



# Integrating Health and Social Care in Scotland: Potential impact on children's services

## Report One: A Review of Literature

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## A. EXECUTIVE SUMMARY

This review is the first of three reports from a study of the potential effects of the Public Services (Joint Working) (Scotland) Act 2014 and the resultant integration of (adult) health and social care services on children and young people in Scotland and the services they use. The study was commissioned by Social Works Scotland [previously the Association of Directors of Social Work (ADSW)] and carried by a partnership of CELCIS and Children in Scotland. This document aims to provide a useful summary of information relevant to current debates about integration, highlight the relevance of these debates for children and family services and provide context for the primary research strands of this study. This report will be followed in due course by the second report which will outline findings from other strands of the study and a third report which will drill down in more detail in one or more thematic areas.

For this review, the search strategy was flexible and broadly inclusive of academic peer-reviewed articles and grey literature sources such as policy and practice reports, legislation and guidance. The material was read by members of the research team from CELCIS and CiS to identify sources which provide direct or transferable insights into how integration might impact on children's services. We have done this by looking at three bodies of literature. Working broadly from the macro to the micro levels we have considered the development of relevant policy on Scotland, practical issues around service integration, and how changes to adult services may impact on children.

Findings show that greater levels of integration have been called for over a number of decades in Scotland. Increasingly this is mandated in legislation or inferred in guidance. Various structures and systems have been used to promote the integration of health and social care in Scotland; these have often been interpreted or enacted differently in different areas. Whilst this may be a response to local needs and conditions it has resulted in more success in some areas than others.

This policy trend has accelerated further over recent years, in particular with the Christie Commission, subsequent consultations and development of the Public Bodies (Joint Working) Act 2014. The Act requires the NHS and local authorities to work together through one of two specified models to deliver integrated health and social care services to adults. The integration of children's services is also permissible. Areas are required to produce a plan and work towards nationally agreed outcomes. The Act sets out a number of principles which should underpin integration.

Research shows that integration is a flexible and at times poorly defined concept; despite this it has been highly influential in rhetoric, policy and practice. A number of drivers for integration are discussed, including the need to respond to demographic changes and the need to improve services and outcomes; however, some authors argue that the need to achieve greater efficiency and savings is the key driver.

Integration can take place at different levels within organisations and structures. Integration at locality level has been shown to be necessary and effective but needs to be supported by integration at other levels. Revised organisational and financial structures will be required to sustain integration. Partners need to have clarity and develop trust in order to facilitate the highest levels of financial integration (i.e. pooled budgets); this may initially require a period of less intensive financial integration models such as budgetary alignment.

Integration of services other than health and social care is possible and there is some evidence to suggest that wider integration may be beneficial, particularly for population groups who use a wide range of services including health, social care, housing, benefits, education, transport and leisure.

The findings highlight challenges to integration including professional differences and communication difficulties. Approaches to addressing these challenges are discussed; these often include co-location, interprofessional training and shared IT systems.

Our findings highlight a number of links between children and young people and adult services, either as service users themselves or as family members of service users. We show how changes to adult health and social care services will have implications for the four groups of children and young people we have considered here:

- For the increasing numbers of **young people transitioning to adult services** and their families it was noted that transition was an especially difficult time. This is a varied group with diverse needs. Earlier planning and collaborative person-centred approaches are reported to be helpful.
- For the increasing numbers of **young carers** it was noted that despite competency in some areas there may be significant support needs requiring input from diverse service types. Young carers often remain somewhat 'hidden', which further confounds their risk of poor outcomes through poor access to support.
- Numbers of **care leavers** remains high; these young people typically have poor outcomes across a range of dimensions. Support needs encompass health, social and emotional factors as well as practical issues such as housing, education, employment and benefits. Not all entitled care leavers receive throughcare or aftercare.
- High numbers of **vulnerable children in the families of adult service users** are at increased risk of neglect or abuse. Providers of adult services can be instrumental in identifying and protecting these children through collaborative working with child protection services.

Thus the review suggests that the integration of adult health and service care is likely to impact on various groups of children and young people. In many cases collaborative approaches have been shown to be helpful; however, these benefits will only happen if children and young people's needs are considered and factored into decisions. The integration of children's health and social care services also has promise; however, the evidence suggests outcomes are, as yet, untested or unclear. Similar drivers, challenges and concerns are cited for children's services as for adult services; however child protection is often cited as the most fundamental driver.

We conclude that the Act is therefore a significant opportunity for children and young people in Scotland, proving that their needs are not overlooked given the substantive drivers and undisputed needs of adult service users.

## B. INTRODUCTION

This review is the first of three reports from a study of the potential effects of the Public Services (Joint Working) (Scotland) Act 2014 and the resultant integration of (adult) health and social care services on children and young people in Scotland and the services they use. The study was commissioned by Social Work Scotland (SWS) [previously the Association of Directors of Social Work (ADSW)] and carried by a partnership of CELCIS and Children in Scotland.

Policy, practice and legislation increasingly prioritise or require the integration of services. This is a clear and sustained trend which is likely to continue. Whilst the drivers of integration and the potential benefits are becoming clearer, it is not always easy to know exactly how to go about integration in order to realise these benefits most effectively.

This review aims to fulfil several functions; firstly, to provide a useful summary of information relevant to current debates about integration; secondly, to highlight the relevance of these debates for children and family services; and thirdly, to provide context and background for the primary research strands of this study currently being carried out. The review will be followed in due course by the second report which will outline findings from other strands of the study, including a national survey of key informants and case studies of two contrasting local authority areas. The study will conclude with a third report which will drill down in more detail in one or more thematic areas emerging from the first stages of the study. The topic for this extension report will be agreed in partnership with SWS at a later date.

In this review, we do not aim to provide an exhaustive or systematic review of all possible literature and material; rather we conduct a selective review covering areas which we feel are of particular relevance to the study. We do this in relation to three pertinent bodies of work; firstly, we consider the development of relevant policy in Scotland and provide a short discussion of the Act itself; secondly, we examine literature related to the integration of health and social care services; and thirdly, we explore material which considers some of the direct and indirect effects that adult services have on children and their families. This approach is summarised in Figure 1:

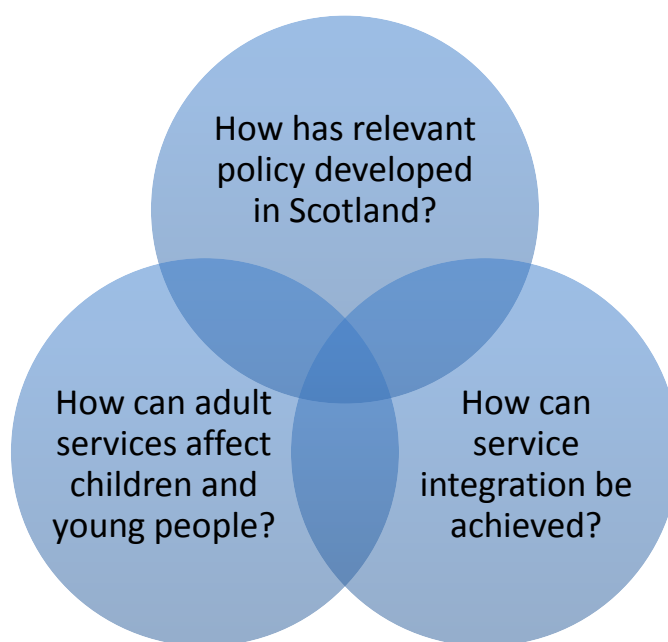


Figure 1 Areas covered in this review

## C. METHODS: HOW WAS THE REVIEW CONDUCTED?

Unlike a fully systematic review, our search strategy and approach to the inclusion of sources was flexible and broadly inclusive. This means that some of the documents we refer to are peer reviewed academic articles but others include legislative information, guidance, practice sources and policy. However, it is useful to outline some of the approaches we took to find material. This included:

- Existing knowledge of members of the team along with recommendations from colleagues
- Approaches to relevant stakeholders for recommendations
- Searches of academic databases including Scopus, Social Care Online and Google Scholar
- Hand-searches of reference lists
- Online searches through generalist search engines.

