Transition to Adulthood: From Coherence to Fragmentation, Policy Affecting Young People with Cerebral Palsy in Scotland

This paper examines the unusual shift from a coherent government policy on cerebral palsy (CP)\(^1\) in childhood to a fragmented service in adulthood. Cerebral Palsy is the most common cause of disability in childhood. As children, such patients receive a generally well coordinated service where health, social work and education professionals, work together to provide an integrated care package for the individual. However, service users have identified a fragmentation in the service provided as they transition toward and into adulthood. This discourse therefore sets out the major research questions, summarises the current policy and presents initial findings:-

1. What policy, if any, exists in Scotland in relation to transition for such patients?

2. How consistent can that policy and its delivery be said to be across Scotland, and why?

3. Is there a clear process of policy formulation and implementation, or does the process in this case need to be understood differently?

4. Are local authorities and health boards in Scotland learning from each other? i.e. is information being shared and, if appropriate, is collaboration taking place?

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\(^{1}\) “Cerebral palsy is the commonly used name for a group of conditions characterised by motor dis-function due to non progressive brain damage early in life. There are usually associated disabilities as well as emotional, social and family difficulties. Cerebral palsies are the most common cause of childhood disability. The range of severity may be from total dependency and immobility to adequate abilities of talking, independent self-care and walking, running and other skills, although with some clumsy actions. A number of people with cerebral palsy are now able to benefit from mainstream education and further education. They participate more in various activities in society. These opportunities are assisted by legislation, advances in technology and changing attitudes in their society”. (Sophie Levitt, 2010, p.1).
5. Are they transferring practices from other regions and territories where the process is already functioning well?

These questions will be answered using documentary analysis looking primarily at best practice guidelines, legislation and transition protocols; semi-structured interviews consisting of interviews with politicians, civil servants, medical professionals and social workers; and a survey directed at patients and carers which will consider the impact of transition and ongoing care policy upon service users.

The discussion demonstrates how interested professionals might collaborate with and learn from other organisations to develop their policies around transition and finds that some professionals are involved in both policy development and implementation, and that variation in policy can emanate from differences in the composition of the groups developing them. The interviews have also provided information about the extent to which various councils and health boards have sought to involve service users in both development and evaluation of transition policies. This data demonstrates that there are clear examples of good practice, learning and collaboration in areas across Scotland which could become models of excellence for other Scottish regions and further afield.

The Research Problem

The prevalence across Europe of cerebral palsy is between 2 and 3 in every thousand live births and approximately 2 per thousand in the U.K. (Surveillance of Cerebral Palsy in Europe cited in Cans, 2000, p. 816) CP patients in Scotland who survive into adulthood can face an uncertain future when transitioning from paediatric to adult services. It is worth noting at this point that for the purposes of this discussion ‘transition’ refers to the process of the transfer from paediatric care for children and young people to adult services in the health and social care sectors.

While this paper and indeed the connected PhD research project focus on cerebral palsy as the research basis, it must be understood that where transition is being discussed in terms of legislative enactments,
Care for neo-nates and young children in paediatric services is co-ordinated well, and the various disciplines co-operate to provide this service (e.g. physicians, physiotherapists, occupational therapists, education specialists and social workers). Conversely, care within the adult environment can be less consistent and less well coordinated. This leads to sometimes fragmented provision of the on-going monitoring and treatment which should follow as this comment from one service user suggests; “As you get older your disability affects you a hell of a lot more….. a hell of a lot more. How can you go from Doctors to Social Workers to Physiotherapists to err, Consultants, to absolutely nothing, I..., I don’t understand it!”(Heather - young adult cerebral palsy patient). (BBC2 Scotland (2011)).

The fragmentation alluded to seems logically to perhaps result from low policymaker attention allied to a high level of discretion creating a space for such policies to fall unnoticed through the cracks. Early interviews with medical and social work professionals during the current study and earlier research tends to add weight to this supposition and indicates that the policy area is complex, multi-faceted and affects various disciplinary areas within the service delivery organisations. Consequently, this study presents a novel research problem in that it is considering issues surrounding why a decision was not taken in one area, when perhaps it was in another. The selection of Scotland as a case study has in brief, emanated from the fact that much of the previous work carried out on the issue of transition considered other areas of the UK while almost none of these carried out an in depth analysis in Scotland. Scotland presents a special case of interest in the light of its current devolution arrangements which leave some of the issues around transition and ongoing care as reserved matters while devolving others. The disparity in the provision of care alluded to here may seem unwarranted when considered against the coordination which can exist between organizations in order to make certain societal processes function, but there are possible explanations for this situation.

guidelines and protocols, or opinions or recommendations of interest groups, unless otherwise stated, this will generally refer to transition for all young people progressing through the process regardless of disability.
As a public policy matter cerebral palsy is unusual in that the issue of transition and ongoing care for adult patients is not a wholly new one. It was regarded previously as what might be described as a niche concern of medical and health professionals. At the very least it suffered from a lack of the planning which would result from the scale of the problem being well anticipated by policy makers. This lack of anticipation may emanate from various factors. Firstly, CP is a condition for which there is no cure and for which statistical estimates of the incidence vary. As far back as 1990, survival rates for CP patients were found to be quite high. Evans et al in a study of children born in the south east Thames region in the period 1970 to 1979 which looked at a total of 732 children found that 651 (90%) were still alive in December, 1989. Therefore they argued that cerebral palsy must be seen as a condition with which people can live rather than a condition from which they necessarily die, and although survival rates vary with different diagnoses and severity, survival must be planned for. (Evans, Evans and Alberman, 1990, p. 1329) Two decades later survival rates among CP patients reaching adulthood is thought to be around 87%, i.e. 87% of patients are still alive at the age of 30. For patients affected in all four limbs, i.e. a severe diagnosis in terms of those ‘physically disabled’, survival rates are approximately 85% (Ali, Ahmed, and Qadir, 2009, p.44-45).

