

Coming Home

A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs

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Dr Anne MacDonald

**Scottish Government
2018**



Acknowledgements

Thanks to all those from the Health and Social Care Partnerships who completed the data returns; it is acknowledged that this was a significant time commitment from people, and it is appreciated.

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Table of Contents

Acknowledgements	1
Table of Contents	2
List of Tables	3
List of Figures	4
1 Ministerial Foreword	5
2 Executive Summary	6
2.1 Introduction and Overview of the Project.....	6
2.2 Data Collection and Analysis	6
2.3 Summary of Findings.....	7
2.4 Summary of Issues.....	8
2.5 Conclusions and Recommendations	9
3 Introduction and Overview of the Project	10
3.1 Overview of Project	10
3.2 Definition of Terms.....	10
3.3 Policy Context	11
3.4 The Challenge	12
3.5 The Vision.....	13
4 Data Collection and Analysis	15
4.1 Quantitative Data.....	15
4.2 Data Analysis.....	16
4.3 Qualitative Data	17
4.4 Positive Behavioural Support Project	18
5 Summary of Findings	20
5.1 Out-of-Area Placements	20
5.2 Delayed Discharge	34
5.3 Feedback from Stakeholders.....	41
5.4 Positive Behavioural Support Findings	45
6 Summary of Issues	46
6.1 The Need for Transformational Change	46
6.2 Specific Themes Arising from the Data.....	46
6.3 What Makes Good Support	48
7 Conclusions and Recommendations	51
7.1 Values and Principles	51
7.2 Theme One: Strengthening Community Services	52
7.3 Theme Two: Developing Commissioning and Service Planning.....	55
7.4 Theme Three: Workforce Development in PBS.....	61
7.5 Next Steps.....	63
8 Summary of Recommendations	65
9 References	66

List of Tables

Table 1: Characteristics of Out-of-Area Group	21
Table 2: Characteristics of Priority to Return Group	24
Table 3: Challenging Behaviour, Treatment & Risk Management in PTR Group	26
Table 4: Placement Information for Priority to Return Group	28
Table 5: Characteristics of the Autistic Subgroup	32
Table 6: Characteristics of Delayed Discharge Group	34
Table 7: Challenging Behaviour, Treatment & Risk Management DD Group.....	35
Table 8: Placement Information for Delayed Discharge Group.....	38
Table 9: Discharge Plans.....	40

List of Figures

Figure 1: Number Out-of-Area per HSCP.....	20
Figure 2: Length of Time Out-of-Area.....	21
Figure 3: Reasons for Out-of-Area Placements	22
Figure 4: Requirement for Repatriation in Non-Choice OOA Group.....	23
Figure 5: Number of Priority to Return per Health Board Area	24
Figure 6: Length of Time Out-of-Area for Priority to Return Group.....	29
Figure 7: Barriers to Repatriation for Priority to Return Group	30
Figure 8: Costs of Placement for Priority to Return Group	30
Figure 9: Annual Costs per Health Board Area for Priority to Return Group.....	31
Figure 10: Costs of Placement in Autistic Subgroup	33
Figure 11: Reason for Admission.....	37
Figure 12: Length of Admission for Delayed Discharge Group.....	38
Figure 13: Length of Delay	39
Figure 14: Barriers to Discharge	40
Figure 15: Costs of Placement Delayed Discharge Group.....	41

1 Ministerial Foreword

I welcome this important study which was commissioned in 2016 in response to concerns raised by the Mental Welfare Commission in their report “No Through Road”. There has been an awareness that out-of-area placements and delayed discharge for individuals with complex care are not in the best interests of individuals or their families. This report is the first time that a collective and comprehensive overview has been made available in Scotland on both the characteristics and circumstances of people with complex needs who are placed into care settings that are distant to their families and communities, or who remain in hospital settings beyond the clinical need of them to be there.

I thank Dr MacDonald for her professionalism and dedication to revealing the national picture on this issue. I urge everyone concerned in the welfare of this vulnerable group to work in partnership to consider how best to take forward the recommendations set out here. I want us to work together towards the aspirations of the individuals covered in this report to be moved closer to home as soon as this is practically possible. In future, we want to see fewer people moving to live far from their families and the communities they call “home”.

CLARE HAUGHEY MSP
MINISTER FOR MENTAL HEALTH

2 Executive Summary

2.1 Introduction and Overview of the Project

A priority within *The Keys to Life* is that all adults with learning disabilities, including those with complex needs, experience meaningful and fulfilled lives. This includes where individuals live, as well as the services they receive. Some people with learning disabilities and complex needs are living far from home or within NHS hospitals; there is an urgent need to address this issue. The Scottish Government commissioned a two-year project to look specifically at the support provided to people with learning disabilities who have complex needs. The focus of the project was to identify the number of people involved, and also to suggest support solutions for individuals with learning disabilities who have complex needs, and who are either placed out-of-area, or are currently delayed in hospital-based assessment & treatment units.

The Scottish Government wants to support Health and Social Care Partnerships (HSCPs) to find alternatives to out-of-area placements, and to eradicate delayed discharge for people with learning disabilities.

The Scottish Government's vision for people with learning disabilities and complex needs within Scotland is that everyone is supported to lead full, healthy, productive, and independent lives in their communities, with access to a range of options and life choices.

2.2 Data Collection and Analysis

The scope of the data collection was all individuals with learning disabilities who were 16 or over, who were living in placements which were not within their funding authority, and also those whose discharge from hospital was delayed. Individuals with autism but without a learning disability were not included. Data were collected in relation to the date of 31st January 2017; that is, anyone that was out-of-area or a delayed discharge on that date.

It is acknowledged that some people may be living out-of-area and that this may be appropriate for them. Respondents were therefore asked to specify the reasons for someone being out-of-area and where anything other than 'their choice or their family's choice' was selected, then this was judged to be a significant factor in identifying that these individuals may be part of a more significant subgroup, who were inappropriately out-of-area.

A follow-up filter was then applied to establish if HSCPs felt that repatriation was required for this group. Where HSCPs did indicate that repatriation was required, then the group who met both these criteria became specified as inappropriately out-of-area, and they are therefore regarded as the group who are 'priority to return'. They are the focus of attention for the main analysis in this report.

2.3 Summary of Findings

2.3.1 Out-of-Area Placements

The project found that there were 705 people out-of-area in Scotland from 30 HSCPs. This does not include one HSCP which did not participate in the project; given that this was a large HSCP, it is likely that the figures are substantially higher. 45% had been out-of-area for more than 10 years, and 23% for more than five years. Of this group, 79 people were placed out of Scotland (in England and Wales).

453 of the group were identified as being placed out-of-area not through choice, and of these, 109 were classed by their HSCP as requiring repatriation and are therefore considered to be priority to return.

The priority to return group were significantly more likely to be male than female; around 50% were autistic and 72% had moderate or severe learning disabilities.

Around 20% were reported to have a mental health diagnosis and 66% were described as currently having challenging behaviour, indicating that addressing behavioural needs is likely to be a high priority in supporting this group appropriately.

The most common challenging behaviour noted was physical aggression, followed by property destruction and verbal aggression. In relation to support for behavioural challenges, 37% were recipients of positive behavioural support (PBS), 21% were subject to physical restraint, and 44% were in receipt of as required medication to manage their behaviour.

31% were placed out-of-area in crisis, which would indicate that there is a lack of support in the community to deal with crises when these arise, and that better crisis support is required.

In relation to reasons for out-of-area placement, 77% were placed out-of-area due to lack of specialist services locally, and another 11% due to local specialist services having no capacity, indicating a significant shortage in local services able to meet people's needs.

The main barriers to repatriation were found to be a lack of suitable accommodation or lack of skilled service providers. Specifically, this related to lack of providers able to sustain support to people through periods of challenging behaviour, and how HSCP service responses support them to achieve this

2.3.2 Delayed Discharge

Data returned indicated that 67 people were delayed discharge as of the specified date of 31st January 2017. As noted above, this does not include data from one HSCP.

This group were also primarily male, and challenging behaviour was also a significant factor, with 73% displaying current challenging behaviour. 57% were identified as having been admitted to hospital due to challenging behaviour, or service breakdown in relation to challenging behaviour.

More than 22% had been in hospital for more than 10 years, and another 9% for five to ten years. The main barrier to discharge was lack of accommodation, followed by lack of suitable service providers. This relates to a range of issues, such as difficulties in commissioning, and a need for different community-based solutions.

2.3.3 Positive Behavioural Support

The project found limited evidence for use of PBS in social care settings; providers made reference to either external health professionals supporting them with PBS, or they saw this as part of the role of their physical intervention trainers. This indicates a lack of internal expertise, as those who are primarily physical intervention trainers are unlikely to have the skills and expertise required to lead on implementation of PBS.

2.4 Summary of Issues

The discharge of people with learning disabilities and complex needs from hospital and their return from out-of-area placements is a complex issue that appears to defy simple solutions. It involves complex interrelated processes, agencies, and services, all of which must work together for better outcomes for individuals. Unless all stakeholders work together, no one specific element is likely to be successful or sustainable. A transformational change approach is therefore required to address this issue throughout the sector; this will require an overall change in culture and approach.

It is clear from this report that one of the main issues for this group is the presence of challenging behaviour, and the impact that challenging behaviour has on service breakdown or hospital admission. This is in part due to a lack of coordinated or robust responses, particularly when services begin to experience difficulties in maintaining placements during periods of behavioural crisis.

It is worth emphasising that challenging behaviour is understood as a communication from the individual and as a product of the environment they live in and of the support they receive. It is not a diagnosis, and although it is associated with certain conditions and syndromes, it is not innate to the individual, but rather an expression of their unmet need.

Throughout the work of this project, an aim was to come to an understanding of what good support for people with learning disabilities and complex needs should look like. A number of key elements were identified:

- Person-centred approaches
- Environments which support communication
- Active support and full lives
- Positive behavioural support
- Suitable accommodation
- Skilled and motivated staff
- Good management and practice leadership

2.5 Conclusions and Recommendations

The conclusions and recommendations identified in this report should be viewed in the context of a human rights approach and in line with the following principles:

- Maximising choice and control
- Prevention and early intervention
- A whole life approach

Recommendations are grouped under three key themes: the first five recommendations are for Integrated Authorities/Health and Social Care Partnerships, and the remaining recommendations are for the Scottish Government.

2.5.1 Theme One: Strengthening Community Services

Recommendation 1: Develop options for access to crisis services for people with learning disabilities and complex needs, with a view to providing direct support to service provider or family placements which are at risk of breakdown.

Recommendation 2: Consider the role of flexible support responses, to be used when placements are experiencing significant difficulty. The need for this should be informed by the use of risk registers to identify individuals at risk of out-of-area or hospital placement.

Recommendation 3: Ensure that greater consideration is given to family support for the family carers of people with learning disabilities and complex needs.

2.5.2 Theme Two: Developing Commissioning and Service Planning

Recommendation 4: Take a more proactive approach to planning and commissioning services. This should include working with children's services and transitions teams; the use of co-production and person-centred approaches to commissioning; and HSCPs working together to jointly commission services.

Recommendation 5: Identify suitable housing options for this group and link commissioning plans with housing plans locally.

2.5.3 Theme Three: Workforce Development in Positive Behavioural Support

Recommendation 6: The Scottish Government should seek partnership with a university to provide PBS training across the health and social care workforce in relation to people with learning disabilities and complex needs.

Recommendation 7: The Scottish Government should support the establishment of a PBS Community of Practice.

3 Introduction and Overview of the Project

3.1 Overview of Project

A priority within *The Keys to Life* (Scottish Government, 2013) is that all adults with learning disabilities, including those with complex needs, experience meaningful and fulfilled lives. This includes where individuals live as well as the services they receive. Some people with learning disabilities and complex needs are living far from home or within NHS hospitals. There is an urgent need to address this issue and therefore the Scottish Government commissioned a two-year project to look specifically at the support provided to people with learning disabilities who have complex needs. The focus of the project was to gather national data on individuals with learning disabilities who have additional complex needs, and who are either placed out-of-area, or are currently within hospital-based assessment and treatment units, classed as delayed discharge.

The aim of the project was to provide information about the issues, and to help identify the actions that could improve outcomes for those people with learning disabilities in Scotland, who currently are unable to receive appropriate support in their local communities, and who have either been admitted to assessment and treatment units, or are living in out-of-area placements. The Scottish Government wants to support Health and Social Care Partnerships to find alternatives to out-of-area placements, and to eradicate delayed discharge for people with learning disabilities.

3.2 Definition of Terms

3.2.1 Learning Disability

A learning disability is defined within *The Keys to Life* as a “*significant lifelong condition which is present prior to the age of eighteen and which has a significant effect on a person’s development. People with a learning disability will need more support than their peers to:*

- *understand information*
- *learn skills and*
- *lead independent lives”*

Learning disability does not include specific learning difficulties such as dyslexia. An acquired brain injury which occurs at age eighteen or over would also not be considered as a learning disability.