The material was read by members of the research team from CELCIS and CiS, notes taken and findings merged. Much has been written and much is relevant, useful sources being found in grey literature as well as academic writings in journals and books. Our aim was to identify material of good quality which provided direct or transferable insights into how integration might impact on children's services. Quality in such a broad context primarily relates either to the reliability of the source (with legislation or policy documents) or to the methods used in research and analysis (in academic literature). In terms of empirical research we try, where possible, to draw on recent examples of studies undertaken in Scotland as we feel this has particular relevance to our research questions. However, such information is relatively scarce and we acknowledge that there is much to be learned from older sources and from work conducted outwith Scotland.

Users of services may be conceptualised and described in different ways, ranging from consumers and clients, to 'experts by experience' (McLaughlin, 2009). The way we talk about service users has implications for the ways in which they are involved or engaged in identifying needs and planning services. In this document we use the generic term 'service user' for the sake of simplicity, but it is not our intention to infer service users are passive recipients; indeed, in successful integrated services there is evidence that the converse may be true.



## D. FINDINGS 1: HOW HAS RELEVANT POLICY DEVELOPED IN SCOTLAND?

### Rise of integrated working in Scotland

In Scotland, as elsewhere, the drive towards integration of various public services has been an enduring policy trend, to the extent that some authors identify an increasing hegemony of integration (Couturier, Gagnon, Carrier, & Etheridge, 2008; Hood, 2014; Wistow & Dickinson, 2012).

For a number of decades policies have been put in place to promote integration of health and other services. During the 1980s and early 1990s various criticisms of health and social care alongside a discourse of growing demand and rising costs underpinned arguments for more joined up services, the emphasis often being on cost reduction and the introduction of market processes (see for example DoH, 1989). During the late 1990s the emphasis shifted towards quicker decision making, preventing gaps and service improvement (see for example The Scottish Office, 1999).

In parallel, a number of structures and systems emerged in Scotland to promote integrated working; these included Local Healthcare Co-operatives (LHCCs) which were voluntary bodies set up from 1999 as a response to the 1997 White Paper *Designed to Care* (DoH & The Scottish Office, 1997). LHCCs were established with the intent of increasing the scale of partnership working between health, local authorities and voluntary agencies. By 2001 there were 79 LHCCs covering the majority of the mainland (Audit Scotland, 2001).

In 2000 a national group, the Joint Futures Group, was set up to consider joint working between health and local authority services. Their work was primarily focused on community care for older people and included consideration of joint funding for some services (Scottish Executive, 2000). The Scottish Executive accepted many of the 20 recommendations of the Joint Futures Group (Scottish Executive, 2001).

The Community Care and Health (Scotland) Act 2002 enabled, but did not require, NHS Boards and local authorities to work together. This was followed by the Local Government Act (2003) which introduced Community Planning Partnerships (CPPs) and the National Health Service Reform (Scotland) Act 2004 which effectively replaced the voluntary LHCCs with 34 statutory Community Health Partnerships (CHPs) set up to help bridge the gap between primary and secondary healthcare, and between health and social care (Audit Scotland, 2011).

In a comparison of integration policy in England and Scotland, T. Forbes, Evans, and Scott (2010) note that since devolution there has been scope for policy divergence. Whilst they found similarities and differences they suggest that in areas where Scotland has developed unique policy, the implementation of this policy has been variable. They suggest this was largely due to the weakness of guidance which allowed differences in interpretation, both at the local level and between partners. In the case of health and social care integration, Forbes et al. suggest that this allowed health partners to dominate debate and planning. These authors suggest that, at times, this has alienated local authorities (Evans & Forbes, 2009).

The Christie Commission was set up to review the future delivery of public services in Scotland. The report, which highlighted the need for extensive reform to create services which were more integrated, involved providers from public, voluntary and private sectors and emphasised prevention (Christie, 2011). The report provided renewed emphasis and Scottish Government launched a consultation on the integration of public services (Scottish Government, 2012). The government's response to the consultation report noted concerns over variation in the quality of services and outlined plans for forthcoming legislation, stating:

*This programme of change seeks to address those concerns and challenges by reinforcing the importance of effective partnership working within a statutory context. By making these proposed changes, we are looking to remove the bureaucratic and financial barriers that exist within the current system for delivering adult health and social care services, and to ensure clear accountability for the delivery of national outcomes, providing transparent performance information for different areas in Scotland. (Scottish Government, 2013c parag. 11)*

## The Public Bodies (Joint Working) (Scotland) Act

The resultant Public Bodies (Joint Working) (Scotland) Act passed Stage Three in February 2014<sup>1</sup>. The legislation will enable and require NHS Boards and local authorities to work together with partners under one of two models to create and deliver an integrated service plan for adult health and social care. The Act does not require local bodies to integrate services for children as:

*The Scottish Government believes that local partners (Health Boards and Local Authorities) will be best placed to decide whether children's services should fall within the scope of these new arrangements. (Scottish Government, 2013c parag. 16)*

Furthermore, although not specified in the Act, the Cabinet Secretary for Health and Wellbeing has clarified to Parliament that it is permissible for local partnerships to integrate children's services into these new arrangements.

The Act sets out a number of important principles for the delivery of integration:

*(a) that the main purpose of services which are provided in pursuance of integration functions is to improve the wellbeing of service users,*

*(b) that, in so far as consistent with the main purpose, those services should be provided in a way which, so far as possible:*

*(i) is integrated from the point of view of service users,*

*(ii) takes account of the particular needs of different service-users,*

*(iii) takes account of the particular needs of service-users in different parts of the area in which the service is being provided,*

*(iiiia) takes account of the particular characteristics and circumstances of different service-users,*

*(iiiib) respects the rights of service-users,*

*(iiiic) takes account of the dignity of service-users,*

*(iiid) takes account of the participation by service-users in the community in which service-users live,*

*(iiie) protects and improves the safety of service-users,*

*(iiif) improves the quality of the service,*

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<sup>1</sup> For progress of the Act see <http://www.scottish.parliament.uk/parliamentarybusiness/Bills/63845.aspx>

*(iv) is planned and led locally in a way which is engaged with the community (including in particular service-users, those who look after service-users and those who are involved in the provision of health or social care),*

*(v) best anticipates needs and prevents them arising, and*

*(vi) makes the best use of the available facilities, people and other resources.*

*("Public Bodies (Joint Working) (Scotland) Act," 2014)*

The Act will require Health Boards and local authorities to jointly deliver nationally agreed outcomes which will be focused on improving an individual's care experience. By introducing national health and wellbeing outcomes, the Government will be introducing a mechanism which ensures Health Boards and local authorities are jointly and equally accountable for planning and delivery of effectively integrated services. To strengthen this, outcomes will be set in legislation.

Under the Act, integration authorities will be required to produce a Strategic Plan, setting out how they will plan and deliver services for their area over three years. They would also be expected to plan for the longer term, and clinicians, care professionals, the third and independent sectors, service users and carers would be part of the planning process. Health Boards will be required to allocate funding for integrated service delivery according to the plan.

Community Health Partnerships will be removed from statute and replaced with Integration Joint Boards to provide joint governance, joint accountability and integrated oversight of service delivery. Each Board will be accountable to its local authority and Health Board for delivering outcomes, including locally agreed outcomes, using an integrated budget covering adult social care, community healthcare and some secondary healthcare.

Two potential models of integration authorities are outlined in the Act:

**Body corporate model:** whereby a Joint Board will be established from the local authority and health board with a chief officer who will lead development of the strategic plan and manage the integrated budget and planning and delivery of services. The integration authority will be established as a body corporate with its own functions and budgets acquired through delegation to the Integration Joint Board.

**Lead agency model:** whereby a joint monitoring committee of the local authority and health board would be established to scrutinise the integrated arrangements for the local authority and health board. It would hold the lead agency to account for the agreed resources and budgets on behalf of the health board and the council. The committee would report to the health board and council using a reporting mechanism specified in the plan. No chief officer would be required.