Although the survival rates for CP can be seen to be increasing, so too are the survival rates for other lifelong and long term conditions. This means that these patients who require support and whose needs also may be extensive, for this reason may too face problems in gaining that support. This competition for limited resources may result in both groups facing difficulties in gaining the optimal level of care. Another factor in explaining the lack of anticipation of the need for adult care for CP patients is perhaps a long held belief among physiotherapists that their effort can be of greater value in treating infants and young children as opposed to considering how the goals, generally independent walking or best possible mobility, focused on when treating children, can be maintained as they enter and progress through adulthood. (Bottos, Feliciangeli, Scuito, Gericke and Vianello, 2001 p 516) In part, this child focused approach may emanate from a sense that, in their adolescent years and early adulthood, adherence to physiotherapy programmes reduces. (For
details of factors affecting this see Redmond and Parrish 2008) A final factor which perhaps should be considered is the gradual reduction of institutionalised care, not just for CP patients, but for disabled people in general, for whom this process over the past 40 years has resulted in fragmented care provision as community care, which replaced institutionalised care, must now be provided in communities which are very different to those of 40 years ago and is often reliant on part time or unpaid carers. (Harris and Roulstone, 2011) The foregoing leads to the illumination of some of the difficulties surrounding the analysis of the policy regarding the transition and ongoing care process for CP and other patients with disabilities The provision of adult services and the transition of young people into those services as a policy problem can be difficult to define, with involvement of both Health and Social Work in the development and implementation of the policy. Health professionals, that is, paediatric consultants from specialisms such as orthopaedics or complex needs, deal with specialist health related issues for CP patients whilst GPs deal with more general health related issues. Allied health professionals such as occupational therapists who can work as part of NHS trusts or social work departments assist with modifications to the home while social care assistance can help with day to day care. (Centre for Developmental Disability Health, 2005)

An additional but less obvious factor is the involvement of both the Scottish and Westminster governments regarding the benefits system, with the role of these governments in this regard being unclear. Under the devolution arrangements in Scotland the Scottish government has responsibility for health policy, therefore they have responsibility for the NHS role in this policy process, but the situation is further complicated by the fact that local government and NHS boards have responsibility for the day to day running of social care and health care respectively. Issues surrounding social security i.e. the levels at which benefits are set, eligibility for particular benefits such as Disability Living Allowance (DLA), and how claimants who receive these benefits are categorized remain the responsibility of the government at Westminster.(Birrell, 2009, p. 105) (For more information on DLA go to: http://www.dwp.gov.uk/healthcare-professional/benefits-and-services/disability-living-allowance). As a result, identifying the source of
power or decision making in relation to the various systems from health care to benefits can be problematic. All of this means that the development research design for the PhD study has required a good deal of consideration.

Given these complexities this research will therefore consider the following questions:-

- What policy, if any, exists in Scotland in relation to transition for such patients?
- How consistent can that policy and its delivery be said to be across Scotland, and why?
- Is there a clear process of policy formulation and implementation, or does the process in this case need to be understood differently?
- Are local authorities and health boards in Scotland learning from each other? i.e. is information being shared and, if appropriate, is collaboration taking place?
- Are they transferring practices from other regions and territories where the process is already functioning well?

The current policy position requires some explanatory discussion and a description is given of the theoretical frameworks and concepts, i.e. implementation, policy transfer, agenda setting and governance and accountability with regard to how they relate to the current case study.

What is the policy?

Policy is a word often used but which can have a myriad of meanings ranging from legislation to guidance to advice and at times with little or no clarity. The policy surrounding transition for CP patients in Scotland is complex and multifaceted. This policy consists of legislation and guidelines which are produced at a national, Scottish Government level and also at Westminster (welfare i.e. benefits and social security is still a reserved matter) but is complicated by the fact that local authorities and health boards also produce documentation.
which sets out what the process for transition and ongoing care will be within an individual local authority or health board.

**At Scottish Government level**

The policy in Scotland in relation to transition and the care of disabled adults is complex and is drawn from the undernoted enactments. Although there is some legislation covering provision of care for disabled adults:

- National Assistance Act 1948
- Chronically Sick and Disabled Persons Act, 1970
- Disabled Persons (Services, Consultation and Representation) Act, 1986
- Children (Scotland) Act, 1995
- Adults with Incapacity (Scotland) Act, 2000
- Community Care and Health (Scotland) Act, 2002
- Additional Support for Learning (Scotland) Act 2004 as amended
- Social Care (Self-directed Support) (Scotland) Act 2013

these enactments emanate from perceived needs around the care of disabled people over decades.

These Acts afford certain basic rights and protection to disabled adults but what they do not do is make statements regarding the process of transitioning to adult services. The Scottish government has produced guidelines in relation to how transition to adult health care services should work, however, while they include references to the idea of transition and its process, none of these guidelines are about transition in its own right, but rather the transition recommendations were connected to larger scale policy developments. The draft for consultation of the National Delivery Plan for Children and Young Person’s Specialist Services made some short comments about hospitals perhaps developing specific services for young people transferring from paediatric to adult services, and that training should be provided for staff in dealing with such patients. Staff dealing with transition related issues should be clearly identified. Transition should be flexible to suit particular needs of
patients in terms of maturity, or other special sets of circumstances created by their condition. (The Scottish Government, 2008, p.49-50) At the time of publication of the actual report on the National Delivery Plan for Children and Young People’s Specialist Services it did not deal with transition except to say that staff dealing with adolescents should have special training in this area and that an analysis would be undertaken to make this possible. A special document was to be produced (The Scottish Government, 2009a, p.24) specifically discussing hospital services for young people in Scotland. Transition was again discussed, this time specifically in relation to hospital services and recommendations were made in relation to what NHS authorities would be asked to do in order to improve transition in Scotland, including making sure that workforce plans produced by each regional board “recognise the range of skills and competencies required for the holistic care of young people in hospitals including in particular, their psychological needs” (The Scottish Government, 2009b, p.30). What is not clear from this and the other appropriate sections in the report is how far, if at all, these recommendations will be achieved through statutory or legislative instruments. Although it is appreciated that different local authorities have different budget availability and population make up, there is no clear benchmark for a minimum standard of transition process. It is also left open to question how any crossover of responsibility between the NHS and local authorities, in particular social work departments, ought to be dealt with.