3.2.2 Challenging Behaviour

The term challenging behaviour is sometimes replaced with ‘behaviours of concern’ or ‘stressed and distressed behaviour’. However, within this report, the term challenging behaviour is used as it is still the most common term within the sector, and is also the term that is used within a research context. It refers to behaviour which challenges services and support providers, rather than implying that the person is themselves challenging.

The definition used for challenging behaviour for the purposes of this project was:

“Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion”

(Challenging Behaviour: A Unified Approach’ Royal College of Psychiatrists, British Psychological Society & Royal College of SALT 2007)

3.2.3 Complex Needs

It is acknowledged that it can be difficult to define what is meant by complex needs and that there are a range of current definitions. For the purposes of this project, the term complex needs is used to refer to people with learning disabilities who also have one or more of the following:

- Severe challenging behaviour (it is noted that this may include behaviour which is not severe in itself, but becomes severe due to its high frequency)
- Forensic support needs
- Mental health needs
- Autism
- Profound and multiple disabilities (it is noted that although this group is generally included in the term complex needs, the data from this report found small numbers of people with these types of needs)

3.2.4 Out-of-Area

Out-of-area was defined as living within a placement not within the individual’s funding authority. This could include living in either an NHS or a private hospital.

3.2.5 Delayed Discharge

Delayed discharge was defined as per the NHS Scotland Delayed Discharge Definitions Manual (NHS National Services, 2016):

“A delayed discharge is a hospital inpatient who is clinically ready for discharge from inpatient hospital care and who continues to occupy a hospital bed beyond the ready for discharge date.”

3.3 Policy Context

3.3.1 The Keys to Life

The Keys to Life is Scotland’s learning disability strategy and was launched in 2013. It includes a specific focus on health inequalities and is underpinned by a commitment to human rights for people with learning disabilities and the principles of choice, control and independence.

In 2015, the Scottish Government published an implementation framework centred on four strategic outcomes: a healthy life; choice and control; independence; and active citizenship. Within this, under strategic outcome three *“Independence: people*

with learning disabilities are able to live independently in the community, with equal access to all aspects of society”, a commitment was made to explore alternatives to out-of-area placements for people with complex needs; this project is the result of that commitment.

3.3.2 Revised Keys to Life Framework

The Scottish Government intends to publish a revised implementation framework for *Keys to Life* early next year. The four key themes for that work are: Living, Learning, Working and Wellbeing.

3.3.3 A Fairer Scotland for Disabled People

Since the publication of *The Keys to Life* and the implementation framework, in 2016 the Scottish Government has also published *A Fairer Scotland for Disabled People*. This plan is part of the programme for *A Fairer Scotland*, and was shaped by the experiences and insights of disabled people. It is the delivery plan to meet Scottish Government obligations under the *United Nations Convention on the Rights of Persons with Disabilities*, and has five long-term ambitions aimed at transforming the lives of disabled people, including people with learning disabilities, in Scotland, and ensuring that their human rights are realised.

The five ambitions are:

- Independent living: support services that promote independent living, meet needs and work together to enable a life of choices, opportunities and participation.
- Financial independence: decent incomes and fairer working lives.
- Accessibility: places that are accessible to everyone, including housing, transport and the wider environment.
- Protected rights: the rights of disabled people are fully protected and they receive fair treatment from justice systems at all times.
- Active participation: disabled people can participate as active citizens in all aspects of daily life.

The work of this project and the areas for action identified within this report are set within the context of the *Fairer Scotland for Disabled People* delivery plan.

3.4 The Challenge

Support to people with learning disabilities and complex needs has historically proved a challenge in Scotland and across the wider UK. From the time of the large learning disability hospital closures in the 1980's, finding appropriate and sustainable community placements for this group of people has proved difficult. It is true that the sector has some examples of very good practice where people with complex needs are well-supported and live full and active lives in their communities; however, there are also many examples of individuals who have undergone multiple placement breakdowns, hospital admissions, and difficult experiences, and who have not received the right support at the right time, in order to meet their outcomes and achieve full and meaningful lives. Solutions to this situation are therefore likely to need more than individual service changes, but must instead be seen within the context of transformational systems change.

3.4.1 Impact on Individuals

The impact of out-of-area placements and delayed discharge for the individuals affected, is often huge and life-changing. Breakdown of support has, for some, resulted in the loss of their home, sometimes moving far from their family, or into hospital settings, resulting in fractured family relationships and loss of community networks. There have been high stress levels, confusion and uncertainty about the future, and the unsettling experience of receiving support from a new and unknown group of staff, often without a clear understanding of why things have changed, or why there has been a move to a new living environment. Many of these individuals have significant communication difficulties and find it difficult to understand and deal with changes; many are autistic and find it a struggle to accept new routines and structures; and for many, these frustrations and frightening experiences, will manifest as challenging behaviours, directed at themselves, others, or the environment.

3.4.2 Impact on Services

This also has a significant impact on services. An over-reliance on out-of-area placements to provide support to people with complex needs or challenging behaviours, can result in resources not being targeted at development within the local area. This can also result in an ongoing lack of local specialist provision, and a vicious circle in the use of out-of-area placements.

In addition, the lack of access to assessment and treatment units for those who need it, means that individuals who do require admission to hospital for appropriate reasons, for example, to assess or treat their mental health in a safe environment, may experience delays or barriers to admission due to a lack of appropriate beds being available.

The impact on the social care sector generally is also significant, with substantial amounts of money being spent on small numbers of individuals, with often no clear evidence that the support is appropriate or is meeting people's needs.

3.5 The Vision

The vision for people with learning disabilities and complex needs within Scotland is that everyone is able to lead full, healthy, productive and independent lives in their communities, with access to a range of options and life choices. This includes:

- That everyone with a learning disability should have access to the support they need: the right support, at the right level, and at the right time.
- That regardless of an individual's complex needs or challenging behaviours, they should have choices about where they live, who they live with, and how they are supported.
- That services will engage in genuine partnerships with people with learning disabilities and their families, not token representation, but a sharing of decisions and responsibilities, on the basis that any service developments should involve people with lived experience.

Support to people with learning disabilities needs to be framed in the broader context of equality and social justice, not just within the narrower focus of service delivery; in particular, that better services, and more importantly better lives, for people with complex needs is a human rights issue.

The most effective way forward is to take an assets-based approach which seeks to embrace the capabilities and talents of people with learning disabilities and align them to assets within their communities.

4 Data Collection and Analysis

4.1 Quantitative Data

4.1.1 4.1.1 Scope

The scope of the out-of-area data collection was that all individuals with learning disabilities who were 16 or over and who were living in placements which were not within their funding authority, were to be included in the data collection. This included individuals who were living outwith Scotland as well individuals, if they were 16 or over, who were living in residential schools.

All individuals with learning disabilities who were 16 and over, who were considered to be delayed discharge, for any reason, were to be included in the delayed discharge data collection.

Individuals with autism but without a learning disability were not included.

Data were collected in relation to the date of 31st January 2017; that is anyone that was out-of-area or a delayed discharge on that date.

4.1.2 Data Collection Process

Each Health and Social Care Partnership (HSCP) was asked to complete an individual return. During the planning of the project, Chief Officers from each of the HSCPs were contacted by letter to inform them about the project and ask for their support in data collection. They were asked to identify a contact who would supply the requested data in their area, and all the HSCPs that replied, did this.

The data came from people in a range of different roles, depending on the HSCP. On the whole these appeared to be professionals working within adult learning disability services, but for a few HSCPs, the data were supplied by someone working more specifically in a data-related role.

4.1.3 Data Collection Tool

Respondents were asked to complete an Excel spreadsheet for every individual; there was one sheet for out-of-area individuals which contained 29 questions, and one sheet for delayed discharge individuals, with 27 questions. Questions were mainly answered by selecting one option from a dropdown list, for example to choose in which HSCP a person was placed if out-of-area. Where more than one answer was required, for example to list different types of challenging behaviour, a list of options and codes were given in the guidance, and these could be added as free text. All questions were to be answered individually for each person.

The data collection tool and guidance was consulted on with stakeholders from both health and social work backgrounds in order to test its fitness for purpose. Feedback was taken into account and relevant changes and additions were made. One of these was the need to make the tool as user friendly as possible; therefore the dropdown format with a range of pre-selected options was used. Advice from stakeholders was given as to the likely options to be required for different questions.

The data returned contained no identifying information for data protection issues.

4.1.4 Issues with Data Collection

There were a number of issues with accessing the data. Data were due to be returned by 31st March 2017. However, data were still being sent in 6 months later, and this may have impacted the accuracy of some returns.

Also, as would be expected with a data collection of this size from so many different sources, some inaccuracies and anomalies were found at a later date. In terms of the information received, it may be more helpful to regard this as indicating themes or trends in relation to the issues, rather than precise numbers.

One HSCP did not participate in the data collection process, and therefore all overall figures nationally have to be regarded with this exception; this is particularly significant since this is a large authority, whose data would have changed the reported numbers substantially.

If an individual was placed in a hospital outwith the funding authority, then they were recorded as out-of-area and included in the out-of-area returns. It was acknowledged that individuals could be both out-of-area and delayed discharge, and therefore there was the possibility of double reporting. In order to ensure that that this had not taken place, for any individual recorded as out-of-area and placed in hospital, data from that HSCP in relation to the delayed discharge return were cross referenced to ensure that the same person had not been entered twice. Using data such as age, gender and diagnosis, it was possible to confirm that this had not happened.

4.1.5 Data Protection

In order to adhere to data protection guidelines and to ensure that no individuals could be identified, no numbers less than five are reported in the out-of-area data and no numbers less than 10 in the delayed discharge data.

4.2 Data Analysis

4.2.1 Approach to Analysis

Out-of-area and delayed discharge data are analysed separately, as there were a range of different questions and issues for each group; however there are many issues in common, so in terms of identifying themes and key issues, they are regarded as a combined group.

Most data are presented as percentages as this is more useful for comparison; however, on occasion, actual numbers are used and this is specified where it is the case. Percentages are rounded up to the next whole number.

4.2.2 Out-of-Area Analysis

It is acknowledged that some people may be living out-of-area and that this may be appropriate for them, for example it is based on a positive choice, rather than a lack of local services; or they are only just out-of-area, and may actually be nearer their

family or local community where they are living; or they have been living there so long that there is no connection with their funding authority.

Respondents were therefore asked to specify the reasons for someone being out-of-area and chose from a list including:

- based on their choice or their family's choice
- lack of capacity in local services
- lack of local specialist services
- to prevent hospital admission

Where anything other than 'their choice or their family's choice' was selected, then this was judged to be a significant factor in identifying that these individuals may be part of a more significant subgroup, who were 'inappropriately' out-of-area.

A follow-up filter was then applied to establish if HSCPs felt that repatriation was required for this group. No reason was required for the decision as to whether repatriation was required or not; this was regarded as a judgement for the funding HSCP, based on their knowledge of the individual, their current placement and progress there, and the wishes of them and/or their family. Where HSCPs did indicate that repatriation was required, then the group who met *both* these criteria became specified as inappropriately out-of-area, and they are therefore regarded as the group who are 'priority to return'. They are the focus of attention for the main analysis in this report.

This was felt to be a reasonable way of identifying the group for whom it is most pressing that services are developed and that action is taken; that is, those who are out-of-area not through choice, *and* for whom the HSCP has identified an imperative to return. They are referred to in this report as the '**priority to return**' (PTR) group.

4.2.3 Specific Groups for Additional Analysis

There were two additional subgroups which merited specific consideration for separate group analysis: these are the subgroup who are autistic in addition to having a learning disability, and the out-of-Scotland group. Analysis for each these groups is therefore presented in addition to the main analysis of the priority to return group.

4.3 Qualitative Data

4.3.1 Individual Case Studies

A range of individuals' cases were considered as case study examples of either good practice or to highlight the issues which challenge the sector. Some of these were supplied by HSCPs, some came directly from discussions with family carers.

4.3.2 Meetings with Health & Social Care Partnerships

A number of meetings took place with representatives from different HSCPs across Scotland. Some of these meetings were in groups, for example the Social Work Scotland Learning Disability subgroup; others were done on a health board basis; most were individually with the HSCP. The aim of the meeting was to garner the

views of HSCPs in relation to the issues of supporting people with learning disabilities and complex needs; discussions ranged over topics such as housing, social care providers, costs and financial challenges, and the best models of care for the future.

4.3.3 Meetings with Social Care Providers

In addition, a variety of meetings were held with social care providers to discuss their experiences of supporting people with complex needs and their views on what is helpful in ensuring successful services. Providers were encouraged to discuss examples of services which had broken down, as well as services where they were providing successful support. Both third sector voluntary and private providers were involved.