Discussion in consultations around the passage of the Act included concerns about how the new Act is related to other legislation. Of particular note in our context is the recently passed Children and Young People (Scotland) Act 2014. Several organisations expressed concern that links between these two Bills, the United Nations Convention on the Rights of the Child and policy for Getting It Right for Every Child (GIRFEC) was not made fully explicit. In addition, attention was drawn to the Social Care (Self-Directed Support) (Scotland) Act 2013 and the proposed Community Empowerment (Scotland) Bill, as these and a range of other legislation and guidance may also be affected by the Public Bodies (Joint Working) (Scotland) Act since they are concerned in different ways with collaboration between a range of children's services. Key sources are listed in Appendix 1.

## Summary: Findings 1

Greater levels of integration have been called for over a number of decades in Scotland. Increasingly this has been mandated in legislation or inferred in guidance. Various structures and systems have been used to promote integration of health and social care in Scotland; these have often been interpreted or enacted differently in different areas. Whilst this may be a response to local needs and conditions it has resulted in more success in some areas than others.

The integration policy trend has accelerated further over recent years, in particular with the Christie Commission, subsequent consultations and development of the Public Bodies (Joint Working) Act 2014. The Act requires the NHS and local authorities to work together, through one of two specified models, to deliver integrated health and social care services to adults. Areas are required to produce a plan and work towards nationally agreed outcomes. The Act sets out a number of principles which should underpin integration.

## E. FINDINGS 2: HOW CAN SERVICE INTEGRATION BE ACHIEVED?

It is not our intention here to provide an exhaustive review around integration since this is beyond the scope of this study and broad ranging reviews have been conducted by others (see for example Cameron & Lart, 2012; Cameron, Lart, Bostock, & Coomber, 2014; Curry & Ham, 2010; Minkman, 2012; Petch, 2011, 2012, 2013; Wistow & Dickinson, 2012). Our aim here is to provide a succinct overview of the most pertinent issues.

### What is integration?

An understanding of service integration is useful in that it provides background, context and insights related to the aims of this study. Gaining an understanding of this material can be challenging, particularly, as various authors point out, there continues to be no clear, uncontested view as to what integration *is* (Armitage, Suter, Oelke, & Adair, 2009; Minkman, 2012; Wistow & Dickinson, 2012). The lack of a consistent definition of 'integration' potentiates miscommunication and could compromise service planning and delivery (Armitage et al., 2009; Petch, 2011).

Broadly, integration includes some form of collaborative working which can occur with different levels of intensity and at different levels or spheres within (or between) organisations and systems; it may occur simultaneously in different formats or intensities at different levels (Curry & Ham, 2010; Robertson, 2011). Curry and Ham (2010) identify three levels at which organisations may be integrated and coordinated: macro level (services to populations), meso level (services to particular groups) and micro level (services to individuals).

In her review of evidence, Petch (2012) (see also Petch, 2011, 2013) highlights the fact that high level system change is insufficient to guarantee improved outcomes for service users. Instead she suggests that a focus on change in practice and culture at the local level is required and that the most effective changes are often incremental, negotiated and driven by local needs and opportunities. Encouragingly, Petch notes that recent developments in policy and practice in Scotland have some promise in this regard. The recent report *All hands on deck* (Strang, 2013) also underlines the need for a genuine and concerted integration at the locality level, involving all relevant stakeholders. Strang points out that this needs to be enabled by wider partnerships and facilitated and encouraged by flexible national frameworks.

Change at the local level is clearly insufficient on its own. There is a danger that by focusing only on this level, the scale of change would be insufficient; it is important to ensure that at all levels systems dovetail and reinforce each other. Curry and Ham (2010) stress that in order to maximise its potential to improve outcomes, integration requires change at all levels:

*Although we have distinguished between these three levels for the sake of analysis, in practice they are often used in combination; this is in recognition of the fact that changes at the macro level, on their own, are limited in their ability to make a difference for service users and also to address the weaknesses of care fragmentation... integration is unlikely to deliver on its promise of improving outcomes unless there is action at all levels. (Curry & Ham, 2010, p. 7)*

Because of the complexity of the change required and the need to have commitment and involvement at different levels, it may take many years to successfully complete integration. In the Torbay health integration project it took significant time and persistence to build relationships and overcome obstacles and Thistlethwaite (2011) details this activity over more than eight years. Integration must be a long-term project with long-term commitment; there is a danger that it will be regarded as a failure if change is expected over unrealistic timescales (Ling, Brereton, Conklin, Newbould, & Roland, 2012).

Consideration is also given in the literature to the scope and extent of integration. Whilst the integration of health services and social care services is important, further integration with wider services such as housing, transport or education may also be relevant (Fisher & Elnitsky, 2012). Similarly, it is important to consider integration within the sub-structures of larger organisations, such that health services work well with other health services and various social care services are coordinated.

Some authors argue that population groups who use many different public services are those most likely to benefit (Fisher & Elnitsky, 2012). Integrated services are not always universal services; targeted integrated provision may be formulated to address the needs of a section of the population such as older people, families with young children, disabled people or people with problematic substance use. This may be particularly helpful if these groups find it difficult to use other services; for example, a recent study of an integrated service for homeless people in Scotland and Norway was conducted by Anderson and Ytrehus (2012). They highlight the fact that whilst specialist integrated services have been criticised for not tackling exclusion, there is an increasing recognition that they are sometimes necessary and can help people to transition to mainstream provision.

Successful service integration may have potential benefits for users of services, those caring for them, service providers themselves and wider society. However, some authors feel that 'integration' can be seen by some professionals as a vague 'top down' requirement with little guidance and support being given to how it should be achieved in practice (Robertson, 2011). Any positive impacts that are anticipated should therefore be effectively communicated in order to promote acceptance of changes required to achieve integration (Cameron et al., 2014). Below we discuss a number of the main purposes or drivers for service integration alongside various issues that arise in connection with them; key drivers include demographic changes, increased efficiency or cost reduction, increased effectiveness or improving outcomes and promoting participation.

## Demographics

People are living longer, but may require support from health and social care services to live well. Demographic change is a major driver for health and social care integration (in Scotland and elsewhere). Older people may also have less access to informal support from family and community due to increasing mobility and fragmentation of families and communities (Four Nations, 2013). The Christie report starkly states that:

*Unless Scotland embraces a radical, new, collaborative culture throughout our public services, both budgets and provision will buckle under the strain.* (Christie, 2011, p. viii)

These demographic changes are relevant to this study since in this context the needs of older people are necessarily at the forefront of health and social care integration. This is not inherently wrong, but may divert attention from the needs of other groups such as younger adult service users (including those who are parents of young children), young people approaching transition to adult services and children who are carers of adults.

## Efficiency and budgets

Allied with the need to meet increasing demand is the hope of greater efficiency or overall cost reduction (Anning, Cottrell, Frost, Green, & Robinson, 2010; Pollard, Sellman, & Senior, 2005). The current financial climate also drives calls for greater efficiency through integration (Centre for Policy on Ageing, 2011). However the limited evidence available suggests that integration itself is not an easy or cheap option and in the short term costs may increase:

*Integration set-up costs may be high and require considerable upfront investment. Ongoing costs to services need to be sustainable and mechanisms need to be in place to link upstream*

*substitution of programmes to cost savings.* (Weatherly, Mason, Goddard, & Wright, 2010, p. 3).

Raine and Watt (2013) note that whilst budgetary saving are often highlighted as a substantial reason for integration, there are usually co-existing drivers such as service improvement. In addition, authors such as Curry and Ham (2010) suggest that the evidence for savings from integrated working is currently unclear. Authors such as Robertson (2011) argue that if increased efficiency or cost reduction is the main aim, then integration may eventually be regarded as a failure. Robertson further suggests that the evidence base on which to judge the effectiveness of integration is intrinsically problematic, since definitions of integration and its aims vary in ways that mean it is not possible to aggregate findings from diverse studies.