Transition was also considered as part of a 2007 literature review commissioned by Scottish Executive Social Research which described many of the barriers to smooth transition created by multiple and complex needs such as the requirement for age appropriate care and difficulties created by problems including a lack of verbal communication or challenging behaviour. (Rosengard, Laing, Ridley and Hunter, 2007, pp 37-39) Although this report provides some useful information, because of the wide-ranging definition of complex needs used in the report, which could extend as far as drugs misuse and housing issues, and the fact that transition is only one of many concerns, it is possible that the issue will become clouded by the many others under consideration. In 2009 the Scottish Government published a report which looked at service provision for children and young people with complex needs
in a community setting from the perspectives of nursing and allied health professionals. (Law, McCann, O’May, Smart, and Buchan, 2009) This report takes a more restricted definition of complex needs such that the discussion is more strongly focused upon health issues, however the report again raises the issue of the need to clearly define age appropriate care and for there to be a focus placed upon the need for cross sector i.e. health/education/social work, communication and the need for these agencies to work together. Again this report only considers transition within the context of many other issues surrounding complex needs, with the result that transition becomes overlooked.

A report entitled, ‘Report of the National Review of Services for Disabled Children’ which aimed to provide a clear picture of the services provided for disabled children in Scotland again noted that although financial support may be provided for specific areas such as short-break respite often the issue of young peoples’ transition to adulthood can be neglected with ‘Action for Children’ noting that specifically in relation to the issue of short breaks respite, there is no clear pathway for transition. It is also noted that families feel that during transition, they must ‘fight for services. The report points out that where services were working well these were often underpinned by a number of factors including:

- shared perceptions and approaches between child and adult services and partners
- sufficient expertise in both child and adult teams and partner agencies
- clear agreement and time scales to avoid crisis driven responses
- accurate transfer of information between services
- exploring self directed care options well in advance of transition

In addition the report stated that the development of transition services for young people with learning disabilities were more advanced than those for young people with physical disabilities and mental health problems. (The Scottish Government, 2011, pp 13-20) This was followed by a progress report about the concerns raised within the initial report and stated forthcoming
government actions on the basis of the report including dissemination of good practice with regard to various issues including transition. (Progress report on the Report of the National Review of Services for Disabled Children, 2012a, p 4)

Additionally in 2012, the Scottish Government updated its guide to the ‘Getting It Right For Every Child’ framework to give more detail on the issue of transition but again this guide only makes general comments about specific issues around transition, for example, the role of the lead professional, rather than giving clear pathway details. (A guide to Getting It Right For Every Child, 2012b, p 14)

Transition has also been discussed by the Scottish Government under the auspices of the 16+ learning choices framework through which every young person must be provided, by the local authority responsible for their education, an offer with regard to their post school options. This includes young people with physical disabilities and/or learning difficulties and provides the possibility to extend the learning choice period if appropriate beyond the normal 16 to 19 years (Scottish Government, 2012c, p4). This framework also reiterates the requirement for good links with other partners as required under the statutory guidance mentioned previously. Transition for young people with additional support needs should under these statutory guidelines be as follows:-

(Scottish Government, 2010, p. 113)
The Doran Review which was a strategic review of learning provision for children and young people with complex additional support needs also raised the issue of transition suggesting that this issue was a concern for parents and carers sometimes as early as the late years of primary school. They also pointed out that the transition to adult health services is often badly coordinated and argues that the ‘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 right help at the right time in the right place, 2012d, p 30)

The Scottish Government responded to the Doran Review, recognising the requirement for leadership referred to in the review and said that transition would be a theme of the additional support needs report to be delivered to the Scottish Parliament in 2014 by the Advisory Group for Additional Support for Learning. (Meeting the needs of Scotland’s children and young people with complex additional support needs: The Scottish Government’s response to the Doran Review, 2012e, p 12)

It is worth mentioning that prior to the National Delivery Plan for Young People’s Specialist Services, and indeed the post 16 choices framework, the Scottish Executive had previously raised concerns around transition in the year 2000, when the Executive acknowledged that, “As they grow older, children who suffer from enduring illness are particularly vulnerable as they go through the often difficult transition from specialist children’s services to those provided for adults. We expect the NHS to work with partner agencies to ensure that this transition is managed sensitively and with attention to young people’s needs”. (The Scottish Executive, 2000 p.24) Subsequently, in 2007 the Scottish Executive produced documentation concerning rehabilitation for adults and was aimed at helping adults with long term conditions live at home and function as well as possible in their communities. Although the report acknowledges, like many of the documents on transition, the requirement for individuals and carers to be involved in decisions regarding their needs, it also states that patients, and those caring for them, are experts on the impact of
their condition on their lives and their requirements. This infers that professionals need to take seriously the views of those patients and carers they have contact with, and are involved in making recommendations for their future care. (The Scottish Executive, 2007, p.31) While this does not deal with transition for young people into adult services it does make a pertinent point regarding the importance of involving both the patient and those who care for them in decisions surrounding their care package. Whilst these indications of concern are admirable, what has perhaps been overlooked in this process is the connection between the care package of a given patient and the process through which government and other agencies ensure that adults who have previously been cared for by children and young people’s services, come to the attention of the appropriate adult services or at the very least they are provided with a ‘roadmap’ to guide them to the most appropriate solutions for them.

From describing the basis of the Scottish Government, or to be more accurate, national level policy as regards transition, what becomes clear is that within these documents there is a role for local authorities and health boards with regard to transition for young people, and that like the national policy these policies exist across a range of documents rather than as one comprehensive ‘handbook’. Each local authority has a policy made up of various documents pertaining to their local area’s, specific requirements with the result that the policy which exists can vary from one local authority or health board area to another.

**At Local Authority and Health Board level in Scotland**

The following local authority and health board policy documents are those which have already been identified as being relevant to this research; Single Outcome Agreements; Transition Protocols; Community Plans; Community Care Plans and Care Eligibility Criteria.