4.4 Positive Behavioural Support Project

4.4.1 Overview of Positive Behavioural Support

Positive Behavioural Support (PBS) is an ethical, evidence-based and proactive approach to supporting people with learning disabilities, particularly those with complex support needs. It focuses on improving the person's quality of life and reducing challenging behaviour. It is accepted internationally as best practice and it is well-established as an effective framework for supporting people with learning disabilities and challenging behaviour.

It has been defined and refined in a number of studies over the past 25 years (Gore et al, 2013), and there is now a range of evidence demonstrating that PBS is an effective approach to reducing challenging behaviour and improving quality of life for individuals with learning disabilities (Goh & Bambara, 2012; La Vigna & Willis, 2012). It is also linked with reduced use of restraint (Singh et al, 2016); is effective in addressing severe challenging behaviour (McClellan & Grey, 2012); can be implemented in family settings (Durand et al, 2013); and can be implemented via a staff training approach (MacDonald & McGill, 2013).

PBS is a person-centred framework for multi-component intervention; it is not a single intervention. All interventions are based on an understanding of the person's behaviour and what communicative function their behaviour serves for them. It may therefore recommend changes to the environment or the person's support in order to better meet their needs. It pays attention to a person's health and well-being, to their day-to-day activities, to how they are supported, where they live and how their carers interact with, and support them.

4.4.2 Rationale for the Positive Behavioural Support Project

The key aim of PBS is to support those with additional needs to have the same life opportunities as everyone else, and it focuses on what services and carers need to do in order to meet people's needs. It has become more widely used in learning disability services and is recommended by a range of good practice guidelines (ACEVO, 2015; DOH, 2014), particularly following the Winterbourne View scandal and the development of the Transforming Care agenda in England (NHS England, 2014). It is a key factor in successful support for services for people with complex

and challenging needs, and it was therefore judged that part of this project should focus specifically on scoping PBS within Scotland.

Research evidence tells us that following the process of implementing PBS, the workforce would be expected to be more skilled (Wardale et al, 2014), knowledgeable (Lowe et al, 2007), and confident in working with people with behaviours that challenge (Davies et al, 2015), and would have a better understanding of the reasons for challenging behaviour occurring (Rose et al, 2014). PBS implementation would also result in the use of practice leadership, providing better support, guidance and feedback for staff, thus changing how well supported staff feel, decreasing stress, and improving morale.

PBS also has a role in providing less restrictive alternatives to physical restraint and psychotropic medication, and it is likely to be an important element in developing effective community-based support to individuals currently living in hospitals.

4.4.3 Survey of Use of Positive Behavioural Support

A survey was undertaken within health and social care services to find out about the use of PBS. The survey was sent out to approximately 30 care providers and support organisations in Scotland, and was also sent to all 31 HSCPs across Scotland.

Questions asked were around training (who delivers training in your organisation; what level of training is delivered; where did these trainers receive their training); around practice (how is implementation of PBS supported; what supervision, support and mentoring is provided; is there a PBS policy in place); and around outcomes (how is the implementation of PBS evaluated).

In addition to the survey, a review of literature took place in relation to both research and good practice guidance in PBS, and additional information was gained by meeting with PBS training provider agencies, and in liaising with PBS professionals and academics throughout the UK.

5 Summary of Findings

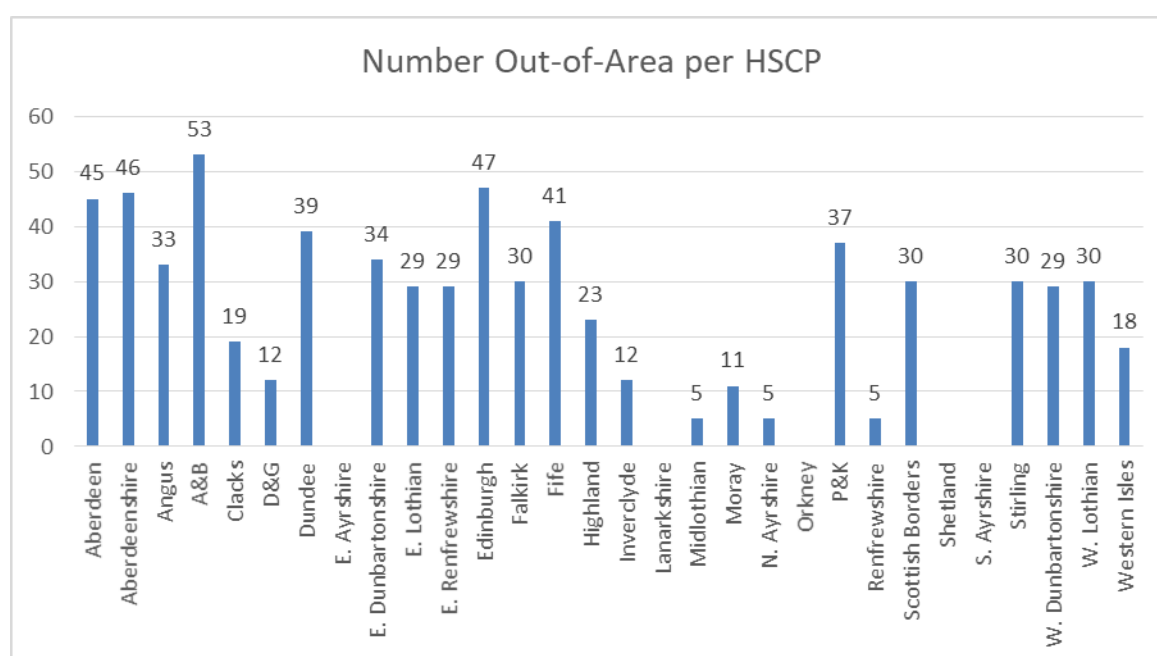
5.1 Out-of-Area Placements

5.1.1 Overall Out-of-Area Group

5.1.1.1 Overview

The project found that there were 705 people out-of-area in Scotland from 30 Health and Social Care Partnerships (HSCPs); this does not include one HSCP which did not participate in the project. North & South Lanarkshire reported their data together, and Stirling/Clackmannanshire reported separately, so this is how the data are reported here. Numbers of people out-of-area for each HSCP are shown in Figure 1. As previously noted, any numbers less than five are removed.

Figure 1: Number Out-of-Area per HSCP



5.1.1.2 Characteristics of Out-of-Area Group

The out-of-area group was predominantly male, and more than one third were autistic, although one fifth of the respondents selected 'don't know', or missed this question. On the whole they are a moderate to severely learning disabled group, with less than 10% having a forensic background.

More details about characteristics of the group are described in Table 1.

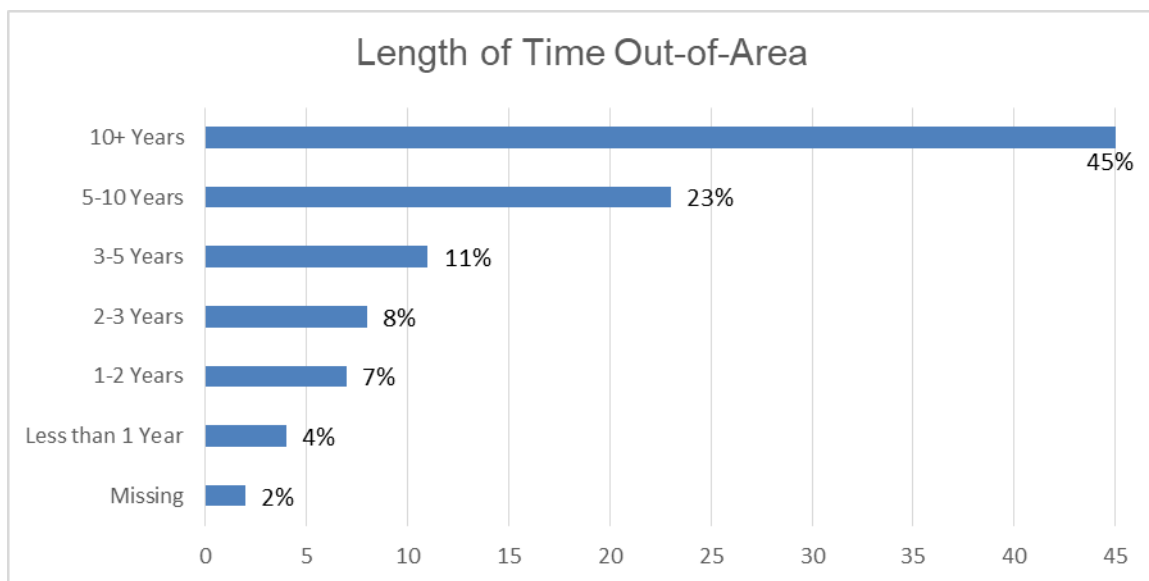
Table 1: Characteristics of Out-of-Area Group

Characteristic	Options	Percentage
Gender	Male	63
	Female	37
Autistic	Yes	37
	No	42
	Don't know/missing	21
Forensic	Yes	8
	No	80
	Don't know/missing	12
Level of Learning Disability	Mild	16
	Moderate	42
	Severe	25
	Profound	7
	Don't know/missing	10
Age	16-17	2
	18-20	7
	21-34	29
	35-44	19
	45-54	21
	55-64	13
	65+	9

5.1.1.3 Length of Time Out-of-Area

Figure 2 shows the length of time out-of-area for the overall out-of-area group, with nearly half being out-of-area for more than 10 years, and almost another quarter for more than five years. This length of time out-of-area may be part of the reason for HSCPs judging that repatriation is not required for some, i.e., even though these individuals did not originally go out-of-area through choice, they have now been placed there for so long that they may be regarded as settled and established and it may therefore be judged as no longer appropriate to repatriate them.

Figure 2: Length of Time Out-of-Area



5.1.1.4 Reasons for Out-of-Area Placement and Need for Repatriation

The reasons for being placed out-of-area are shown in Figure 3, indicating that just over a quarter of the group had gone out-of-area through choice, and that 65% (453 people) were identified as being placed there not through choice. The main reason given for out-of-area placements was the lack of specialist services available locally.

Figure 3: Reasons for Out-of-Area Placements

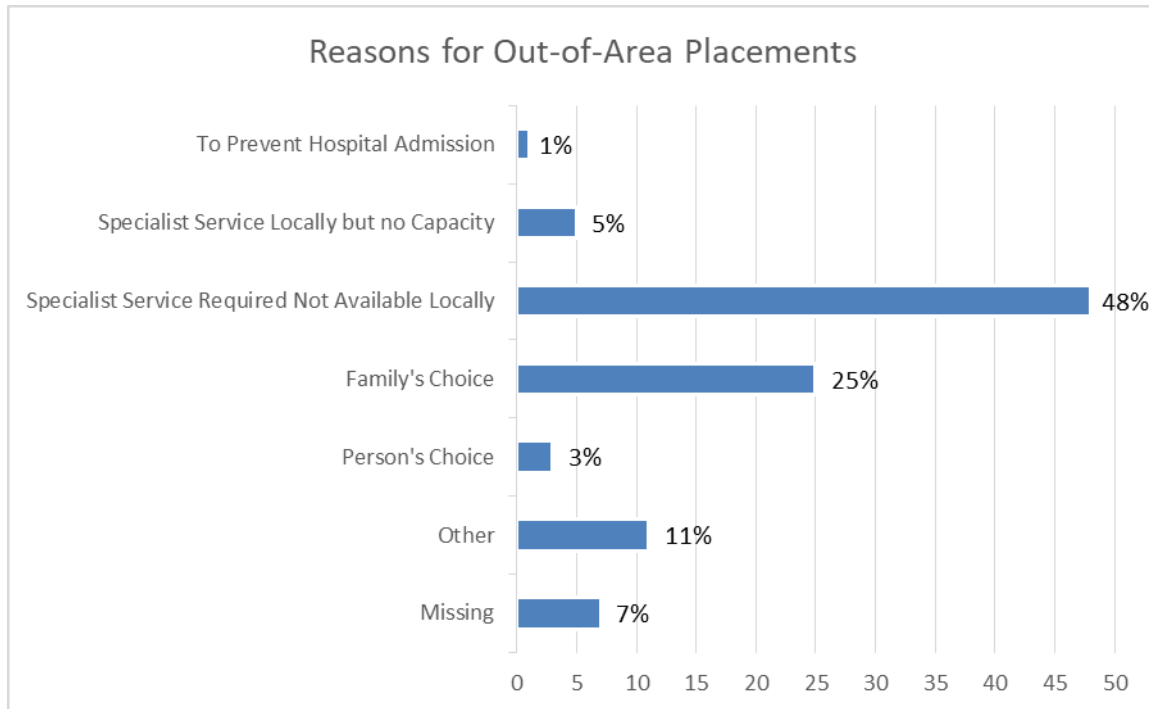
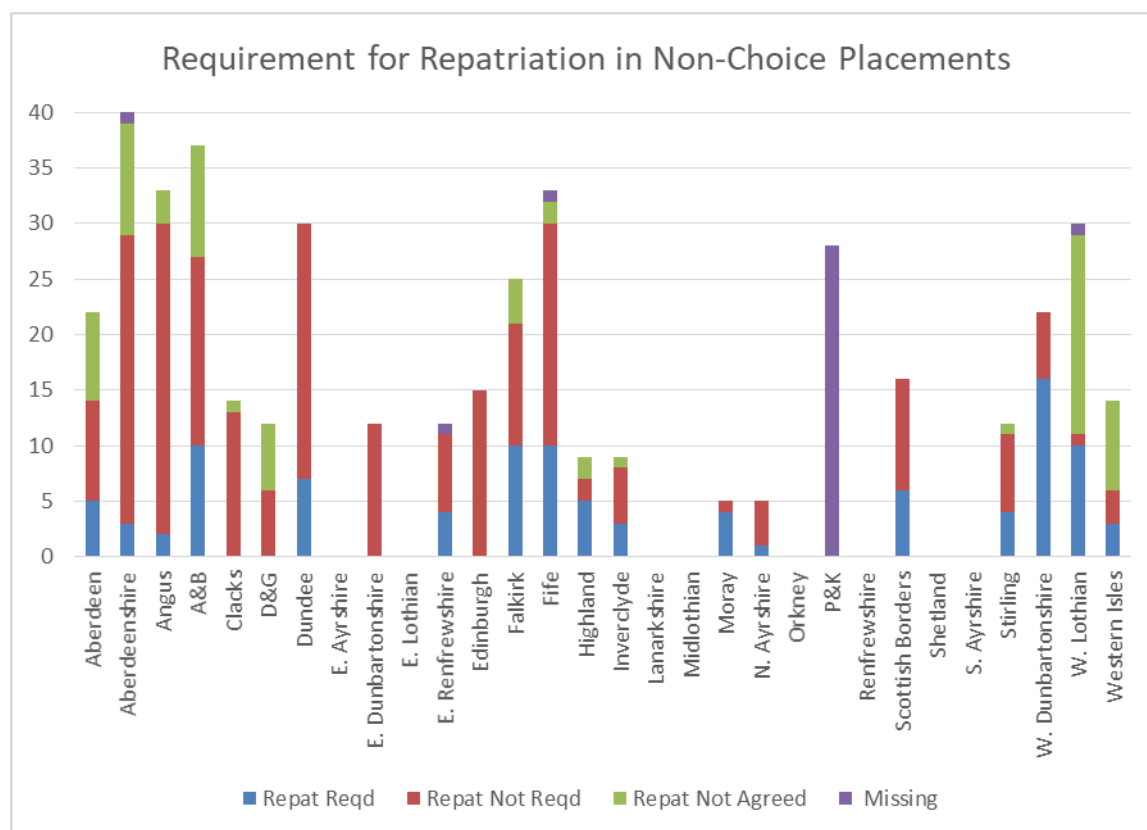