Furthermore, when considering efficiency, it is important to consider the preventative role of integrated services; these savings may also be difficult to quantify. The Centre for Policy on Ageing (2011) warn that preventative services are particularly vulnerable to budget cuts and they suggest that this may be a false economy:

*... supporting and stimulating the provision of 'that bit of help' in the community can provide older people with the assistance they need to sustain the health, activities and relationships that are important to them.* (Centre for Policy on Ageing, 2011, p. 1)

The authors cite examples of significant savings derived from delivery of preventative services such as specialist day services, telecare, advice and information services, care and repair, rapid response adaptations, support for carers and crisis response services. This is not to say that these savings are due to integrated working rather than early intervention.

People's health and wellbeing is determined by individual, familial, social, economic and environmental factors. As a result, people may have complex health and social care needs which cut across the boundaries of traditional service delivery and require the involvement of a range of different agencies, professionals and practitioners (Cook, Petch, Glendinning, & Glasby, 2007). It is claimed that by working together professionals can be more effective, responding more sensitively and fully to complex needs and offering services which recipients experience as being more holistic, seamless and complete (Irvine, Kerridge, John, & Freeman, 2002; Tett, Crowther, & O'Hara, 2003). For example, collaborative working may avoid or reduce an inappropriate service response such as delayed discharge from hospital due to the unavailability of suitable housing or care or a poor understanding of a person's concerns (Glasby, Littlechild, & Pryce, 2004; Kydd, 2008; Majeed et al., 2012).

A small number of studies have shown potential benefits from integrated funding (INLOGOV, 2011; Raine & Watt, 2013). Benefits include the removal of budgetary barriers to service integration and in Northern Ireland health and social care services have been integrated for more than three decades:

*... The most distinctive features of integration are that all professionals are employed by the same organization, have the same source of funding, share the same goals and objectives and work alongside each other.* (Heenan & Birrell, 2006, p. 62)

It is possible to integrate funding in different ways; two broad models are described:

*Aligned budgets – where the partners each consent to assign an agreed part of their own budgets in support of the common initiative or shared responsibility. In so doing, each partner retains responsibility and accountability for their own spending contributions.*

*Pooled budgets – where partners contribute resources to a special fund to achieve common objectives to which all have agreed. Two alternative approaches present themselves for such*



*pooled arrangements. On the one hand, they may involve a 'hosting' approach in which one of the partners takes lead responsibility for managing the special fund, and into which all the other partners pay their contributions. On the other, is a 'third-party' approach in which a special unit is established to provide independent and dedicated leadership in relation to the functional activity or service, and through which the partners 'pool' their financial contributions.*

(INLOGOV, 2011, pp. 2-3)

Heenan and Birrell (2006) suggest that the pooling of budgets in Northern Ireland has allowed packages of care to be more effectively tailored to users' needs since all elements come from the same budget and assessments do not have to take account of which organisation will pay. They do, however, note that tensions remain, in particular anxiety that 'health' tends to dominate decision making such that social care budgets can be vulnerable to cuts to make up for shortfalls in acute care. They further link this phenomenon to the generally strong position of the medical profession with a hierarchy of power.

Similarly, Raine and Watt (2013) highlight that pooling of budgets requires partners to have high levels of clarity, co-operation and trust and they suggest that whilst fully pooled budgets may be the best model, it may initially be necessary to explore other models such as budgetary alignment. They also highlight that models through which pooling can be achieved also need careful consideration:

*The research also illustrates that both a 'hosting' and a 'third party' organizational model for pooled budgets have their potential downsides. With a 'host' (or lead) authority, and particularly with multiple partners, there is the risk of the 'host' being perceived as unduly dominant while, with the 'third party' model, the danger is of partners becoming 'semi-detached'. (Raine & Watt, 2013, p. 895)*

## Outcomes and user involvement

Authors such as Robertson (2011) note that little attention has been paid to measuring the outcomes of integration. Wistow and Dickinson (2012) argue that much of the policy rhetoric around service integration is focused on changes to systems, structures and processes rather than on changes to outcomes for service users. This is important, since what may be 'effective' in terms of systems may be 'ineffective' in realising positive outcomes for service users. More encouragingly, in their review of research evidence, Cameron et al. (2014) highlight that greater attention is being given to outcomes; however, they also note that studies were often small, measurement was poor and few used robust comparison groups (see also Cameron & Lart, 2012).

An outcomes approach is suggested by authors such as Redding (2013) who advocate greater use of person-centred approaches, whilst highlighting that the success of these approaches is also likely to be determined by the degree to which local agencies adopt suitable ways of working.

Approaches to integration which favour choice and individual outcomes include those aiming for personalisation; for example, increasing attention has been paid to self-directed care as a form of integration. Authors such as Mitchell (2012a) highlight the value of self-directed services in allowing flexible, integrated and sometimes creative approaches to care. Alternate forms of personalisation include an emerging assessment-based model described by Bryans, Cornish, and McIntosh (2009) in a study of Scottish Health Visitors. They suggest an ecological approach based on Bronfenbrenner's (1979, 1994) person-in-context framework allowing for an integrated understanding of needs and how these might be met.

Various personalisation approaches have been shown to increase the sense of agency, independence and control (Glendinning, 2008). However, a number of authors are more cautious



about personalisation and draw attention to concerns that some forms of personalisation such as direct payments or 'cash for care' systems can be difficult to administer, may disempower users, create additional 'red tape', may further exclude some groups and widen existing gaps in wellbeing (Duffy & Murray, 2013; Kendall & Cameron, 2013; Manthorpe et al., 2014; Moran et al., 2013; Welch, Hatton, Emerson, Collins, et al., 2012). Finally, findings presented by Jacobs et al. (2013) suggest that self-directed approaches are unexpectedly resource-intensive and may require more, not less, input and support from practitioners.

The Christie Commission called on public services to use asset-based models which see users of services as active agents capable of participating fully: *In short, these approaches do things for and with people rather than to them.* (Christie, 2011, p. 27).

It is clear that whilst there is a general consensus that involving service users in policy making, planning and design is a positive and desirable approach, there is less clarity about what effective engagement is or how it should be achieved. In a study of teams delivering care to cancer patients in Scotland, Forbat, Hubbard, and Kearney (2009) describe a 'muddle of conceptualisations'. They further found that many of the conceptualisations referred to relatively shallow levels of engagement such as the use of satisfaction questionnaires or public meetings to disseminate decisions.

Many authors argue that a greater degree of user involvement is required in order for integrated working to fulfil its potential. Some such as Redding (2013) propose that the growing narrative of person-centred care may facilitate this process.

It may, however, be presumptuous to assume that many service users are interested in issues such as organisational restructuring. In one study, families did not have sufficient levels of knowledge or understanding to comment on changes in service structure; instead they focused on national debates such as cuts in provision (Kaehne & Catherall, 2013). Provision of information about service change may be poor. It is therefore unsurprising that several authors find that the inclusion of young people (and others) in strategic decision-making is complex; a further example of this is found in a study of self-directed support for young disabled people transitioning from child to adult services in Scotland (Mitchell, 2012b). Conversely, integration itself may facilitate the engagement of service users, for example, where one partner has the ability to involve users in ways which other partners have found difficult (Mellin & Weist, 2011).

## Communication and professional status

Many authors underline the importance of effective communication for integrated working (see for example; Cameron et al., 2014; Mellin & Weist, 2011). These concerns have been raised in relation to several types of communication; the following examples illustrate some of the areas where communication has been problematic. Firstly, communication between practitioners; for example, in one recent study of a Scottish pilot integration programme, poor inter-professional communication and information sharing was found to markedly hinder the delivery of personalised services (A. Stewart & MacIntyre, 2013). Secondly, communication within organisations; for example in a study of middle managers in health and social care in Scotland, Lunts (2012) found that although they were well placed to manage change for integration projects, the reasons for integration and the process through which it would be achieved had not been clearly communicated. Lunts found that frequent changes in senior managers resulted in lack of clarity and hindered progress. Thirdly, communication with all necessary stakeholders; for example, in a study of the three self-directed support test sites in Scotland, the authors note that important partners for adult protection were not engaged in the change process, did not have information about new structures and were unable to raise concerns or influence how these services developed (Hunter, Manthorpe, Ridley, Cornes, & Rosengard, 2012).