**Single Outcome Agreements** (SOAs) are agreements signed by the Scottish government, local authorities, and local authority community planning partnerships. They result from a concordat signed between the Scottish Government and local authorities which ties them into a relationship of
working together in a climate of mutual respect and which is of benefit to the Government and the authority. The SOAs lay down how each party in the agreement will move forward. This will be in a manner which improves outcomes for local people in such a way as it fits in with the local situation and priorities within the context of the 16 Scottish Government national outcomes. (The Scottish Government 2011) The 16 national outcomes are in effect the government’s priority policy areas or issues, e.g. improving business and employment opportunities and reducing crime. Of the 16 outcomes, basically only four are pertinent to this study insofar as they could encompass issues to do with the provision of adult treatment and care for CP patients in Scotland. These four are:

- “we live longer, healthier lives”
- “our young people are successful learners, confident individuals, effective contributors and responsible citizens”
- “our public services are high quality, continually improving, efficient and responsive to local people’s needs”
- "we have tackled the significant inequalities in Scottish society"

The SOAs therefore are relevant as a measure of the level of commitment displayed by local authorities to the issue of adult treatment and care. However these documents, although a statement of well-meaning intention, are not always entirely clear on the detail, and therefore may not serve as a real consistent guide of policy in each local authority area.

**Transition Protocols** are documents which set out the process of transition for adults with long term complex needs and/or physical disability, of which cerebral palsy is one. These are important as a measure of the extent of consistency of the optimal process if not the actual outcome.

**Community Plans** are the plans produced by local authority community planning partnerships in order to create a clear process by which they will work toward their local goal and those within the national government outcomes.
Community Care Plans which are produced by the local authority in conjunction with the health authority, are a plan of the required service provision and are reviewed on a regular basis. These are useful insofar as they demonstrate the extent of joint working and coherent planning which is in place for the services required for adults with disabilities.

Care Eligibility Criteria are the criteria through which local authorities decide who is eligible for certain types of assistance, such as personal care or other day to day needs, and are useful for gauging how closely these match the concerns raised by transition protocols. These also allow for comparisons between how care is provided to patients in different local authority areas and how any statement about levels of provision tie in with responses from individual patients. This should indicate any disparity between the interpretation by different authorities of their criteria.

These protocols and criteria are important as they affect both what happens during the transition process and afterwards in terms of what care is provided to individuals. Legislation and statutory guidance are important here as they ensure that local authorities provide certain services, e.g. those which would assist disabled persons to live independently at home, and the provision of these services affects the outcome for CP patients.

Good practice guidelines produced by organizations other than government bodies, e.g. the Royal College of Physicians in Edinburgh, are important because sometimes local authorities or NHS boards follow these guidelines rather than produce their own protocols.

Having considered the range of documents which make up the policy surrounding transition, it becomes clear that the nature of the policy being as it is, with each local authority producing their own document, leaves room for the possibility of variation in the policy and its delivery. The current stage of the research therefore is to assess the extent of that variation through documentary analysis and from additional information accrued through semi-structured interview with civil servants, medical professionals and social workers. The impact of the policy upon service users will be assessed by means of a survey.
The literature of political science in general and public policy in particular is wide ranging and offers a number of useful concepts to assist in explaining given outcomes in particular areas of policy but what it can also do is offer insights to inform later parts of a study. This was the case with regard to the agenda setting literature when considering transitional care for CP patients in Scotland. When considering the policy, it becomes clear that transition in general has not received very much attention outside of particular groups such as medical professionals, disability groups and others with specific interests around the issue, for example, social workers and those involved in education at national level.

**Setting the Scene**

Most ‘policy issues’ on public policy agendas, after initial inclusion on those agendas have sustained lengthy periods during which they receive little or no attention until at some point or other, due to focus by interested parties such as interest groups or parliamentarians or other experts, they once again ascend the list of priorities. Reasons for this may be varying levels of attention by the public, government, or the media, which in turn dictates at what level on the agenda the issue falls. If policy can be said to take place in more than one arena, that is at the local, regional, and national levels, then attention on an issue, and therefore, its place on the political agenda can be different within these different arenas (Cairney, 2012, pp. 182-183). It is even possible for this to take place to the extent that a policy issue exists within one arena, that is, high attention level, but is almost non-existent within another, i.e. low attention level. Transition is generally afforded only a low level of attention in national government circles with policy development being dominated by experts, either of the medical profession or other associated health, education or social care professionals. Although interest groups exist and they are participating in review, they are hugely outnumbered by professionals and officials and these reviews are not transition specific so the level of attention on the issue of transition is likely to be small. In addition, where transition has been considered in government review or through professional guidelines, it is considered within the context of those professional’s dominant concern, in
other words where medics describe transition, this tends to be in the context of health care needs or condition specific requirement, vis a vis the transition process.

At the local level it would appear that attention on the issue of transition is variable. In some local authorities the issue of transition is focused on through the lens of education, additional support for learning and post school options, which means that the resultant policy tends to discuss the issue in educational terms placing responsibility on schools whilst in other local authorities, the main responsibility has been placed with the social work department, which can mean that the issue is defined in terms of learning disability and this is seen as encompassing CP patients whilst, for others the transition protocol under which they would deal with CP patients is a complex needs protocol or a physical disability protocol. In relation to how that attention came to be focused, for some local authorities this came out of the publication of the ‘post 16 framework’. This framework is education and additional support needs related with the consequence that the local authorities whose catalyst came from that framework would appear to be more likely to have a more education focused protocol. For others the increase in attention came out of service user, that is client’s and/or their carer’s, feedback.

Jones and Baumgartner argue that the inability of people and organizations to pay attention to all issues all of the time may result in policies being positioned at or near the top of the agenda of government and at other times slipping further down the agenda or not on it at all (Jones and Baumgartner, 2005, pp. 20-21). Levels of attention to an issue can also be affected or manipulated that is, increased or reduced by certain factors such as, for example ‘focusing events’ like a crisis or a disaster (Kingdon, 2011, p. 94).

The idea of transition has been considered, as can be seen above, within a number of different political venues, therefore it is important to note that not only can the agenda be manipulated by focusing events or crises, but it can also be manipulated by a process of venue shopping, whereby actors with an interest in the issue look for areas of political activity which would be most receptive to considering the specific subject at a given time, therefore
changing the way in which the issue is presented in order to fit in with that venue or forum. (Princen, 2010, p. 37)

This leads to the questions:

- How has the problem been defined and prioritised?
- Is the definition different depending on the groups in question, e.g. the British Medical Association, Royal College of Nursing, Scottish Government as compared to Capability Scotland and other disability interest groups?
- Is the problem defined and discussed differently by Scottish and UK Government because their concerns in relation to the problem are different?