Figure 4 shows the requirement for repatriation for those who had not been placed out-of-area through choice. As previously noted, any numbers less than five are removed. Of the 453 individuals, 109 were classed by their HSCP as requiring repatriation, although this excluded 32 individuals whose data regarding need for repatriation were missing, including all 28 from one HSCP. There were also a substantial number (80) whose status regarding the need for repatriation was not yet agreed. For clarity, data here is shown as numbers, not percentages.

Figure 4: Requirement for Repatriation in Non-Choice OOA Group



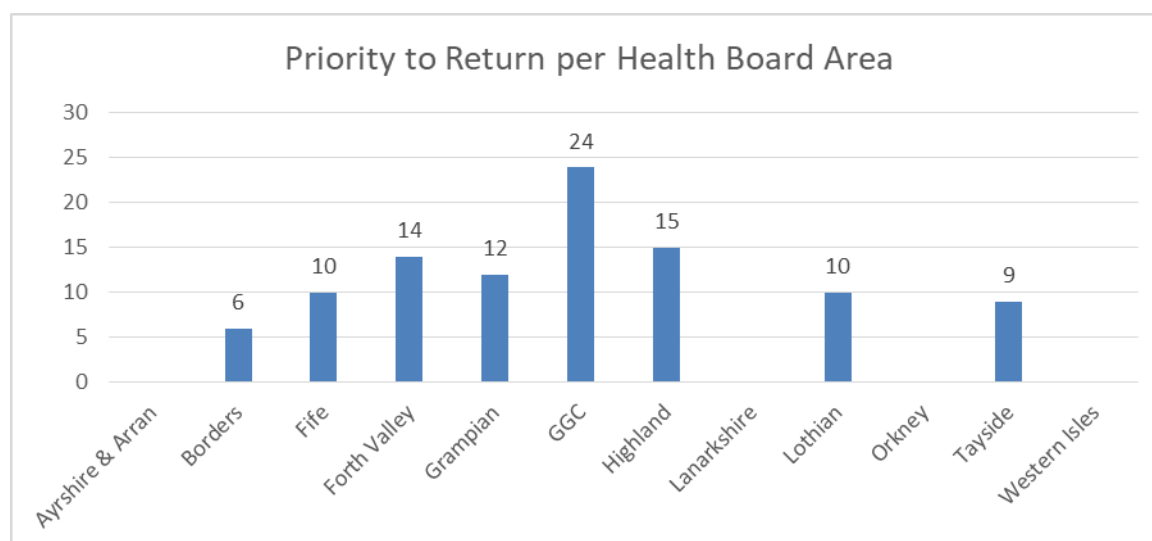
5.1.2 Priority to Return Group

5.1.2.1 Overview

109 people are considered to be priority to return, that is, those who were not placed there on the basis of their choice or their family’s choice, and for whom the HSCP said repatriation was required. Numbers of those who are priority to return are shown in Figure 5. Numbers are shown per health board area, in order to protect small numbers in some HSCPs. For any health board areas with numbers less than five, these numbers are removed but the health board label is still included.

These figures are likely to be under-reported as all data are missing for one HSCP, data in relation to need for repatriation are missing for 32 individuals, and there were another 80 individuals for whom the need for repatriation was recorded as ‘not yet agreed’. However, based on the data supplied, this group is judged to be the one which we can confidently label as inappropriately out-of-area, since the HSCP has specifically indicated the need for their repatriation. They are the group priority to return group on which the main analysis is focused within this report.

Figure 5: Number of Priority to Return per Health Board Area



5.1.2.2 Characteristics of Priority to Return Group

Characteristics for this group who are priority to return, are shown in Table 2. They were significantly more likely to be male than female, around half were autistic, and 72% had moderate or severe learning disabilities. Autism was the most common additional diagnosis; other diagnoses in addition to a learning disability were Down’s syndrome, Fragile X syndrome, Prader-Willi syndrome, Smith-Magenis syndrome, and Tourette’s syndrome.

More than one in five of the group had epilepsy and the main other physical health issues noted were physical disability, and visual impairment.

Around one in five were reported to have a mental health diagnosis. The most common mental health diagnoses were depression (4.6%) and anxiety (3.7%), followed by dementia, personality disorder and psychosis.

Two thirds were described as currently having challenging behaviour, indicating that addressing behavioural needs is likely to be a high priority in supporting this group appropriately.

Table 2: Characteristics of Priority to Return Group

Characteristic	Options	Percentage
Gender	Male	72
	Female	28
Autistic	Yes	49
	No	44
	Don’t know/missing	7
Forensic	Yes	18
	No	79
	Don’t know/missing	3

Level of learning disability	Mild	14
	Moderate	48
	Severe	24
	Profound	9
	Don't know/missing	5
Age	16-17	6
	18-20	17
	21-34	34
	35-44	16
	45-54	16
	55-64	7
	65+	*
	Don't know/missing	*
Epilepsy	Yes	22
	No	65
	Don't know/missing	13
Physical disability	Yes	9
	No	79
	Don't know/missing	12
Visual impairment	Yes	5
	No	83
	Don't know/missing	12
Mental health diagnosis	Yes	21
	No	69
	Don't know/missing	10
Challenging behaviour	Both current & historical	65
	Current but not historical	*
	Historical but not current	16
	No current or historical	17
	Don't know/missing	*

* Numbers removed

5.1.2.3 Challenging Behaviour

In order to understand the data in relation to challenging behaviour, it may be helpful to summarise current understanding of challenging behaviour, based on research and best practice. Challenging behaviour is functional, that is, it serves a purpose for the individual and is an attempt for them to influence their world and meet their needs. These needs may be to gain interaction and attention from staff or others; it may be a way to avoid or escape an activity, situation, or environment that they find difficult, confusing or overwhelming; it may be to achieve a tangible item such as food or drink or other preferred items; it could be to address unmet sensory needs by providing sensory stimulation to calm or to stimulate; or it may to express pain and physical discomfort, perhaps in the absence of any other way to communicate this. Challenging behaviour is therefore understood as a communication from the individual and as product of the environment they live in and of the support they receive. It is not a diagnosis, and it is not innate to the individual, but rather an expression of their unmet need. Given the right combination of circumstances, we would all have challenging behaviour. More details regarding challenging behaviour are shown in Table 3.

Table 3: Challenging Behaviour, Treatment & Risk Management in PTR Group

Types of Challenging Behaviour	Percentage Displaying	Support for Challenging Behaviour	Percentage Use
Current challenging behaviour	66	PBS input	37
Physical aggression	55	Active support	32
Verbal aggression	39	Communication strategies	50
Self-injury	31	Psychological therapies	19
Self-neglect	17	Sensory diet	6
Property destruction	40	Risk Management	Percentage Use
Disruptive behaviours	28	Physical restraint	21
Non-compliance	26	Seclusion	11
Sexual challenges	18	As required medication	44
Removing clothes	11	Additional staff	41
Absconding	*	Environmental restriction	36
Smearing	5	Technological restriction	9
Substance misuse	*	Mechanical restriction	*

*Numbers removed

As the data indicate that two thirds of the group were reported to have current challenging behaviour, it is worth further exploring the nature of these challenging behaviours, any support provided around behavioural needs, and the risk management strategies used to minimise risk related to these behaviours. Almost everyone reported as having current challenging behaviour also historically had challenging behaviour (only 17% are described as never having had challenging behaviour), indicating that these individuals have probably had a history of difficulties in receiving appropriate support.

The most common challenging behaviour noted was physical aggression, followed by property destruction and verbal aggression. When this is added to the fact that nearly three quarters of the group are male, most do not have a physical disability, and they are on the whole a fairly young group, the indications are that this is a very challenging group whose behaviour has the potential to cause serious harm and injury, both to themselves and to others around them, including staff and other supported individuals, and also to the environment. This is an important factor to recognise in terms of the challenge facing HSCPs in sourcing suitable social care providers for this group; and, given the longevity of challenging behaviours, this is likely to have been a long-term difficulty.

Moving on to consider the support provided for challenging behaviour, the most common support was the use of communication strategies, and given that challenging behaviour is a method of communication, it is appropriate that

communication strategies would be used in support. However, only half of the group were in receipt of these, and this is concerning, given that they are on the whole a significantly learning disabled group, and therefore we would expect to see nearer 100% in receipt of communication strategies.

Just over a third were recipients of Positive Behavioural Support (PBS), and this is also concerning given PBS is regarded as the most effective and appropriate support for people with learning disabilities and challenging behaviour. PBS is a person-centred approach to challenging behaviour, and therefore involves the development of strategies specifically designed to suit that person, based on a thorough analysis and assessment of their behaviour, and developed around their particular presentation in order to meet their needs. It would therefore be best practice to see every individual with challenging behaviour in receipt of a PBS plan.

It is also worth highlighting the reported use of risk management strategies. Physical restraint was used for over a fifth, and seclusion for more than one in ten. These are figures of concern, given that restraint and seclusion are very restrictive interventions that deprive the individual of their freedom, either by forcefully holding them against their will, often carried out by several members of staff; or by locking them in a room or area against their will, where they are deprived of human contact (Mental Welfare Commission, 2014). There are considerable risks that can be associated with both these interventions, particularly restraint, which has been linked with high levels of physical injury and death (Leadbetter, 2002).

An additional concern in relation to risk management is that almost half the group were in receipt of 'as required' medication as a risk management strategy for challenging behaviour, despite the fact that only one fifth were diagnosed with a mental health condition. The current use of anti-psychotic medication is particularly concerning since a range of research, including a randomised control trial, has found that these were no more effective than placebo in reducing challenging behaviours (Tyrer et al, 2008).

A final point to note in relation to the risk management strategies for challenging behaviour is that nearly half of the returns indicated that additional staff were used to deal with challenging incidents. This has implications for the support of individuals with challenging behaviour within community settings, as it is less usual for additional staff to be readily available within ordinary social care settings, and care providers are not usually funded to make these potentially large numbers of extra staff available on a flexible basis.