Many approaches to improving communication in integrated working have been taken and three are considered below. One approach is to co-locate workers or services in the anticipation that proximity will improve communication and there is some evidence to suggest that this can be helpful (Lee, Crowther, Keating, & Kulkarni, 2013; Morrow, Malin, & Jennings, 2005; Rose, Harris, Comino, Anderson, & Harris, 2011). However, co-location is seen both as a poorly defined concept (Ginsburg, 2008) and as being insufficient on its own and potentially counterproductive if other aspects of integration are not present (Lawn, Lloyd, King, Sweet, & Gum, 2014). Professionals have been shown to have varying opinions on the benefits of co-location of health and social care practitioners (King et al., 2012). Whilst in a study of services for families with a disabled child, parents were usually positive about co-location, this depended on the nature of their family's needs (Kaehne & Catherall, 2013). A second approach that has been shown to have some benefit for communication is inter-professional education (Hall, 2005; Whitehead, 2007; Wilcock & Headrick, 2000). Similarly, whilst inter-professional education has been shown to be helpful in some situations, some professionals feel that these tend to minimise their professional knowledge or reinforce pre-existing power differences (Baker, Egan-Lee, Martimianakis, & Reeves, 2011; Bokhour, 2006). Finally, a third approach to improving communication involving the implementation of shared databases and management IT systems has been shown to assist with communication (Howarth, Holland, & Grant, 2006; King et al., 2012). However, these systems can be problematic; in their consideration of the implementation of an electronic system for Single Shared Assessment in Scotland, King et al. (2012) report a number of difficulties related to the compatibility of IT systems as well as other difficulties. Furthermore, authors such as White, Wastell, Broadhurst, and Hall (2010) and Wastell, White, Broadhurst, Peckover, and Pithouse (2010) argue that poorly designed and implemented systems can undermine professional motivation and autonomy, and hamper inter-professional communication.

Wistow (2012) suggests that the major barrier to the integration of health and social care is the fact that services are organised around the professional groups that deliver them, rather than being organised around the needs of service users. This means that there are often competing professional paradigms, with health services tending to be focused on 'cure' over the short term and social care services tending to be focused on providing 'support' over a longer time frame (McMurray, 2006).

Role boundaries and professional status have often been identified as barriers to integration. Individual workers need to conform to particular models of professional behaviour in order to attain and maintain status within their profession (Schinkel & Noordegraaf, 2011; C. Taylor & White, 2000). As a result, professionals from different backgrounds may view needs and potential solutions from competing paradigms (Baxter & Brumfitt, 2008b; Couturier et al., 2008; Edgley & Avis, 2006). In one Scottish study, King et al. (2012) found problems arising from the presence of established professional and structural groupings which resulted in competition rather than cooperation or collaboration. Similarly, a study of nurses and nurse leaders in three Scottish Health Boards (Haycock-Stuart & Kean, 2013) found a need for primary and secondary healthcare clinicians to value the work of colleagues from other sectors. Baxter and Brumfitt (2008a) identify a number of different benefits for staff from inter-professional working, including mutual support and shared knowledge and responsibility; however, they found that these should be considered alongside disadvantages such as a lack of clarity about roles and boundaries. A lack of understanding of the roles of other professions is also noted in a review of inter-professional work conducted by Maslin-Prothero and Bennion (2010) who additionally draw attention to the potential for the roles of managers and professionals to clash.

Differences between professional groups can be particularly corrosive to integrated working when one professional group is more powerful or influential than others (Anning et al., 2010; Clark, 2010; Lorente, Hogg, & Ker, 2006). In particular, high status proto-professions such as law and medicine are frequently seen as having more power than semi- and bureau professions such as nursing and

social work (Atwal & Caldwell, 2003; Robinson & Cottrell, 2005; Whitehead, 2007). In a consideration of the concept of social and human capital in relation to inter-professional work for children and families in Scotland, J. Forbes (2009, 2011) focuses on the effect of professional dispute and practitioner relationships. Forbes suggests that attention to improving inter-professional social capital and relationships at a local level will result in successful integrated work.

## Summary: Findings 2

Integration is a flexible and at times poorly defined concept; despite this it has been highly influential in rhetoric, policy and practice. A number of drivers for integration have been discussed, including the need to respond to demographic changes and the need to improve services and outcomes; however, several authors argue that the need to achieve greater efficiency and savings is often paramount.

Integration can take place at different levels within organisations and structures. Integration at locality level is seen as necessary and effective but needs to be facilitated by integration at other levels. Revised organisational and financial structures will be required to sustain integration. Partners need to have clarity and develop trust in order to facilitate the highest levels of financial integration (i.e. pooled budgets); in some cases this may initially require a period of less intensive financial integration models such as budgetary alignment.

Integration of services other than health and social care is possible and there is some evidence to suggest that wider integration may be beneficial, particularly for population groups who use a wide range of services including health, social care, housing, benefits, education, transport and leisure.

Challenges to integration may include professional differences and communication difficulties; approaches to addressing these challenges are discussed and include co-location, interprofessional training and shared IT systems.



## F. FINDINGS 3: HOW CAN ADULT SERVICES AFFECT CHILDREN AND YOUNG PEOPLE?

Very little research focuses specifically on how health and social care services provided for adults impact on the lives of children and young people; however, as part of the community, children are not isolated from these services and may rely upon them in different ways. To illustrate this we explore material related to four groups; young people transitioning into adult services, young carers, young people leaving care and families where potentially vulnerable children are cared for by adult service users. This is not an exhaustive list and adult health and social care services, along with other adult services, will impact on the lives of children and young people in many different ways.

We do not review the integration of children's services per se as this is beyond the scope of this study; however, we do include a short section briefly highlighting relevant sources of evidence.

### Young people transitioning to adult services

Increasing numbers of children with chronic health conditions now survive into adulthood, (Baines, 2009; Kennedy & Sawyer, 2008). Many of these young people will continue to need health and social care services to enable them to live full lives as adult members of society. As recipients of children's services, disabled and chronically ill young people must at some point transition into adult services; transitions may potentially need to be negotiated within each individual service strand and, more generally, across a set of services used (Kennedy & Sawyer, 2008).

Much of the literature related to transitions has been generated by researchers writing from a health service perspective. Whilst some of this material focuses specifically on transition from a paediatric health service to an adult equivalent, other sources consider wider transitions and the relationship between services from a range of provider types including social care. Much of this literature contains learning which might be of use.

In Scotland, as in many other locations, it is difficult to compile accurate data and information about the number of disabled young people. Considering learning disability alone, Cheseldine (2010) estimates that there are more than 17,000 children and young people in Scotland with a learning disability [a significant intellectual impairment]. Many of these young people will continue to use support services as an adult. In addition, young people with chronic health problems, sensory impairments or physical disability will also transition to adult services.

The process of transition can be daunting for young people and their families. Chamberlain and Kent (2005, p. 111) suggest that the transition from familiar services with their apparent cohesiveness to the seemingly uncoordinated sphere of adult services can feel like 'hurtling into the void'. Other authors agree, and a recent study in Scotland found, that parents of disabled young people approaching transition described it as:

... 'terrifying', 'a black hole', 'a scary void', something they were 'absolutely dreading'. (Stalker et al., 2013, p. 45)

These and other authors call for improvements in transition through better coordination, integration, better provision of information and earlier planning.

Planning for transition is often portrayed as an activity which is initiated and driven by children's rather than adults' services (Kennedy & Sawyer, 2008). In Scotland, Cheseldine (2010) suggests that adult services need to be involved to a much greater level and at an earlier stage. Equally, consideration needs to be given to the ways in which children's provision is organised and delivered such that transition planning and integrated care begin sooner (Chamberlain & Kent, 2005).