These questions are connected to the key research questions above in that, differences in agenda setting and prioritisation of problems can serve as one of the explanatory factors, both for what is actually written in the policy statement, i.e. what the actual policy is, and apparent contradictions in the implementation of this policy which can make it appear more or less consistent.

**Implementation**

The implementation literature offers a number of insights which might offer possible explanations for variation in the policies surrounding transition in Scotland including the work of Lipsky who considers the extent of the discretion afforded to individual officials at ground level implementing policy (Lipsky, 2010, pp. 13-16). In the case of CP this would refer to social workers or possibly members of the education department, therefore the extent of the discretion afforded to social workers when implementing the transition protocols for their local area will be discussed during interviews.

A number of studies have attempted to apply Lipsky’s argument to a range of cases, one key example which is important to the current project is that carried out by Bergen and While who attempted to combine Lipsky’s work with implementation theories which test policy implementation against a set of
perfect conditions. They found that the outcome on the ground of the implementation of the policy they were researching was that whether the subjects followed the prescribed policy depended on a number of variables these being:

- The clarity of policy guidance
- The extent to which it coincided with professional values
- Local practices and policies
- The personal vision of the individual subject

(Bergen and While, 2005, p1)

The first of these, clarity of policy guidance, is most closely associated with the ‘top down’ theory of implementation while the others are more closely aligned to Lipsky’s work. This type of variable measurement would be very useful as one could use this to ascertain the differing extent to which these variables applied across NHS boards and regions. Maynard-Moody and Mashino offer another picture of how discretion within the front line public services works, depicting such workers as walking a line of tension between a state agent and citizen agent narrative to explain their decisions. Under the state agent narrative, discretion is seen as something which is ever present. The area of concern is not the number of such decisions but how rules which this theory argues cannot fit all cases, are adapted by workers on the ground as some of these rules are complex and contradictory. Even though discretion is acknowledged, the importance of laws and rules as the context within which these decisions occur is emphasised. The state agent narrative focuses on self interest that can guide the use of discretion, for example, the use of discretion to reduce the case load by focusing on clients within their group who might be easier to help, and formulating short term rather than long term fixes to problems. Citizen agent narrative focuses on how individual bureaucrats handle different cases differently rather than having the same emphasis on rules and procedures and concentrates more on the judgement made about character of individual clients or groups of clients. (Maynard-Moody and Mashino, (2006), p. 10-12)
Another suggestion that is made about organisations and the process of implementation is that the policy to be implemented, especially where it is being implemented in various regions across a number of organisations, begins to take on various meanings and rationales as it passes through the various organisations responsible for implementing parts or all of the policy. For example Pope, Robert, Bate, Le May, and Gabbay found that when it came to treatment centres in the NHS in England the exact definition of the role of these treatment centres differed slightly between regions. This difference in meaning across different organisations might be quite important in relation to transition for CP patients given that each organisation i.e. council or health board not only produces their own protocol, but also must work across those organisations to implement these protocols. (Pope, Robert, Bate, Le May, and Gabbay, 2006, p. 67-69)

Goggin et al suggest another form of implementation where although goals might be specified by more senior officials, those carrying out the implementation process have space to interpret those goals so that the implementation fits more closely with the preferences of local organisations (Long and Franklin, 2004, p. 311). In the case of cerebral palsy transition for example, it might be that some of the variation in policy and its delivery might emanate from the fact that, although the Scottish Government has produced guidelines, perhaps each council protocol is in line with the local values which they espouse as part of community plans. It is also worth noting that differences in the policy as it operates within the various regions of Scotland may emanate from a failure to meet one or more of Hogwood and Gunn’s conditions for perfect implementation. (Hogwood and Gunn, 1984, p 198-205)

Another issue which may explain the differences between regions may emanate from a clearer separation between implementation and formulation in some areas than exists in others. For a more in-depth analysis, John Stewart discusses whether implementation and other stages such as formulation can really be seen as a separate stage of the policy process. (Stewart, 1996, p 36) Constraints on implementation of a policy may be more issue specific than those referred to by Hogwood and Gunn, such as the nature of the case-load of a given region or other health related issues. (Scott, Matthews and Gilson, 2012, p 143)
Cairney notes that although the Scottish Government has a reputation for consulting widely, this is not always the case and this may affect the resulting implementation and its success or failure. These consultations tend to be related to the broad principle rather than minute detail. This may offer another factor to add to ideal conditions ie, that consultations should not just cover the broad principles but should also cover the small details so the problems may be identified as early as possible (Cairney, 2009, p. 10). Another condition which ought to be added to those listed above is that the policy implementers fully understand what is being asked of them. Spillane, Reiser and Reimer argue that important misunderstanding often occurs between those who produce policies and those who are expected to implement them. Many conventional accounts of implementation they suggest do not take account of the fact that making sense of a policy for those implementing it is an active rather than passive process and that process by which policy implementers come to understand policies therefore, must play an active role in how it comes to be implemented. (Spillane, Reiser and Reimer, 2002, p.391-392) According to Spillane and colleagues, implementers of policy are therefore thought of as sense makers, i.e. active beings who have to be able to make sense of a new policy, they must assimilate and accommodate policy with their cognitive processes and in doing so, certain mediating factors in this sense making process must be considered: prior knowledge, different interpretations of the same messages, misunderstanding new ideas as familiar and that understanding may focus on superficial features of policy and deeper relationships are missed. To explain the work carried out by Spillane et al, their work looks at education policy and consequently the examples which they give are related to education and schools policy, however, many of the principles of what they argue could be applied to other cases, including that of transition and ongoing care policy for Cerebral Palsy patients. The key would seem to the development of schema, a mental picture of ideas which can be informed by previous experience. Many of these factors, including the backgrounds of individual professionals, can affect implementation.
Governance and Accountability

Governance and accountability may seem at first sight to be offering similar depiction and explanation for the variation which might be found within transitional care for CP patients in Scotland, but arguably because of the wide ranging nature of both the implementation field of study and the equally wide ranging governance and accountability literature it becomes clear that one can find different and novel perspectives on the variation.