5.1.2.4 Placement Information for Priority to Return Group

A range of information about these individuals' current placements was explored, including whether the person had been placed as a result of a crisis. Nearly one third were placed out-of-area in crisis, which would indicate that there is a lack of support in the community to deal with crises when these arise, and that better crisis support is required. The fact that a third of the group were sent out-of-area from the family home may indicate that this crisis support is required for families, as well as for social care service providers.

In relation to the reasons given for out-of-area placement, over three quarters were placed out-of-area due to lack of specialist services locally, and another 11% due to local specialist services having no capacity, indicating a significant shortage in local services able to meet people's needs.

It is worth noting however, that despite the reported reason for a significant majority of the placements being due to the need for specialist services, nearly half the respondents indicated that the service the individual was currently in, was described as a 'general learning disability' service.

In addition, although nearly half the group were autistic, only around a quarter were reported as placed in an autism-specific service; and although 18% were described as having forensic support needs, only 5% were placed in forensic services. This may indicate that even out-of-area, there is a lack of specialist services to meet people's specific needs.

More information about placement information is shown in Table 4.

Table 4: Placement Information for Priority to Return Group

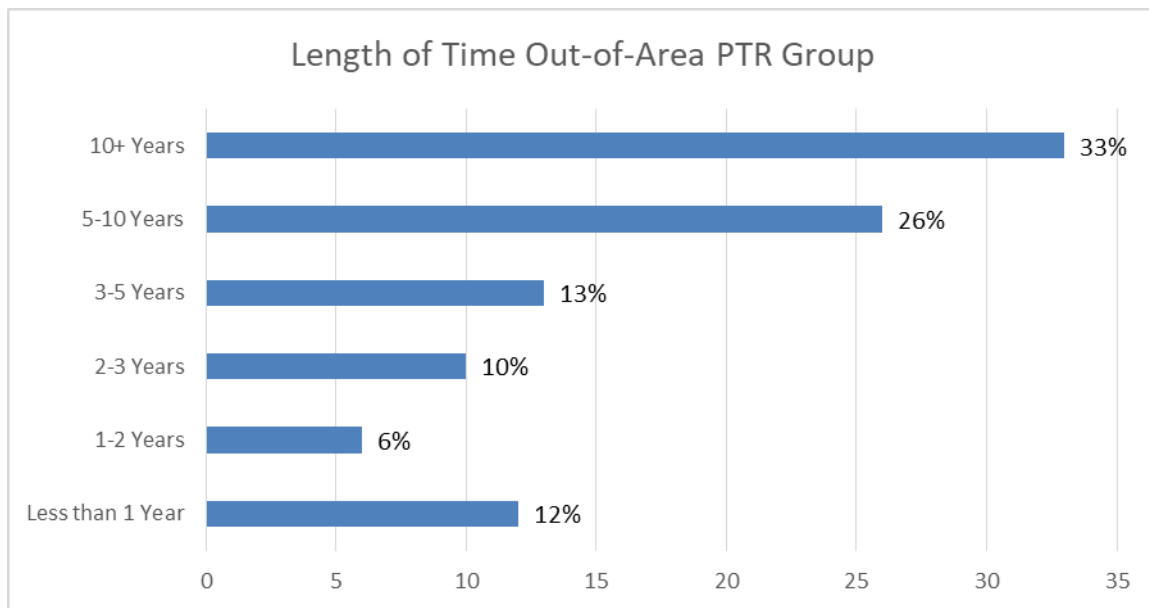
Question	Options	Percentage
Placed out-of-area in crisis	Yes	31
	No	67
	Don't know/missing	2
Reason for out-of-area placement	Specialist service required & none locally	77
	Specialist service required & no capacity in local service	11
	To prevent hospital admission	*
	Other	11
Placement prior to out-of-area placement	Family home	33
	Supported living	12
	Hospital (private or NHS)	18
	Care home	16
	Residential school	13
	Other	8
Delayed discharge prior to out-of-area	Yes	*
	No	12
	NA (as previous placement not hospital)	80
	Don't know/missing	*
Type of out-of-area facility	Supported living	19
	NHS hospital	8
	Private hospital	12
	Care home	46
	Residential school	*
	Village community	*
	Other	7
Type of out-of-area service	General learning disability	45
	Autism specialist	24
	Challenging behaviour specialist	7
	Forensic low secure	*
	Forensic medium secure	*
	Other	17
	Don't know/missing	*

* Numbers removed

5.1.2.5 Length of Time Out-of-Area for Priority to Return Group

In relation to length of placement, a third of this group have been out-of-area for over ten years, and another quarter between five to ten years (see Figure 6). Given that this is a group who were placed out-of-area due to lack of services, rather than due to their choice, and that these are individuals whom the HSCPs have an ambition to return, the length of these placements is especially concerning.

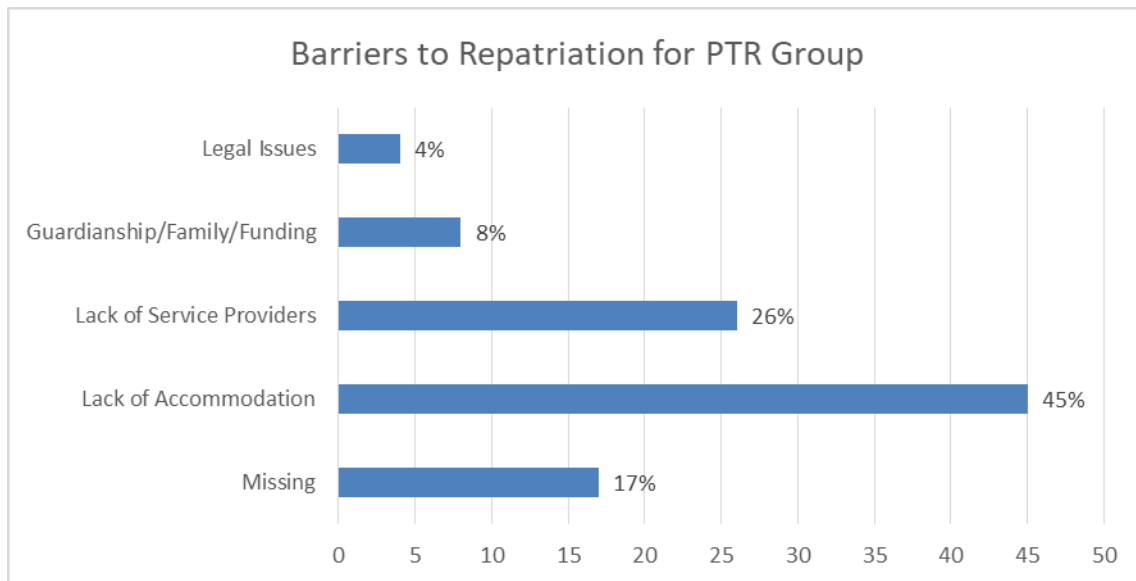
Figure 6: Length of Time Out-of-Area for Priority to Return Group



5.1.2.6 Barriers to Repatriation

Each respondent was asked to list any barriers to repatriation, and then to select the main barrier. Figure 7 shows the main barriers to repatriation; where barriers were noted in relation to less than five individuals, these have been combined. The main barriers reported were lack of suitable accommodation or lack of skilled service providers. The accommodation required does not appear to be that requiring adaptation due to physical disabilities, as less than 10% of the group had physical disabilities. It is therefore more likely that specialist accommodation was seen as the barrier due to challenging behaviours, for example as individuals required more space or more robust housing, or larger outdoor areas, in order to meet their behavioural needs.

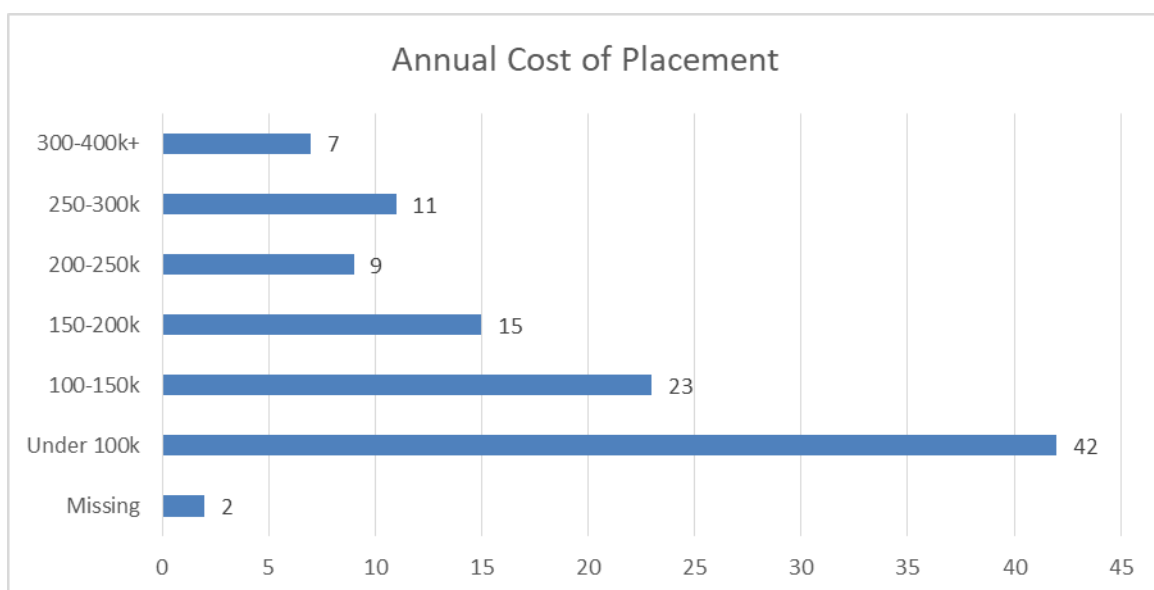
Figure 7: Barriers to Repatriation for Priority to Return Group



5.1.2.7 Costs of Placements for Priority to Return Group

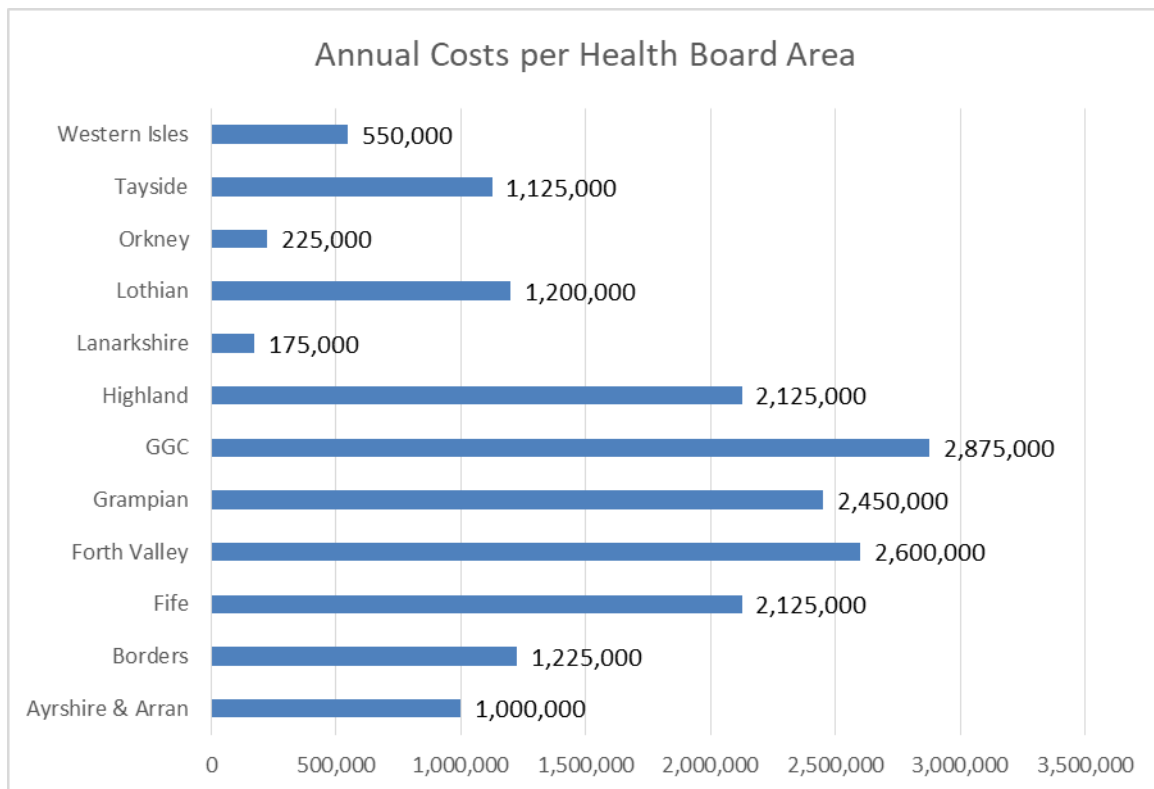
Information was sought on the costs of placements, and respondents were asked to indicate costs on a dropdown menu with categories increasing incrementally by 50k. Figure 8 shows the number of individuals in each category; where cost categories related to less than five individuals, these have been combined. There are 27 people whose placement was reported as costing over £200,000 per year. This figure is likely to be an underestimate as previously noted; however even taking that into account, it is clear that HSCPs are spending a significant amount on this relatively small group of individuals with learning disabilities who have the most complex needs.