Other authors draw attention to the fact that services for disabled young adults are not always appropriate, sufficient or available (Frey & Van Der Pal, 2013; Ko & McEnery, 2004; S. Lewis & Noyes, 2013; N. Taylor, Fauset, & Harpin, 2010). Transition to adult services will be particularly problematic where adult services are themselves restricted or poorly developed as in the case of services for adults with ADHD (Marcer, Finlay, & Baverstock, 2008; N. Taylor et al., 2010). This may be a particular concern where young people have additional, wider support needs.

It has been argued that approaches which are more person-centred, more integrated and less service-driven may be required to ensure that young people with disabilities are able to experience a positive transition to adult services (D. Stewart, 2009). The need for significant cultural change to promote the establishment of planned transition services has been identified as a priority within the NHS (Viner, 2008). In their review of the health care transitions experienced by young people with chronic health conditions, Kennedy and Sawyer (2008) note that examples of good practice tend to be limited and localised within a particular specialism rather than being integrated across all aspects of healthcare or other services provided.

Targeted collaborative transitions services which are jointly delivered by child and adult teams have been shown to be helpful in some situations. These can help to prevent young people disengaging from services. It has been noted that this is particularly important for some groups such as young people with epilepsy and those requiring follow-on care for childhood cancer (Frey & Van Der Pal, 2013; S. Lewis & Noyes, 2013).

Young people's participation in decision making has also been raised as a problematic issue. One study in Scotland found that disabled young people often took a broad and holistic view of what they wanted to achieve from transitions, whereas their service providers were typically focused on narrower, service-defined goals (Stalker, 2002). Stalker also suggests that many disabled young people were excluded from decision making and that they and their families were not given sufficient information about the full range of potential options open to them. This view is supported more recently by others in Scotland (e.g. Cheseldine, 2010). Disabled young people may need to be empowered and supported to enable them to exercise more influence in their own transitions (Viner, 2008).

The families of disabled or chronically ill young people may also need particular support or consideration. As young people mature, some parent-carers wanting to protect their child's happiness and wellbeing may experience a tension between promoting stability and promoting their development of independent self-care (S. Lewis & Noyes, 2013). They may be concerned for a number of reasons including previous negative experiences and a feeling that their child's needs are not well understood by service providers (Stalker et al., 2013). Many families explain that they have had to 'fight' for many years to secure suitable packages of care and support for their child; often transition to adult services is seen as a threat which may destabilise these hard-won arrangements (Welch, Hatton, Emerson, Collins, et al., 2012).

## Young carers

Children and young people are often involved in providing aspects of care and support to members of their family. Where these family members have additional needs related to long term illness or disability young people may have additional or more extensive caring responsibilities. In the 2010-2015 Young Carer Strategy the Scottish Government uses the definition of a young carer originally given in the 2005 Scottish Executive *Care 21* report:

*... a child or young person aged under 18 who has a significant role in looking after someone else who is experiencing illness or disability. (Scottish Government, 2010a)*

Young carers should not be seen as a homogenous group; they may undertake a wide variety of care and support tasks and their experiences and needs vary greatly (Ali, Ahlström, Krevers, Sjöström, & Skärsäter, 2013; Carers Trust, 2013). Some may care for disabled or ill adults including parents and grandparents, others may care for disabled siblings or may help disabled or ill parents to care for younger siblings (Frank & Slatcher, 2009; Sahoo & Suar, 2009; Welch, Hatton, Emerson, Robertson, et al., 2012).

Wider societal changes may be increasing the numbers of young carers. For example, trends such as the rising age of childbearing may be increasing the numbers of children in families where a parent has early-onset Alzheimer's disease (Rosenthal Gelman & Greer, 2011) and high rates of parental addiction may mean that greater numbers of children are caring for parents who misuse drugs and alcohol (Hill, 2011; Russell, 2006).

Children who care for parents who use substances may on the one hand be knowledgeable and capable but they may also be fearful, confused or upset (Hill, 2011). Children of adults with Alzheimer's disease have been shown to experience a range of negative psychological impacts (Rosenthal Gelman & Greer, 2011). Similarly an Edinburgh study involving 61 young carers identified a range of concerns and issues regarding their own mental health and longer-term wellbeing (Cree, 2003). Children whose parents have mental ill health are often reported to have high levels of concern for their parents, to be confused and seeking information (Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004). Children and young people providing informal care for family members with a mental illness typically report that they received little support from professionals (Ali et al., 2013).

The aspirations of young carers can be shaped or constrained by their circumstances, and the decisions they make about their future education and employment may be shaped by their experiences (Hamilton & Adamson, 2013).

Young carers are not always identified, either by schools and other services provided for children, or by adult health and social care services provided for the family member for whom they care (Heyman, 2013). Indeed, young carers often constitute a 'hidden' or 'invisible' population (Banks et al., 2002; Barry, 2011; Thomas et al., 2003). They may have restricted and compartmentalised social networks and may seek to minimise their difficulties and portray themselves as self-sufficient (Barry, 2011). Young people in some families may be reluctant to seek support or may be discouraged to do so by their family for fear of child removal or higher levels of scrutiny (Moore & McArthur, 2007).

Whilst high levels of need have been reported, low levels of support have been found for young carers (Moore & McArthur, 2007). Where support is effective, it tends to be co-ordinated across a number of services and responsive to the needs of each member within the family. However, services may not be available, or where they are, families may not be aware of them or how to access them. One initiative in Scotland which seeks to promote the visibility of young carers and allow them to access the services they need is a Young Carers Authorisation Card, which has been piloted in several local authorities. This enables the young person to identify themselves to service providers and access agreed information about the person they care for (COSLA and Scottish Government, 2011).

Young carers may experience support from peers as being particularly helpful, whether this is received via web-based support or in group activities (Ali et al., 2013; Elf, Rystedt, Lundin, & Krevers, 2012).

A number of authors note that whilst the discourse around young carers is predominantly framed in problematic and negative terms, caring for a family member can be experienced positively by children and young people if they receive appropriate support (Hamilton & Adamson, 2013; Heyman & Heyman, 2013). However, these authors point out that children and young people report that



support for their family member and for themselves is frequently unavailable, insufficient or inappropriate.

The needs of young carers are becoming more visible in relation to policy in Scotland. For example, a number of initiatives have been undertaken as a result of the 2010-2015 Young Carer Strategy (Scottish Government, 2010a). These include the aforementioned young carers card, annual young carers' festivals, some access to short breaks, guidance for schools and colleges and the production of a website for primary aged children<sup>2</sup> (COSLA and Scottish Government, 2013). In addition, recent guidance and training for health and social care practitioners in Scotland has been introduced; the *Equal Partners in Care* project outlines six outcomes for carers and young carers:

- *Carers are identified*
- *Carers are supported and empowered to manage their caring role*
- *Carers are enabled to have a life outside of caring*
- *Carers are fully engaged in the planning and shaping of services*
- *Carers are free from disadvantage or discrimination related to their caring role*
- *Carers are recognised and valued as equal partners in care.*

(NES and SSSC, 2013)<sup>3</sup>

There has also been a recent petition to the Public Petitions Committee on behalf of Scottish Youth Parliament calling for a young carer's grant for children and young people in full-time education (SPICe, 2013). While it can be estimated that there are hundreds of thousands of young carers in Scotland, it is not yet clear whether these initiatives outlined above are having a positive effect on their lives.

### Young people leaving care

Young people leaving care have been shown to be highly disadvantaged in comparison to other children and young people (Dixon, 2008; Rainer, 2007; Stein, 2004; Stein & Carey, 1986; Stein & Munro, 2008). The disadvantages they experience persist into adulthood and may be life-long.