Accountability is a contested concept and can be subject to various definitions and explanations. Cameron suggests that in social work terms accountability occurs where social workers provide an explanation for, and/or justify their actions or lack of them to anyone who might reasonably expect these actions to be explained to them. She then suggests that this arguably brings together the concepts of “accountability to” and “accountability for”. “Accountability to” is to be accountable or to give an explanation to those on whose authority you act, whereas “accountability for” refers to the activity which is being monitored or scrutinised (Cameron, 2003, pp. 54-55). Behn argues that the definition of accountability seems to be constantly changing and evolving but is of the opinion that for the most part accountability can be taken to refer to one party holding another accountable for something. The parties being held accountable, being part of Government i.e. quangos, are generally being held to account in relation to fairness, finances or performance. Behn suggests that finances and fairness should be seen as areas of accountability which relate to how government does its work. He argues that the public sector focuses on this type of accountability at the expense of performance i.e. accountability which focuses on what government or public sector organisations actually do. Behn terms this ‘over-focus’ on how the government does its work as ‘accountability bias’. (Behn, 2001, p 18) Although this in itself is not necessarily problematic, it can be seen as perhaps offering some kind of explanation with regard to policy variation which may be evident within Scotland’s transition policy. Governance and accountability offer useful insight into the current case in the sense that, given that part of the policy is produced by the NHS, and it has non-departmental public body status or is at the very least to be considered a Quango, the reduced monitoring to which such organisations are
subject and the apparent freedom they enjoy as a result of their status as described in Flinders’s discussion around delegated governance and the British state may appear to mean that these organizations are not monitored or are monitored less well than they perhaps ought to be (Flinders, 2008, p. 3). The scrutiny they undergo in terms of accountability is professional accountability, that is clinical accountability, which does not appear in many cases to cover the issue of transition separately, but is part of one large accountability process which can mean that transition might be missed in some areas and picked up in others, thus explaining some of the variation in delivery. The accountability literature describes two competing kinds of accountability and the need for organisations to reconcile these competing demands (Thomas, 2003, pp. 550-552) In the case being discussed, delivery and policy anomalies might also be explained by considering the idea of accountability as compliance i.e. following the rules and accountability as performance or outcome and the need for organisations to reconcile these competing ideals. The idea of interactive governance as a way of considering transition policy might be useful insofar as not only does it allow for the discussion of the position in relation to special status of bodies such as the NHS, but also allows for the discussion of the role played by private actors in the development of public policy in this area. (Torfing, Peters, Pierre and Sorensen, 2012, p 15-16)

It is also helpful when considering accountability as a possible explanation for the variation, and not merely in terms of the type of accountability in question, but also to consider the process within the context of the various components of accountability, that is, first consider the who or the locus of accountability and then the what, so exactly what areas of activity are those organizations or persons responsible for, and through what procedures are those persons or organizations accountable. (Emanuel and Emanuel, 1996, p 230) Bovens notes that one of the difficulties with studying accountability, or indeed achieving accountability, can be the identification of who the person responsible for carrying out a process or activity actually is, therefore, difficulties in identifying the responsible party or individual may explain part of the variation in transition policies across Scotland. (Bovens, 2006, p 18)
Policy Transfer

Policy transfer offers a route enabling the explanation of both the similarity and difference in policies in different regions and ties in well with the current study. According to Dolowitz and Marsh policy transfer should be taken as a term which denotes the process by which knowledge or information is passed from one jurisdiction to another. They note that this knowledge can refer to policies, ideas or institutional arrangements, and that these can either come from the present or the past (Dolowitz and Marsh, 1996 p. 344).

Dolowitz notes that policy transfer can occur along a continuum as below ranging from direct copy to inspiration as below:

Direct copy < > Mixture < > Core idea or concept < > Inspiration

(Dolowitz, 2003, p.104)

In other words, a given country may choose to copy directly an entire policy or just the core idea, for example, welfare for single mothers. A country could choose to copy the whole of another country’s welfare for single mothers policy, or just use this to inspire their own policy. To expand on this, one could take as inspiration the idea that venerable cohorts in society should have some form of support but no more than that and thereafter implement their own policy based on this principle.

In addition to there being a range of levels of transfer from inspiration to direct copies of policy, the transfer of policy can also take place under a range of conditions such that the transfer can be voluntary or coercive or some place in between, that is, it is voluntary but perceived to have some form of necessity attached to it such as international acceptance. (Dolowitz and Marsh, 2000, p.13)

Dolowitz and Marsh have created a framework of questions which research should attempt to answer when studying cases of policy transfer:-
• Why transfer policy?
• When is policy transferred?
• Who is involved in transfer?
• What is transferred?
• From where do policy transfers take place?
• To what extent does this transfer take place?
• What are the Constraints on transfer?
• Was it a success?

The current study will utilise Dolowitz and Marsh’s framework to explain the variation or similarity in the various regional policies formulated by the NHS boards and local authorities in Scotland, and consider these differences or similarities against the answers to the above questions. This will establish whether there is some degree of transfer taking place and determine which local authorities are the originator of the policies and which are the adopters.

The current study will also consider exactly who is involved in the transfer of these policies, i.e. whether they are civil servants, medical professionals, or private consultants for example. (Benson and Jordan, 2011, p. 368-370, Prince, 2012, p. 195-196, and Stone, 2001, p. 17-18) Constraints of transfer will also be considered, for example, the specific aspects of the programme, that is complexities and particularities of the institutional set-up in the originating region or country. (Benson, (undated) p. 7-9) Any examples of non-transfer of particular programmes or ideas and the reasons behind this will be considered including availability of information and factors of local context and feasibility. Diane Stone discusses examples of non-transfer in the case of Ukrainian energy policy and its specifically local context. (Stone, 2003, p. 9) Failure of a policy as an outcome of policy transfer and some of the reasons for this, for example incomplete or inappropriate transfer is discussed in the work of Diane Stone and also James and Lodge. (Stone, 2012, p. 488 and James and Lodge, 2003, p. 188-189) Whilst the ideas discussed here refer to a wide range of cases, it is suggested that these concerns fit well with the current research because,
arguably, due to the wide range of actors involved and the different conceptions of the issue of transition a space is left in which policy failure through transfer might occur or at least in part explain a difference in policy outcome between one area and another.