Figure 8: Costs of Placement for Priority to Return Group



If costs are averaged out within each category by taking a midpoint, and then multiplied by the number of people who are priority to return for each HSCP, then average yearly costs can be calculated. Spending on these placements by individual HSCPs has been added together to give an overall cost for that health board area; this is shown in Figure 9. Clearly these are significant costs for such a small number of people and give rise to the consideration that there may be a more cost effective way of supporting these individuals within current budgets.

Figure 9: Annual Costs per Health Board Area for Priority to Return Group



5.1.3 Autistic People

Nearly 50% ($n=53$) of those who were priority to return, were autistic; this is in comparison to the main out-of-area group where 37% of the group was autistic. Since this autistic subgroup is such a substantial element of the priority to return group, some additional analysis was done on this sub-group. The autistic subgroup were slightly younger, more likely to be male, more likely to have a mental health diagnosis, and were more likely to have challenging behaviour, than the priority to return group; they were also more likely to be placed out-of-area in a crisis. More details regarding the autistic subgroup are shown in Table 5.

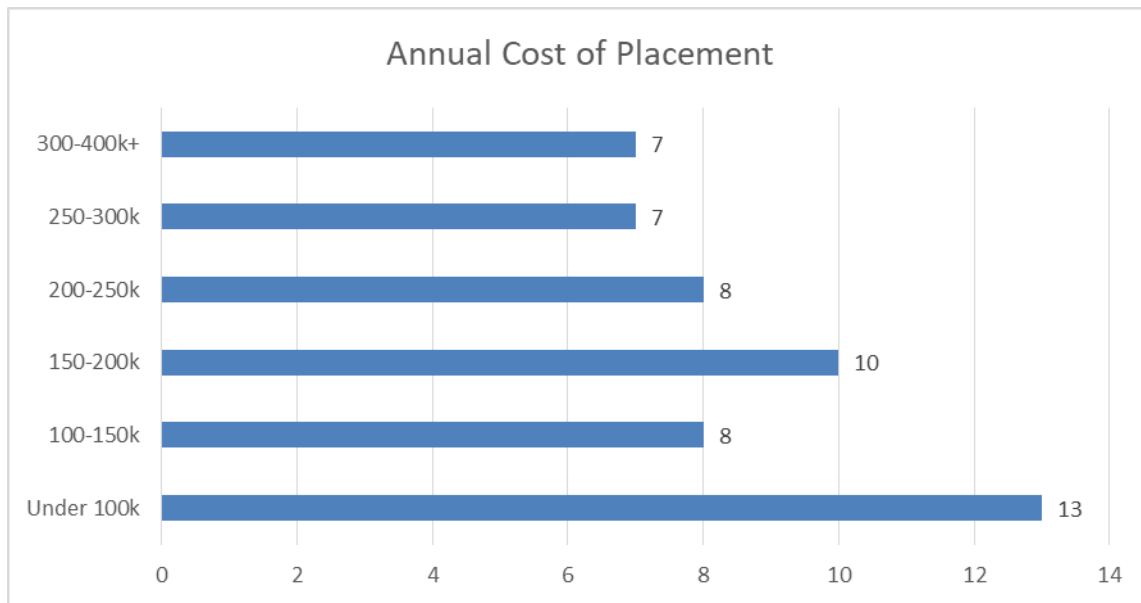
Table 5: Characteristics of the Autistic Subgroup

Characteristic	Options	Percentage
Gender	Male	85
	Female	15
Forensic	Yes	19
	No	75
	Don't know/missing	6
Level of learning disability	Mild	13
	Moderate	40
	Severe	30
	Profound	*
	Don't know/missing	*
Age	16-17	*
	18-20	21
	21-34	42
	35-44	15
	45-54	13
	65+	*
Epilepsy	Yes	25
	No	64
	Don't know/missing	11
Physical disability	Yes	*
	No	85
	Don't know/missing	*
Visual impairment	Yes	*
	No	87
	Don't know/missing	*
Mental health diagnosis	Yes	33
	No	59
	Don't know/missing	8
Challenging behaviour	Both current & historical	78
	Historical but not current	13
	No current or historical	*
	Don't know/missing	*
Placed out-of-area in crisis	Yes	66
	No	32
	Don't know/missing	2
Placement prior to out-of-area placement	Family home	30
	Supported living	15
	Hospital (private or NHS)	19
	Care home	*
	Residential school	17
	Village community	*
	Other	11

* Numbers removed

Cost of placement was also considered for this subgroup and more than 40% of the group were in placements costing more than £200,000 per year. This is in comparison to the priority to return group, where less than a quarter cost over £200,000, and in the whole out-of-area group where only 6% had placements in this category, thus indicating a significant link between autism and expensive packages of support. More details re costs of placement in the autistic subgroup are in Figure 10; as above, where cost categories related to less than five individuals, these categories have been combined. Figures here are actual numbers, not percentages.

Figure 10: Costs of Placement in Autistic Subgroup



5.1.4 People Placed Out of Scotland

The overall out-of-area data reported 79 people placed out of Scotland (in England and Wales), and of these, 47 individuals were placed due to lack of local services, rather than due to their or their family's choice. However, only 17 of these were noted as requiring repatriation, so some closer analysis took place for this small group. Since this is such a small group, some caution must be used in interpretation of the data and any trends should not be overstated; however there are a number of factors worth noting.

More than half of the out of Scotland group were autistic ($n=10$) and 83% ($n=14$) had challenging behaviour, indicating that these two characteristics are significant factors for being placed out of country. As regards management of challenging behaviour, 71% were in receipt of required medication, 18% of seclusion, 35% of physical restraint, and 59% were managed by the use of additional staff; all substantially higher than in the main priority to return group. The concerns noted about all of these types of management of challenging behaviour are clearly also relevant here. However, this group were also more likely to be in receipt of PBS, perhaps a reflection of the more extensive use of PBS in England than in Scotland.

In relation to cost comparison, eight of them (47%) were in placements costing over £200,000, indicating that those placed out of Scotland are also the most expensive group. Although they are a small group, they are therefore significant due to these high costs, and consideration must be given as to how they can be more appropriately supported within Scotland.

5.2 Delayed Discharge

5.2.1 Overview

Data returned indicated 67 people were delayed discharge as of the specified date of 31st January 2017. This does not include data from one large HSCP, and therefore figures are potentially higher.

The *Inpatient Census* carried out by the Scottish Government based on the date of 30th March, 2017, found 66 people with learning disabilities reported as delayed discharge, and the Mental Welfare Commission (MWC) in their report into delayed discharge, *No Through Road*, found 58 people delayed (MWC, 2016). The MWC have recently reported an increase in delayed discharge. These data were collected at different time periods and using different methods, which may account for the differences in figures.

5.2.2 Characteristics of Delayed Discharge Group

Characteristics for the delayed discharge group are shown in Table 6. As with the out-of-area group, the delayed discharge group were also primarily male; however, they were more likely to have a mild learning disability and were less likely to be autistic, with just over a third being autistic. Other than autism, only one person was reported as having an additional main diagnosis (Down's syndrome). Around one in five of the group had epilepsy and the main other physical health issues noted were physical disability, and visual impairment.

The delayed discharge group were significantly more likely to have a mental health diagnosis than the priority to return group, as even with one in five not reporting on this, there were still 40% of the group who were reported to have mental health difficulties. The most common mental health diagnoses were bipolar disorder, anxiety, depression and schizophrenia. Nearly three quarters were also described as currently having challenging behaviour, so this combined with mental health difficulties, indicate that this would be a very challenging group to support, potentially a factor in their discharge being delayed.

Table 6: Characteristics of Delayed Discharge Group

Characteristic	Options	Percentage
Gender	Male	66
	Female	34
Autistic	Yes	36
	No	54
	Don't know/missing	10
Forensic	Yes	21
	No	63
	Don't know/missing	16
Level of learning disability	Mild	24
	Moderate	40
	Severe	31
	Profound	*
	Don't know/missing	*
Age	18-20	*
	21-34	37

	35-44 45-54 55-64 65+	22 24 13 *
Epilepsy	Yes No Don't know/missing	18 66 6
Physical disability	Yes No Don't know/missing	* 81 *
Visual impairment	Yes No Don't know/missing	8 78 14
Mental health diagnosis	Yes No Don't know/missing Bipolar disorder Anxiety Depression Schizophrenia	40 39 21 10 9 8 8
Challenging behaviour	Both current & historical Historical but not current No current or historical Don't know/missing	73 10 * *

* Numbers removed

5.2.3 Challenging Behaviour

Challenging behaviour was a significant factor for the delayed discharge group also and more information regarding types of challenging behaviour, treatment, and risk management are shown in Table 7. This group had higher rates of challenging behaviour, with nearly three quarters having current challenging behaviour (only 5% are described as never having had challenging behaviour), and for over two thirds their challenging behaviour included physical aggression. Those in hospital were more likely to be in receipt of PBS, perhaps a reflection of the fact that health services are generally using PBS more than in social care. Similar to the priority to return group, those in the delayed discharge group had high levels of risk management strategies, although use of both physical restraint and as required medication were substantially higher. However, there was less reported use of seclusion and of additional staff, than in the out-of-area group.

Table 7: Challenging Behaviour, Treatment & Risk Management DD Group

Types of Challenging Behaviour	Percentage Displaying	Support for Challenging Behaviour	Percentage Use
Current challenging behaviour	73	PBS input	43
Physical aggression	67	Active support	24
Verbal aggression	49	Communication strategies	40
Self-injury	31	Psychological therapies	24
Self-neglect	9	Sensory diet	*
Property destruction	28	Risk Management	Percentage Use

Disruptive behaviours	28	Physical restraint	37
Non-compliance	31	Seclusion	10
Sexual challenges	21	As required medication	63
Removing clothes	*	Additional staff	18
Absconding	*	Environmental restriction	43
Smearing	*	Technological restriction	*
Substance misuse	0	Mechanical restriction	*

* Numbers removed

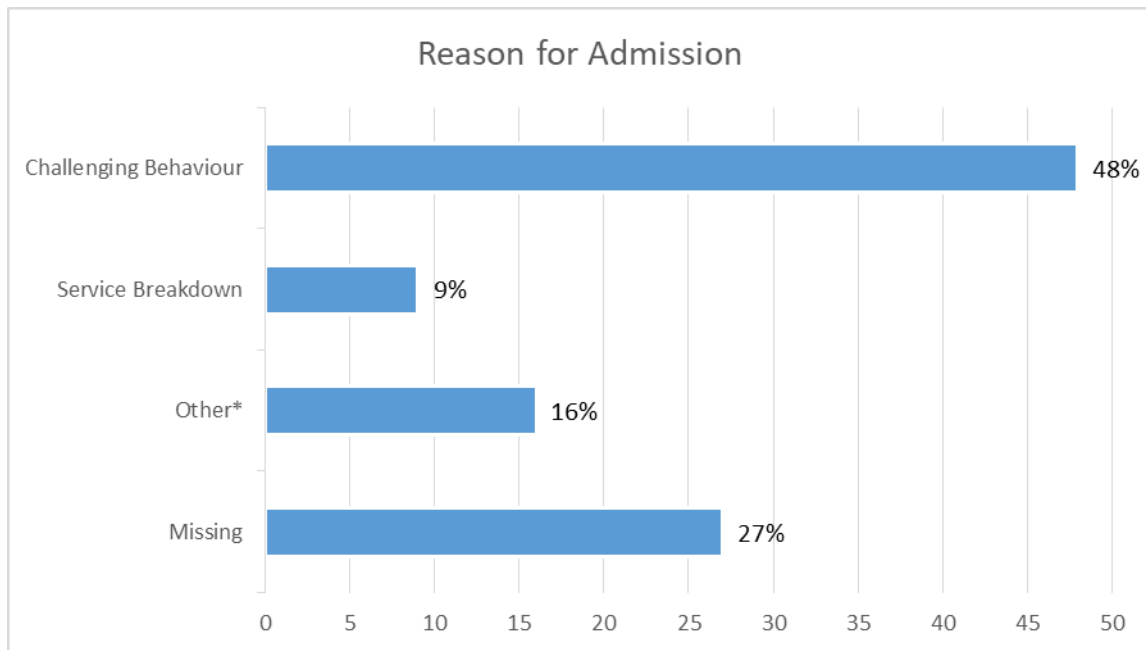
5.2.4 Reason for Admission

Those completing the data collection return were asked for more information about individuals' admission to hospital and some details about their placements. It is worth noting that this part of the data collection was less well completed, with many questions missing from around 20% of respondents; this was mainly due to one HSCP return which had a large number of delayed individuals, but supplied very little other than basic information about those individuals. Obviously, these gaps have impacted the validity of some of the figures reported.