*Each care leaver is unique; each has a different trajectory and different options, opportunities and choices. Some may do very well in life. But taken as a group, care leavers have some of the poorest outcomes in society; they experience:*

- *much higher rates of early death;*
- *poorer access to continuing education or training;*
- *greater unemployment and homelessness;*
- *worse mental health and physical wellbeing;*
- *greater rates of teenage pregnancy; and*
- *an increased likelihood of involvement in or exposure to, criminal activity.*

*(McGhee, Lerpiniere, Welch, Graham, & Harkin, 2014, p. 14)*

Care leavers have typically experienced a range of disruptions and traumatic experiences in their lives. These may have impacted on their development and education, yet they are expected to make

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<sup>2</sup> See [www.erycandtrayc.com](http://www.erycandtrayc.com)

<sup>3</sup> See [www.knowledge.scot.nhs.uk/portals-and-topics/equal-partners-in-care.aspx](http://www.knowledge.scot.nhs.uk/portals-and-topics/equal-partners-in-care.aspx)



earlier transitions to adulthood often with little support (Jackson & Cameron, 2012; Stein, 2012). In Scotland it has been suggested that many care leavers become independent before they are ready (SCCYP, 2008). This is often a troubling time for these young people (IRISS, 2012; Rogers, 2011; Stein, 2011). Young people in Scotland were found to experience a range of issues including homelessness and a lack of support (Dixon & Stein, 2002, 2005).

Support available differs greatly in terms of availability, scope and quality. Across Scotland access to services varies according to location (McGhee et al., 2014); and it has been suggested that over half of residential care homes fail to offer appropriate information and support for young people leaving residential (Care Commission, 2009).

Scottish Government statistics suggest that around 1,200 young people over school leaving age leave care each year; the majority of these will be entitled to Throughcare and Aftercare (TCAC) services (Scottish Government, 2013a). On 31 July 2012, 3,870 young people were eligible for aftercare services; however, not all of these eligible young people will receive services. Some that do will only be minimally engaged and some may not know they are entitled to support (McGhee et al., 2014). As a result of the Children and Young People (Scotland) Act 2014, with effect from April 2015, local authority TCAC services will have a duty to provide support to meet the assessed needs of young people up to the age of 26.

Throughcare services provided by local authorities might typically include personal, social and emotional support, health services, benefits advice, accommodation and tenancy support, practical skills training and education and employment support. These services are delivered in collaboration with a range of statutory and independent sector providers and may be delivered in group settings or on a one-to-one basis.

Also relevant is the concept of the 'corporate parent' (Welbourne & Dixon, 2008). This confers statutory responsibilities on public bodies to work together in a co-ordinated way to promote the wellbeing of looked after children and care leavers (Scottish Government, 2008; Welbourne & Dixon, 2008). Corporate partners such as social care, housing, health services, higher education, police, justice services and leisure all have a responsibility towards care leavers. In Scotland the effectiveness of corporate parenting for care leavers is reported to vary by area, with most success where there is consistent high-level support (McGhee et al., 2014).

### Family work with potentially vulnerable children and adult service users

Adult services across a number of domains are able to contribute to children's safety and wellbeing whilst simultaneously responding to parents' or carers' needs (Scott, 2009). This is important as children have been shown to be at particular risk of poor outcomes or child protection concerns if their families are experiencing long-term problems including poverty, poor housing, parental mental ill health, domestic violence or parental substance misuse (Drake, Jonson-Reid, & Sapokaite, 2006). For example, children whose parents misuse drugs and alcohol are at greater risk of poor outcomes in different areas of their lives (Hill, 2011; Scottish Government, 2013b) and children with a parent who has schizophrenia experience more problems at school, poorer social networks and more psychiatric distress than other children (Somers, 2007). These children may be distressed by their parent's illness and also by their contact with adult health services, such as during hospital visits.

Parents who experience mental ill health are often aware of various negative effects on their children; despite these potential problems, many people also have positive family lives as successful parents (Diaz-Caneja & Johnson, 2004). However, parents may be reluctant to discuss family difficulties with mental health practitioners as they fear they may have their children removed from them (Diaz-Caneja & Johnson, 2004).

Families such as these have been shown to benefit from special family-inclusive services which provide support for all family members (Cowling & Garrett, 2009, 2012; Stanbridge & Burbach, 2007). Parents with mental illness can be helped to help their children in a number of different ways, including helping them express and discuss concerns (Focht-Birkerts & Beardslee, 2000). Somers (2007) suggests that collaborative working between adult and children's services enables effective support to be given to children to help them understand and cope with their parent's illness. Collaborative working between child protection workers and a range of agencies providing support to adults is also promoted by Drake et al. (2006) on the grounds of high levels of service overlap. However other than crisis services, many authors note that parenting and family support for parents with a mental health problem is rarely available.

Drug or alcohol use during pregnancy can damage the unborn child (Mitchell & Burgess, 2009). Adult services working with people with problematic use of alcohol and/or drugs may be able to provide pre-conception advice or pregnancy support to prevent or reduce harm (Scottish Government, 2013b).

Parents with problematic use of alcohol or other substances may be less able to provide effective parenting and their children may be at increased risk of abuse or neglect (Battams & Roche, 2011; Hill, 2011; Mitchell & Burgess, 2009; Scottish Government, 2013b; Velleman & Templeton, 2007).

*Best estimates suggest that there are up to 60,000 children under 16 years old who have a parent with a drug problem and there are up to 65,000 children under the age of 16 who have a parent with an alcohol problem. There is a consensus in the literature that such estimates are likely to be an under estimate of the number of children exposed to parental substance misuse. (Mitchell & Burgess, 2009, pp. 4-5).*

Adult services have an important 'secondary prevention role' in identifying these children and ensuring they receive the support they need:

*Adult services will play a vital role in the support and protection of children. While their main role is with the adult service user, they have an important role in the identification of children living with – and being cared for by adults with problems associated with problematic alcohol and/or drug use (Scottish Government, 2013b, p. 24).*

However, some studies suggest that practitioners in adult services lack sufficient understanding of children's needs and development to be able to identify problems; integrated delivery of child and adult services along with strategies such as inter-professional training may help in this regard (Battams & Roche, 2011; Velleman & Templeton, 2007).

Children of learning disabled parents may also come into contact with adult services, and these families are likely to benefit from coordinated working between adult and children's services (SCLD, 2009). It should not be presumed that learning disabled people are unable to be effective and loving parents; needs should be carefully assessed and appropriate support given.

In Scotland, the National Guidance for Child Protection outlines responsibilities that a range of adult health and social care services have to promote children's wellbeing (Scottish Government, 2010b). This includes being aware of the needs of children in families of adults they work with, sharing concerns and working with children's services to ensure children are safe. Amongst others these responsibilities apply to a wide range of adult health and social care practitioners including those in adult support services, maternity services, general practice (GP), accident and emergency services, mental health services and addiction services.

## Integrated children's services

It is not our intention to fully cover evidence related to the integration of children's services. To do so would be a lengthy task, best achieved by a separate review. However, we feel it may be useful to highlight some areas where there may be relevant material:

- The literature suggests that in addition to the drivers noted above, the integration of children's services is often a response to concerns around child protection, in particular a lack of effective information sharing (Carpenter, Brown, & Griffin, 2007; Howarth et al., 2006; Hudson, 2005; Munro, 2005; O'Brien et al., 2006; Richardson & Asthana, 2006).
- There is currently little reliable evidence to suggest that the integration of services for children in itself improves outcomes; however, there is some evidence to suggest that integrated services may be successful in certain areas or under certain conditions (Bachmann et al., 2009; O'Brien et al., 2009). A number of studies note promising findings for various integrated programmes (Cottle, 2011; Thompson, 2010; Young, Temple, Davies, Parkinson, & Bolton, 2008). The lack of definitive evidence is in part due to the lack of studies with control or comparison groups and the difficulties of measuring outcomes across long enough periods of time.
- Similar challenges to integrating services are noted in respect of children's services as for those discussed above (in Findings 2) (Howarth et al., 2006; J. Lewis, Cuthbert, & Sarre, 2011; J. Lewis, Finnegan, & West, 2011; Malin & Morrow, 2007; Morrow et al., 2005; O'Brien et al., 2006; Potter, 2010).
- Additional concerns in respect of studies of children's services integration include those related to de-professionalisation of the workforce through integrated systems which are overly prescribed or bureaucratic (Hood, 2014; Wastell et al., 2010; White et al., 2010).

