ Head of Psychology CAMHS REH
- Consultant psychiatrist (adults, intellectual disabilities)

- Psychiatrist, general adult services
- Consultant Psychiatrist (Children and Young People with Learning Disability)
- Consultant psychiatrist (adults -transitions experience self-harm, transplants)
- Learning Disability Nurse WL and CEC/Undergraduate Nurse training co-ordinators;
- NHS Lothian Nurse Transition Facilitator
- People First (Edinburgh)
- Special School heads/teachers in 5 special schools
- Health and Social Care Alliance (Scotland) – policy lead for SDS; policy lead for comment on health and social care standards
- Lecturer in Child Health Lead Clinician for National Clinical Managed network for Children with Exceptional Needs (NMCN CEN)/
- CEC Talking Mat's trainersx2
- Autism strategy working group representatives from National Autistic Society; Autism Network Scotland Learning Disability Alliance Scotland; Autism Network Scotland.
- Homeless support servicesx5 and one third sector fostering agency
- Independent parental peer support co-ordinator and mediator (in touch with 200+ parents)
- Consultant psychiatrist, CAMHS, retired 2016*
- GP *
- Professor Leon Fulcher, Child & Youth Care Consultant, Chairperson, *The International Child & Youth Care Network* Board of Governors – in relation to training materials

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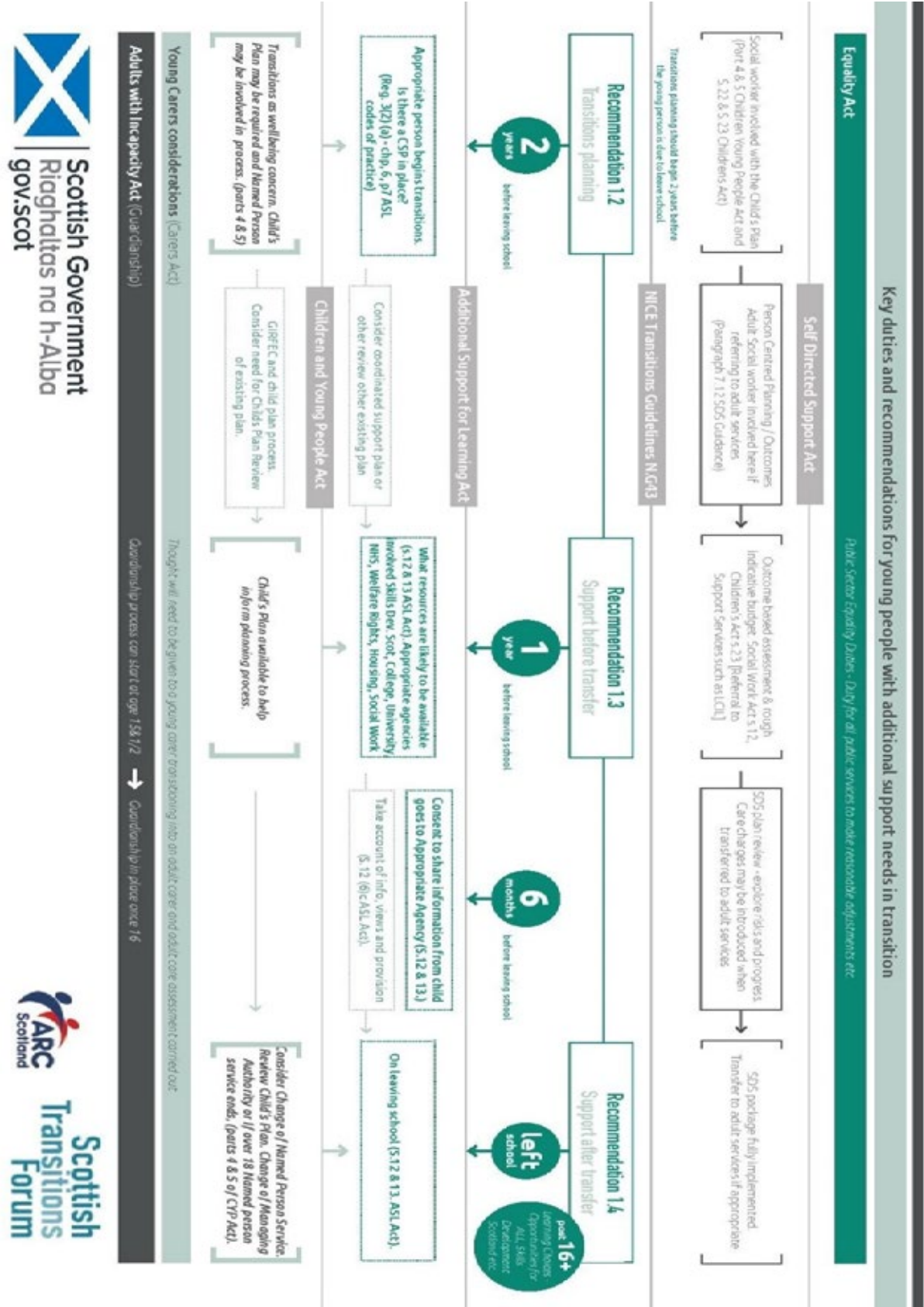
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14. Appendix



(Scottish Transitions Forum POGT3 - full size image can be found at <https://scottishtransitions.org.uk/flowchart/>)

Experiences of Transitions to Adult Years and Adult Services

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