Respondents were asked to indicate the reason for the individuals being admitted to hospital and asked to choose from a dropdown list; the results from this are shown in Figure 11. More than half the group were identified as having been admitted to hospital due to challenging behaviour, and this is clearly significant, even with over a quarter of the data missing. Along with the data reported in relation to out-of-area placements, this confirms that community provision for people with learning disabilities and challenging behaviours is not meeting the needs of this client group, and is the primary reason for people either going out-of-area or into hospital.

Also worth noting in terms of reasons for admission is the fact that less than five people were admitted for a mental health assessment, despite the fact that this should be the primary reason for admission to an assessment and treatment unit.

Figure 11: Reason for Admission



* Mental health assessment; out-of-area return; family reasons; court ordered

5.2.5 Placement Information

Information was sought regarding individuals' previous placement, and it is noticeable that a smaller percentage came from the family home in comparison to those who went out-of-area from the family home. More than a third of the delayed discharge group were admitted to hospital from a supported living environment and this may indicate that for some individuals with high levels of challenging behaviour such as this group have, a supported living environment can be fragile and vulnerable to service breakdown leading to hospital admission. However, it is also important to note that many people with complex needs and challenging behaviour live successfully within supported living settings, and that successful services are related to a number of factors, rather than just the model.

With regard to the availability of individuals' previous placements, the vast majority were no longer available; this is concerning as there is some evidence to indicate that when placements are lost, the length of stay in hospital is likely to be significantly extended.

A third of the individuals were admitted as a repeat admission, demonstrating that this is a group who have had long-term difficulties in receiving appropriate support. Given the fact that over 80% of the group have historically had challenging behaviour and that research tells us that challenging behaviour tends to be an enduring issue for many, then repeat admission is perhaps not surprising. More information about previous placements is shown in Table 8.

Table 8: Placement Information for Delayed Discharge Group

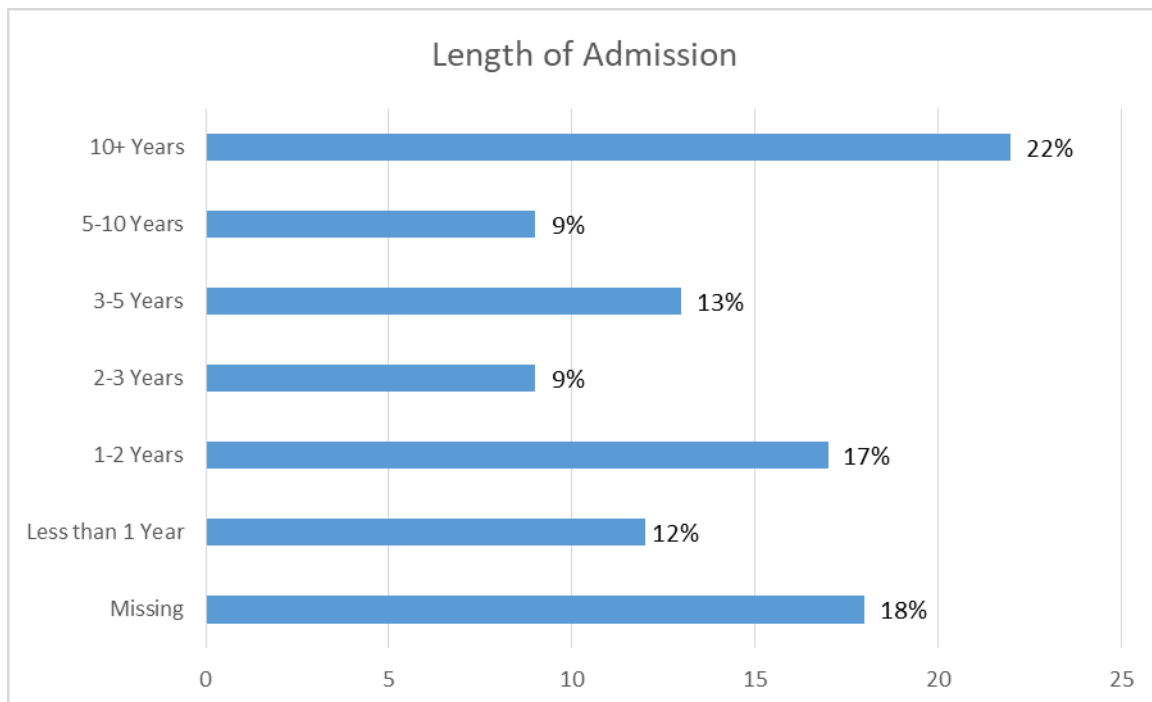
Question	Options	Percentage
Placement prior to admission	Family home	16
	Supported living	34
	NHS Hospital	10
	Private hospital	*
	Care home	*
	Other	9
	Don't know/missing	20
Availability of previous placement	Still available	*
	No longer available	70
	Don't know/missing	*
Repeat admission	Yes	33
	No	49
	Don't know/missing	18

* Numbers removed

5.2.6 Length of Admission

The length of time that people had been in hospital was explored with some concerning results; see Figure 12. More than 22% had been in hospital for more than ten years, and another 9% for five to ten years. The loss of opportunity for an ordinary life that these figures represent, is very concerning to all who have an interest in the wellbeing of people with learning disabilities.

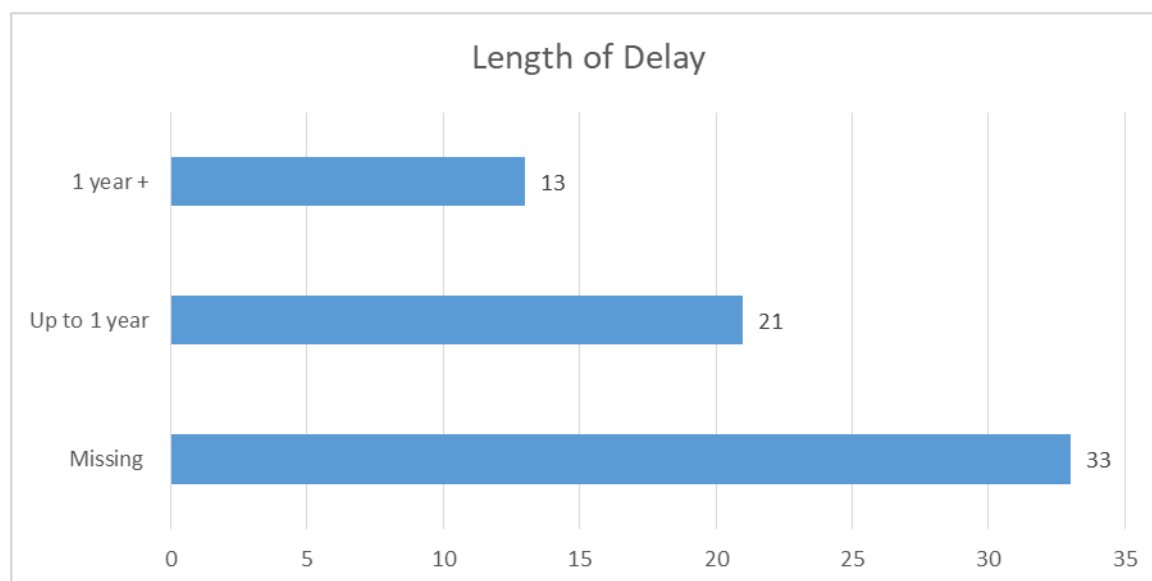
Figure 12: Length of Admission for Delayed Discharge Group



5.2.7 Length of Delay

This question was particularly poorly completed with nearly 50% of respondents supplying no information. For those who did respond this was a free text answer, so that they could state the number of days delayed; however for ease of comparison and to protect small numbers, responses have been grouped into categories and the numbers of individuals in each category are shown in Figure 13. It should be noted that some of these in the '1 year +' category had been delayed substantially longer than one year, with a small number delayed more than five years.

Figure 13: Length of Delay



5.2.8 Delay Codes and Discharge Plans

Plans regarding discharge for those that were delayed are shown in Table 9. Over half the group had active plans for discharge, and the main discharge facility was to a supported living setting.

Delay codes were not supplied for nearly 40% of the returns, making any analysis difficult. However, for those that did answer this question, around a third were a code 100. The *NHS Scotland Delayed Definitions Manual* (2016) states in relation to code 100:

“Some patients destined to undergo a change in care setting should not be classified as delayed discharges and can be categorised as:

- *Long-term hospital inpatients whose medical status has changed over a prolonged period of treatment and discharge planning such that their care needs can now be properly met in non-hospital settings. These might be Mental Health patients or Hospital Based Complex Clinical Care patients who have been reassessed as no longer requiring such care.*
- *Patients awaiting a ‘reprovisioning’ programme where there is a formal (funded) agreement between the relevant health and/or social work agencies.*

Information on all such patients should be recorded as code 100. It is acknowledged that while such patients may be classed as ‘ready for discharge’ the standard discharge planning processes and timescales are not appropriate. Gathering information on code 100 patients should mean that all patients for whom hospital is no longer the optimum setting can be accounted for.”

Table 9: Discharge Plans

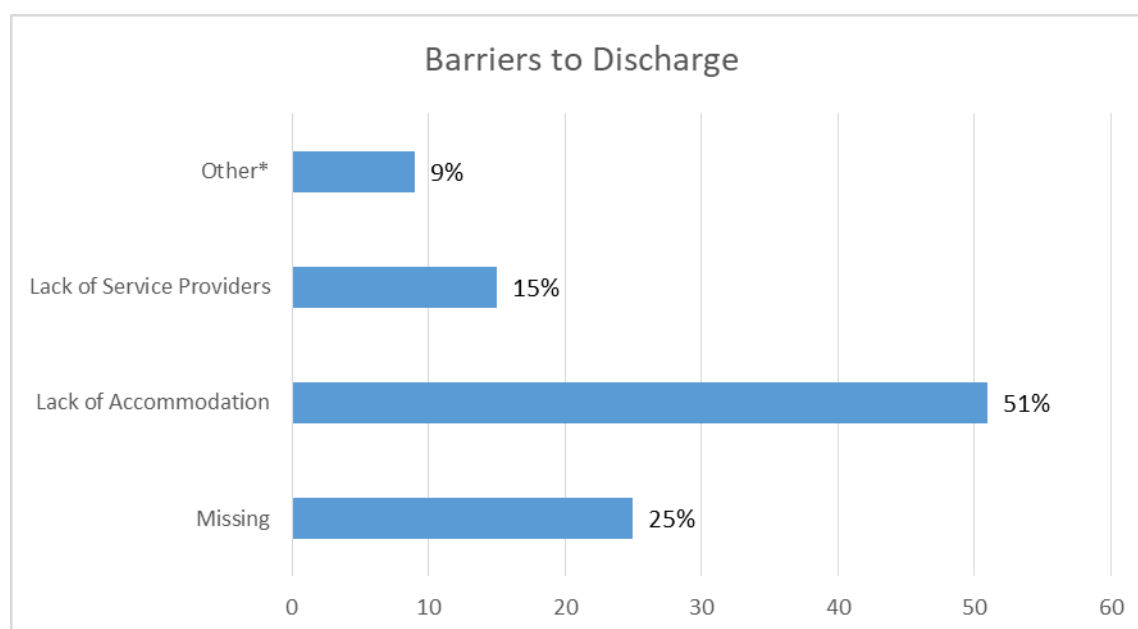
Question	Options	Percentage
Discharge plans	Active plan for discharge	51
	No current plans for discharge	30
	Missing	19
Discharge to	Supported living	46
	Care home	*
	Other	*
	NA, no plans	25
	Missing	19

* Numbers removed

5.2.9 Barriers to Discharge

The main barriers to discharge were reported as lack of accommodation, followed by lack of suitable service providers; these are similar findings to the priority to return group, indicating that both these factors are issues for the two groups. More information is shown in Figure 14.