## Summary: Findings 3

This section has demonstrated a number of links between children and young people and adult services, either as service users themselves, or as family members of service users. Changes to adult health and social care services could potentially have significant implications for the four groups of children and young people we have considered here:

- For the increasing numbers of **young people transitioning to adult services** and their families it was noted that transition was an especially difficult time. This is a varied group with diverse needs. Earlier planning and collaborative person-centred approaches are reported to be helpful.
- For the increasing numbers of **young carers** it was noted that despite competency in some areas there may be significant support needs requiring input from diverse service types. Young carers often remain somewhat 'hidden', which further confounds their risk of poor outcomes through poor access to support.
- Numbers of **care leavers** remains high; these young people typically have poor outcomes across a range of dimensions. Support needs encompass health, social and emotional factors as well as practical issues such as housing, education, employment and benefits. Not all entitled care leavers receive throughcare or aftercare.
- High numbers of **vulnerable children in the families of adult service users** are at increased risk of neglect or abuse. Providers of adult services can be instrumental in identifying and protecting these children through collaborative working with child protection services.

Thus the integration of adult health and service care is likely to impact on these and other groups of children and young people. This is potentially promising, since collaborative approaches have been shown to be helpful; however, these benefits will only be realised if children and young people's needs are considered and factored into decisions about future service delivery.

Integration of children's health and social care services also has promise; however, outcomes are, as yet, untested or unclear. Similar drivers, challenges and concerns are cited for children's services as for adult services; however, child protection is often cited as the most fundamental driver.

## G. CONCLUSIONS

In this literature review we have attempted to consider evidence that may help us understand how the integration of adult health and social care services may impact on children and families and the services provided for them. We have done this by looking at three bodies of literature. Working broadly from the macro to the micro level we have considered the development of relevant policy in Scotland, practical issues around service integration and how changes to adult services may impact on children.

We have shown that integration is a strong policy trend that is likely to continue; the Public Services (Joint Working) (Scotland) Act 2014 reflects a recent intensification of this trend.

Integration can occur at a variety of levels; change in localities is seen as particularly effective but must be facilitated by change at higher levels. Drivers for integration include greater responsiveness to need along with outcome and service improvement but some argue that these are often secondary to a drive towards greater efficiency and cost savings.

Different organisational and budgetary arrangements are possible and different models have advantages and disadvantages; fully pooled budgets require partners to have clear systems and high levels of mutual trust.

Challenges to integration include professional barriers and communication difficulties; different approaches have been tried to meet these challenges. The integration of services beyond health and social care may also be advantageous.

We have also shown that children and young people are potentially affected in a number of different ways by changes in adult services. For example, we considered young people transitioning to adult services, young carers, care leavers and vulnerable children whose parents use adult services. Integration of adult health and social care and / or children's services may result in benefits for these groups as long as their needs are fully considered in any change process.

We therefore conclude that the Act is a significant opportunity for children and young people in Scotland, provided that their needs are not overlooked given the substantive drivers and undisputed needs of adult service users.



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# I. APPENDICES

## Appendix 1: Key items of legislation, policy and planning

The following sources of legislation, policy and planning requirements form an important backdrop to health and social care integration in Scotland and are likely to have implications for how this impacts on children, young people and families.

### 1. Legislation:

- **Children (Scotland) Act 1995:** sets out foundations for duties on local authorities and others to support children and families, including child protection.
- **Social Work (Scotland) Acts 1968 and 1995:** set out duties on social welfare, protection of children, supervision of criminal justice social work, children's panels and hearings, parental rights and responsibilities, etc.
- **Education (Additional Support for Learning) (Scotland) Acts 2004 and 2009:** define additional support needs, place duties on education authorities, coordinated support plans, advocacy, mediation, dispute resolution and appeals, placing requests, provision and publication of information, tribunals etc.
- **Public Health (Scotland) Act 2008:** sets out duties on NHS Boards and local authorities to promote and improve public health.
- **Public Services Reform (Scotland) Act 2010:** sets up regulators: Healthcare Improvement Scotland and SCSWIS.
- **The Children's Hearings (Scotland) Act 2011:** was implemented on 24 June 2013. It brings most of the legislation relevant to children's hearings into one place and replaces large sections of the Children (Scotland) Act 1995. It creates a national body, *Children's Hearings Scotland (CHS)*, a National Convenor and area support teams to support the system at local level. It also creates a national children's panel in place of local authority children's panels and a national safeguarder panel.
- **Social Care (Self-directed Support) (Scotland) Act 2013:** sets out duties on councils and others, assessment, support for adult carers, options for SDS, provision of information to children, support for under 16s, direct payments etc.
- **Children and Young People (Scotland) Act 2014:** sets out to strengthen children's rights, children's services planning, key provisions for Getting It Right for Every Child (including named person, child's plan etc.), early learning and childcare, corporate parenting, kinship care, aftercare.
- **Public Bodies (Joint Working) (Scotland) Act 2014:** sets out structures, procedures and budgeting arrangements for the integration of adult health and social care. Although not specified in the Act, the Cabinet Secretary for Health and Wellbeing has clarified to Parliament that it is open to local partnerships to integrate children's services into these new arrangements.
- **FORTHCOMING Carers Legislation – Consultation on Proposals (January 2014).** Consultation incorporates the needs of carers and young carers.
- **FORTHCOMING Community Empowerment (Scotland) Bill.** Will support communities to achieve their own goals and aspirations through taking independent action and having their voice heard in decisions affecting them.

### 2. Policy frameworks:

- **National Performance Framework (2007):** including national outcomes and national indicators. Sets priorities for achieving a common public service focus on building Scotland's economic prosperity. Below this primary goal there are five strategic objectives: healthier; wealthier and

fairer; smarter; greener; and safer Scotland. There has been a shift in focus from damage limitation to prevention, early identification and early intervention from the earliest years. There are three overarching policy frameworks: **Equally Well (2008)** (aimed at addressing health inequalities); **The Early Years Framework (2008)** and **Achieving Our Potential (2008)** (aimed at tackling poverty including child poverty). **Child Poverty Strategy (2011)**.

- **Getting It Right for Every Child:** child-centred and personalised, multi-agency care based around each child's plans; incorporates roles of named person and lead professional. Aimed at providing a whole-family approach to support children and parents/carers.
- **Early Years Collaborative:** a quality and outcome improvement model for service providers and an **Early Years Taskforce** overseeing progress of early years' priorities.
- **National Parenting Strategy:** aimed at championing importance of parenting, strengthening support on offer and making it easier for parents to access support.
- Policies for looked after children: **We Can and Must Do Better (2007)**, **These are our Bairns (2008)** and **Care and Permanence Planning for Looked After Children in Scotland: Scottish Government Response (2011)**.
- **Mental Health Strategy for Scotland 2012-15:** sets out a range of key commitments across the full spectrum of mental health improvement (including child and adolescent mental health), services and recovery to ensure delivery of effective, quality care and treatment for people with a mental illness, their carers and families.
- **Health Quality Strategy:** to realise 2020 vision for health and social care: seeks to ensure that the NHS, local authorities and others work together and with patients and carers and the wider public with a goal of world-class healthcare. Three quality ambitions around safety, person-centred care and effective care.
- **A Fairer Healthier Scotland? NHS Health Scotland's strategy 2012-2017.** This strategy sets out the role, direction and priorities of NHS Health. It focuses quite a bit on integration.
- **Road to Recovery:** wide-ranging strategy to tackle Scotland's drugs problems and **Changing Scotland's Relationship with Alcohol** a policy framework to address Scotland's alcohol problems. [Relevant to links between adult and children's services.]
- Domestic abuse: work is under way on the new **Violence Against Women and Girls strategy** [Again, relevant to links between adult and children's services.]
- **Getting Our Priorities Right:** guidance on working with parents with problematic alcohol or drug use.

### 3. Planning requirements:

- **Community Plans.**
- **Single Outcome Agreements.**
- **Children's Services Plans** (under Children (Scotland) Act 1995) to be replaced by new planning requirement in Children and Young People (Scotland) Act 2014.
- **Joint Public Health Protection Plans.**
- **Joint Integration Schemes** under the Public Bodies (Joint Working) (Scotland) Act.