There are various English or UK government produced policies in place, and it is important when considering transfer of policies to note their origin within the Scottish context, because discussions with participants in Scotland have suggested that these guidelines, that is those published by the UK government, are being used by some councils, while others are possibly adopting from other local authorities in Scotland, so consideration will be given to the extent of that transfer by looking at documents and also discussion in interviews.

Data Collection

As previously described the data for this study consists of a range of documents and interviews and a survey of service users. At present the data collection process is on-going and therefore this paper utilises only the information which has already been gathered and deals with the position within 17 local authorities for which there has both been documentation provided and the interviews have taken place. Later papers will deal with a more detailed exposition of the position within the remaining local authorities, health boards and the opinions of service users. The chosen focus on the 17 local authorities allows the inclusion of the gathered data within the available space of this paper. As this project is on-going, this paper will only make general comments on the basis of the available data and does not identify specific regions as sources.

Documents

Transition works across a range of documents within a local authority from single outcome agreements to joint community care plans, community plans and transition protocols along with service plans and strategies. Scotland is served by 32 local authorities and while the study of the whole considers all
32, and the 14 NHS boards, due to the ongoing nature of the research, this paper considers only 17 for which both documentation has been procured and the interviews have taken place. Analysis of joint community care plans, service plans and community plans is also ongoing along with analysis, where possible, of associated minutes. Therefore, the current paper considers only the position with regard to SOAs and transition protocols, however it might be worth noting that the current sense with regard to the other documents would be that the appearance of transition as an issue is sporadic, coincides with possible service change, for example integration of services, or it provides some general comment about a commitment to improve rather than real detailed analysis of the position. Whilst all of the 17 local authorities examined have each of these documents in one form or another, what is not consistent is whether transition is dealt with in any or all of these documents, and just how much detail is devoted to transition, particularly in the strategy documents and protocols, is subject to variation.

**Single Outcome Agreements**

Single outcome agreements have been in place in Scotland since the SNP took office in 2007. They are tied to 16 Scottish national outcomes developed by the Scottish Government for details see:

[http://www.scotland.gov.uk/About/Performance/scotPerforms/outcome](http://www.scotland.gov.uk/About/Performance/scotPerforms/outcome)

These run in three phases, phase 1 being 2008 to 2011, phase 2, 2009 onwards and phase 3, 2013 onwards. Across these phases, transition is mentioned within the SOAs on a sporadic inconsistent basis. Of the sample of 17, over the three phases, the following was found to be the case:-

- Phase 1 - 7 authorities refer to transition
- Phase 2 - 8 authorities refer to transition
- Phase 3 - 10 authorities refer to transition

Although this upward trend at first appears to be favourable, only 4 of the 17 refer to transition in all three phases of the documents. Furthermore, the
detail provided varies from one phase to the next as in some cases, do the outcomes to which it is connected. In some cases it is connected to business, economics and employment while in others it is connected to children, young people, health, equality, education, inclusion or any combination of all of these. The organisations, such as those in the voluntary sector, if they are listed in the scope of the agreement apparently makes no difference as to whether transition is included in the document. There are no specific targets generally about transition with the exception of 'positive destinations'\(^3\) which monitors the number of young people moving on into further education, training and employment.

**Transition protocols**

Of the 17 local authorities being considered here 15 had produced transition protocol documents which were tested against the following 11 values. These had been developed on the basis of some of the principles around 'good transition' such as clear sense of who is covered by the process and some sort of visual representation of that process for example, a flowchart:

1. Number of pages long and date produced.

2. Is there a flowchart or other kind of diagram?

3. Is there a transitions team and/or coordinator?

4. Is there background information as to where the policy originates e.g. Scottish government Scottish executive or local context?

5. Is it clear what groups are covered by the protocol?

6. Is it a joint protocol i.e. health/social work/education? Who is the lead according to the protocol?

7. Is there a review date for the protocol?

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\(^3\) This is the proportion of leavers in sustained positive destinations – higher education, further education, employment, training, voluntary work or activity agreements (Scottish Government 2012).
8. Are specific groups mentioned such as those with complex needs and/or learning difficulties?

9. Is handover/transfer (to adult services) specifically mentioned?

10. Is an introduction age for transition mentioned and if so what is the age?

11. Does transition only refer to the move from secondary education to workplace/further education/adult life or are all ages covered e.g. 0 - 65?

Again inconsistency is a feature of many of these documents, the simplest of which to recognise is the actual length of the document in pages. Although this is a very crude measure and not an indicator of content it perhaps give a sense of the level of detail contained within the protocol. Of the 15 protocols examined, only three were markedly lacking in the fields under consideration, the remainder, in the main, produced a positive result when tested against the above criteria, however this is not to say that the quality of these results was consistent. The majority, 9 out of 15 contained some sort of flowchart or table indicating the transition process, however, again the level of detail was variable. From interviews and reviews of literature, flowcharts are seen as being particularly important in the eyes of professionals, giving them information on the timing, stages, and sometimes who should be included/informed, which can allow them to smooth the process of transition for young people and families, while the same information can assist young people and families in understanding transition and its stages. All but one of the 15 protocols clearly listed all the groups covered which is important given the varying and complex conditions with which CP patients and other young people with additional support needs (ASN) can present. The recorded introduction age for transition is mentioned in 13 out of 15 protocols, however the age ranges from P6/7 (10/11 yrs) to 15 years. While most guidance documents recommend early planning, waiting until 15 years does not fall outwith the recommendation shown in the Scottish Government flowchart above, however a more consistent start point may improve the process. In relation to ages, i.e. the range covered by transition, one protocol is silent on the subject while 10 mention only young people, young adults or school leavers, however, one takes transition to post higher education but only three
espouse the idea that transition is a whole life scenario, that is to age 65. These documents provide some basic facts about the ideal process while interviews provide a better sense of the actual practice of this process from the point of professionals and the survey provides a perspective from the point of view of service users.

**Interviews**

All interviewees agree that transition is a period of change in a young person's life and this is talked about as a move to adult services from the child orientated services. Three interviewees showed a wish to see transition as a whole of life scenario, arguing that transition for people with disabilities in particular occurs at a very basic level when they do apparently simple things like changing employment. Transition is also acknowledged as a time of great anxiety for young people and their families and it is often suggested that one of the ways in which this can be alleviated is by the provision of information. All interviewees cite their provision of verbal information to families however, the provision of information leaflets is less common. One local authority produced a very detailed handbook and although it is acknowledged that printed information will become dated it is thought that such media is seen to be desirable to young people and their families. One authority has a dynamic website where contact details and other transition information is regularly kept up to date. Arguably this might be seen as a process which could be implemented more widely.

Only three persons (two of whom work within the same council) interviewed stated that they had any separate budget which they were able to direct toward transition. Beyond this at least two interviewees indicated that they would like this idea to be considered within their authority. Where there were transitions teams, interviewees made it clear that they had allocated time to devote to transition. In one instance, where the protocol was under review, that audit process was specifically considering the need for training around transition related issues as part of continuous professional development (CPD) needs. All of the professionals would appear to grasp the potential range of
needs which may result from a person being affected by CP to the extent that these people are often defined as having complex needs, however there is an understanding that these people should not be categorised merely on the basis of their condition.

In terms of transition as part of the national and local agenda, interviewees regularly refer to additional support for learning legislation and the GIRFEC framework as influencing how their protocol works. In terms of the position of transition on the agenda, interviewees suggest that transition rises up the agenda where perhaps it is felt that an individual case went less well than expected and therefore the process ought to be reviewed. They suggest that transition also rises up the agenda when new legislation or guidance is produced and the documents would seem to suggest that this may also happen where service is being reviewed or altered and some interviews have concurred with that. In most cases where the development of the protocol was a joint process this was perceived positively. Where the development was not a joint one, it was suggested that this was because the individual department was going to develop their own process and then pass it out to colleagues from other disciplines or departments. Professionals in the majority of cases suggest that communication between themselves and other professionals is good but they indicate that this can at times be down to personal relationships more than a clear system. In areas where the population is small, communication is seen as being particularly good. One interviewee suggested that greater use of Skype and other online communication tools would improve links with other professionals and patients, where the weather or indeed logistics made travel difficult. Although transition teams may on the surface, and indeed in literature be seen as a good idea, three interviewees intimated that transition teams may, by virtue of this specialisation, become over-focussed on the issue. This may also result in others in the profession standing back from transition because this kind of case is immediately passed to the teams. The result of this could be a lack of understanding of transition outwith the specialised teams. Discretion around transition is very wide ranging and for the most part is seen as a good thing and an opportunity to personalise services around individuals, however the timescales are always seen as important and while trying to keep to these as far as possible is in general a good thing, the welfare of individual
families is seen as paramount. In some cases, individuals may remain under the
care of children's services because they or their family are not yet ready for the
transfer to happen. It may also be the case that the handover process needs to
be gradual, in which case children's services work alongside their adult
counterpart to provide a service until the young person is ready to transition
fully, however one interviewee pointed out that whilst discretion in terms of
personalisation was a good thing, it was important that it was not used as an
excuse to delay consideration of the process. In terms of the monitoring and
governance of the transition process, there is a perception among interviewees
that the Government does not monitor the details of the transition process.
One interviewee cited this as a particular weakness in terms of this causing
there to be no-one who has a clear general overview of the process. It is also
pointed out that although the government does not monitor the process it can
be, although it is not always part of the inspection process, carried out by the
care inspectorate. Although these inspections do make a difference to practice,
and any issues picked up on are dealt with, it is generally only through
consideration of a small number of cases except where transition is part of the
current run of thematic inspections.

The learning and policy transfer process surrounding transition and good
practice is complex. In terms of learning from other authorities, the learning is
patchy and often where there is learning, it is on an inspiration basis where
only the theme of the idea is utilised, because the local service availability
differs from that available within the authority from which the idea originates.
There is a perception in some areas that this is not reaching the bottom level
of professionals but rather stays in the hands of management. It is very ad hoc
and can at times consist only of a 'Google' search rather than gaining a real
sense of what is taking place in other areas. Some interviewees cited
professional forums such as the Scottish Transitions Forum, or the Association
of Social Work Directors as a route to finding out what was happening in other
areas. The recognition of how successful that learning is, is patchy because of
the lag between utilising the learning and putting a survey in place to obtain
service users opinions. Among those interviewed, there are two local
authorities which are more commonly cited as sources of learning than others.
This may perhaps be a result of one authority being mentioned in government
reports and guidance as an example of good practice and the other authority being a GIRFEC pathfinder.

**Conclusion**

The policy in relation to transition is one where there is room for variation between regions. This may be explained by the differences in how the problem has been defined, whether there is learning or collaboration within or between authorities and who has been involved in the formulation and implementation of the policy. While it is clear that none of the authorities dealt with for the purposes of this discussion are carrying out a process which can be said to fall beyond the bounds of national guidelines, there is an acceptance of the need to focus on the issue of transition and improve local processes. In terms of the documents, the mention of transitions is sporadic and inconsistent. In terms of the position of transition on the agenda, interviewees suggest that transition rises up the agenda where perhaps it is felt that an individual case went less well than expected and therefore the process ought to be reviewed. They suggest that transition also rises up the agenda when new legislation or guidance is produced and the documents would seem to suggest that this may also happen where service is being reviewed or altered and some interviews have concurred with that. The level of discretion around the protocols is described often to be quite high and to focus on the personalisation of the service for individuals i.e. the transition should happen when the person is ready or when it is appropriate for the family. As a result of this thinking, people may be kept on in children's services where there may be resource issues. It has been suggested that care should be exercised when using discretion as it might be used as some sort of 'get out clause'. Transition is always discussed as a time of change in interviews and regularly described as a time of anxiety. In some cases it is suggested that transition is a whole of life scenario. In terms of learning from other authorities, the learning is patchy and often where there is learning, it is on an inspiration basis and there is a sense in some areas that this is not reaching the bottom level of professionals but rather stays at a managerial level. The sense of how successful that learning is, is patchy because of the lag between utilising the learning and putting a survey
in place to obtain service users' opinions. The interviews have produced a substantial amount of useful data but what is still open to question is how far civil servants and management individuals will be able to support the amount of change that is called for.
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