Figure 14: Barriers to Discharge



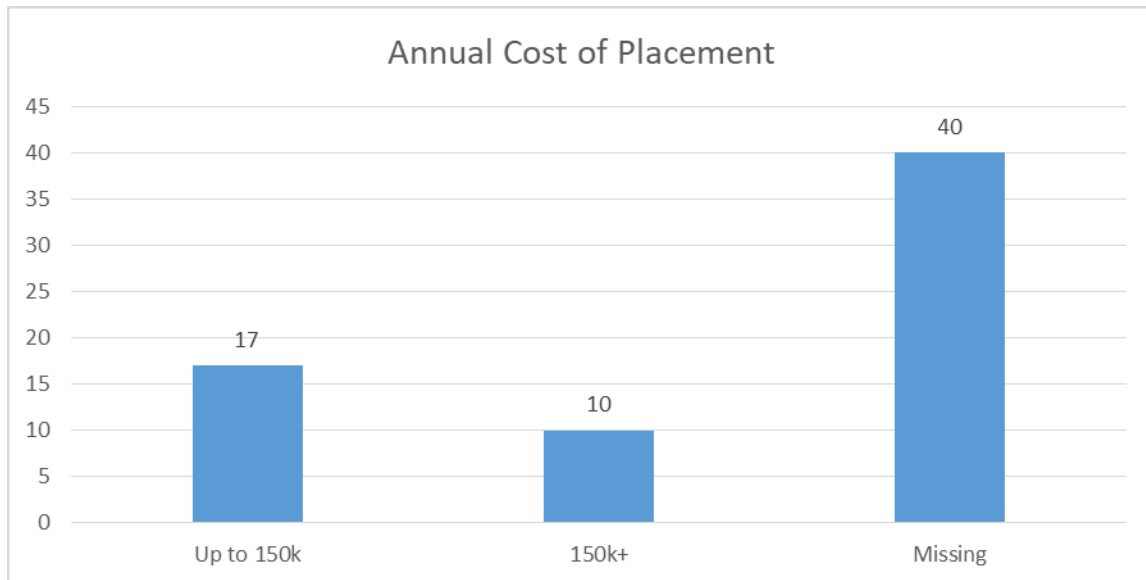
* Legal issues; funding issues; geographical issues

5.2.10 Costs for Delayed Discharge Group

This question was poorly completed with over a quarter of respondents not providing the information requested. This may indicate a lack of information regarding health-

related costs (as most data was provided by social care staff), or it may relate to the difficulty in identifying specific bed-costs within NHS resources. For those that did reply, information can be seen in Figure 15, showing that on the basis of this information there were 10 people whose placement was reported as costing over £150,000 per year.

Figure 15: Costs of Placement Delayed Discharge Group



5.3 Feedback from Stakeholders

5.3.1 Feedback from Families

As previously noted, some people can be described as out-of-area appropriately, for example, it may be seen as a lifestyle choice by them or their family members. Both Garvald and Camphill communities identified as providing a specific way of life for the individuals who lived there and family members were keen to stress the importance of these resources. These communities received high levels of support from family carers for the fact that they offered a lifestyle that was viewed as secure, independent and high quality, with a rural aspect and an ethos of contribution from all, regardless of level of learning disability. Parents spoke passionately about the sense of community and the opportunity for their family member to be part of something and not to feel isolated. They described their family members as complex and taking a long time to get to know and that the secure and family-orientated setting was ideal for meeting their complex needs, providing a safe environment with reassuring routines; a calm pace of life with a range of opportunities, an intentional community. Staff also spoke highly of the experience of working there, and of it being a vocation more than a job.

Some families also voiced support for residential care as these placements were seen to both be safer for their family member, and to provide a sense of community for them. The fear of their loved one becoming isolated was a strong message from these families.

Family carers who had formally raised concerns in a variety of ways about the support their family member received, told stories of lack of local support for their son or daughter with very challenging and complex needs; this included delays in being able to access services for their family members, so that families were left to struggle on in difficult circumstances. Some described being offered inappropriate services which they felt would not meet their needs, or which were far away from the family home, making it very difficult to maintain family links and to regularly visit their loved one. This caused stress and worry for the families concerned. All expressed concerns about the lack of support in times of crisis, some citing the fact that the police had to be involved when their son or daughter had incidents of severe challenging behaviour; others referring to the fact their loved one was admitted to a psychiatric unit as there were no suitable learning disability resources available.

Many carers expressed concern about the skills of social care providers to meet their family member's needs and told stories of service breakdown within community social care provision. This included the need to understand the triggers or antecedents that led to incidents of challenging behaviours, so that support for the individual can be person-centred and that environmental adjustments can be made in order to minimise the likelihood of challenges occurring. They also referred to the need to use appropriate communication strategies, to communicate in a way that worked for their family member, as many of the individuals had very limited or no verbal communication and depended on the use of alternative and augmentative communication methods, such as visual communication via systems such as *Board Maker*, social stories, or the use of communication passports.

Some family carers also expressed concerns about the lack of skills in school settings in relation to managing challenging behaviour, and in particular around the use of restraint and seclusion in a school setting.

5.3.2 Feedback from Health and Social Care Partnerships

All HSCPs consulted with recognised that there is a concern nationally in how we support people with learning disabilities and complex needs who challenge services. Although some HSCPs were further on in their thinking than others, and it is noted that some HSCPs are providing good local support to this group, all agreed that they would like to find better solutions in this area. Smaller and more isolated HSCPs discussed the option of cross-border commissioning to provide regional solutions, and many HSCPs referred to the need for a regional resource, particularly to avoid people being sent to England when there were no appropriate Scottish resources. However, there were also some concerns about the location of any regional resource in relation to which HSCP takes the financial risk. Ordinary residence was also noted as an issue in this context.

All HSCPs consulted also highlighted recruitment and retention in social care, and it was identified that pay and conditions are an issue particularly for third sector organisations who struggle to compete with pay scales for council social care staff, or for the conditions available to health care staff. Others highlighted the recruitment crisis across both health and social care, particularly in terms of staff working with the most challenging individuals, and there was general consensus that the most challenging work should attract better pay. It was acknowledged that working with people with complex needs and challenging behaviour is a very skilled job with a

need for consistency while being able to respond flexibly; the ability to work proactively, to recognise triggers, and to think ahead; and the need to be self-reflective and maintain a healthy balance. The need to attract more staff to social care, and for social care to be seen as a positive career choice was highlighted by many.

Models of support were also raised by some HSCPs, with a concern that getting environments right was a major factor in successful services. The need for a more national approach to principles of good environmental design for people with complex needs, particularly those with autism, was highlighted by some. There was a recognition that environments need to meet the person's need for space, stimulation, activity, outdoor access, contact with others, routine, and availability of staff. In particular for autistic individuals, attention must be paid to meeting any specific sensory needs.

Modular build options have been explored by some HSCPs and by some service providers to good effect, and these have the capacity to provide flexible, bespoke, and robust individualised accommodation for people with the most challenging behaviours.

Some HSCPs have focused recently on building core and cluster models, which have the advantage of providing individualised support, but within the context of back-up support available as required. This can be useful in terms of retaining staff, as staff working where they are isolated and work primarily on their own, with an individual whose behaviours can be challenging, can impact staff confidence, morale and ultimately increase turnover.

Rural authorities reported some particular challenges, particularly around economies of scale and also lack of local resources. This can also make it challenging to maintain contact with individuals who are out-of-area, as the distances can result in difficulty in keeping in contact with the key stakeholders locally, and therefore more fractured relationships within the care team responsible for the individual's support.

Some HSCPs reported that families prefer 'specialist' organisations, for example those with autism badging, and that this can be a factor in the use of out-of-area placements, as families create a demand for these services. Some reported difficulties with specialist providers who offer out-of-area placements for those with complex needs and challenging behaviours and/or autism, but who charge very high rates without the HSCP receiving much information about the service being provided or having much say in the model of support. However, use of specialist and private providers continues, often because HSCPs feel that more local or mainstream providers cannot provide the specialist support, including the use of physical restraint if required. In addition, most social care providers do not have spare capacity, so if a placement is needed in an emergency, then private providers or specialist residential services are more likely to be used.

In relation to admission to hospital, it was acknowledged that it happens because the social care provider or family have often struggled for a long time and are worn out, and can no longer cope, and it is a way of giving them a break. The lack of

community crisis support means that there is often no alternative to hospital admission once situations have become very challenging.

HSCPs reported that when people come into hospital for appropriate reasons, i.e. treatment for their mental health, then this was seen to be a positive use of assessment and treatment units. When people were admitted on the basis of their challenging behaviour then they were likely to have poorer outcomes. This included losing their placements, which was found to be associated with a significantly longer stay in hospital than those whose placements were retained. It was also noted that people are sometimes admitted because the mix of individuals does not work, or because the accommodation is not suitable

Some HSCPs spoke of the lack of a link between children's and adult services. This may be exacerbated in some local authorities where children's services are not integrated with health and social care.

Issues around health and social care integration were highlighted and the fact that integration is still in its early days, particularly in relation to budgets; therefore financial disincentives to discharge people from hospital may continue.

5.3.3 Feedback from Social Care Providers

Many similar issues were highlighted by social care providers; recruitment and retention were noted as issues by most social care providers, and within complex services, providers noted that they would be less likely to be able to use volunteers or students on placement in order to augment support. People with complex needs are also less likely to rely on natural supports as part of their care package, and for those whose communication is limited and whose behaviours can be challenging, it is clearly more difficult to build up social networks and circles of support.

Some providers spoke positively about Community Learning Disability Teams, and the fact that these could be a source of advice, particularly in relation to health issues. However, providers also spoke of the lack of practical crisis support when things are difficult and services become at risk of breakdown. This appears to involve the need for direct support from skilled staff who can provide cover on shifts and who will be resilient in managing challenging behaviours.

Many providers raised concerns about the commissioning process for people with complex needs and that this sometimes did not appear to be as person-centred and needs-led as we would expect. Specifically, there were examples of poor combinations of individuals living together, unsuitable housing selected for individuals, and at times, a rushed transition for those who may require a longer transition due to the complexity of their needs. Concerns were also raised in relation to services for individuals with very complex needs being commissioned on the same financial basis as for individuals with a need for more mainstream learning disability provision.

Providers also spoke about their success stories and what they had learned from these, and in general they all expressed willingness to rise to the challenge, to work with more people with complex needs and to support solutions for this group across the sector. There was an interest in getting more involved with the development of

services, and to provide advice and support to the commissioning process based on the experience of providing services. Some providers had housing solutions, whether that be the offer to buy or build accommodation as required, or some providers who were also housing associations had access to their own housing stock.

5.4 Positive Behavioural Support Findings

The survey found limited evidence for use of PBS in social care settings with only two of the social care organisations who responded having a specific PBS team; other providers referred to either external health professionals supporting them with PBS, or they saw this as part of the role of their physical intervention trainers. This indicates a lack of internal expertise, as those who are primarily physical intervention trainers are unlikely to have the skills and expertise required to carry out functional assessment, which is the starting point for any PBS support plan. Dependence on external expertise is also a concern, as this may mean lack of ready access to PBS specialist input when required, and it almost certainly means no availability for direct practical PBS input on a regular basis.

Use of PBS was reportedly greater in inpatient health services, with the roll-out of *Improving Practice* (NES, 2014) appearing to be the most likely source of PBS training and knowledge for health services. This is a useful resource which clearly many people have found helpful in beginning their acquaintance with PBS; however it is not a detailed training for PBS specialist input, and therefore needs to be augmented with more in-depth PBS training and qualifications. The fact that PBS training was more widely available in health settings, is perhaps a factor in why so many social care settings have struggled to successfully provide services to individuals with significantly challenging behaviours.

Those who did have PBS qualifications were most likely to have achieved those either via the Masters programme from Tizard at the University of Kent, or via the online certificate from ABM University in Wales. On the whole, it is clear that there is a lack of PBS expertise within Scotland, in particular the lack of any university-based programme to supply accredited training at a range of levels for health and social care staff working with people with complex needs.

Providers noted that access to PBS training can be very expensive, and this is a factor that also needs addressed, if Scotland is to achieve a PBS-skilled workforce to support people with complex needs.

With regards the implementation of PBS, there was limited evidence of the whole-systems approach on which PBS is based. This would require evidence of supported implementation via mentoring, practice leadership and monitoring in the workplace. Developing PBS expertise is an ongoing process of formal learning and supported implementation; practice-based mentoring by a more experienced practitioner is therefore key. There was limited evidence of this in the responses submitted.

6 Summary of Issues

6.1 The Need for Transformational Change

The group described in this report are people with the most complex and challenging needs. They are numerically a small group, but with very specific and significant support needs. They are also a relatively well-known group within local services and within Health and Social Care Partnerships, and historically have proved a challenge for services to support well. There is need for a rethink about how we provide effective support, and, in particular, for more cross-policy, cross-authority, and whole-lifespan approaches.

Although small in number, their support is often expensive, but frequently does not demonstrate good value for money in terms of individuals' quality of life or in terms of any impact on their personal outcomes. At the moment there is money, often large amounts, spent on their support, and no one doubts that there are good intentions to provide the best support; however, there is a lack of coherent strategy to effectively address the support needs of this group.

Nationally, the discharge of people with learning disabilities and complex needs from hospital and their return from out-of-area placements is an issue that defies simple solutions. It involves complex interrelated processes, agencies, and services, all of which must work together to change outcomes. Unless all stakeholders work together, no one specific element is likely to be successful or sustainable.

A transformational change approach is therefore required to address this issue throughout the sector. Transformational change involves a change of attitude and culture, a new belief in what is possible, resulting in significant changes in structures and systems. This type of change is what is required to address this problem; it will include a change in relationships and a shift in mindsets from all involved. Within this context, strong, determined and effective local leadership will be key, to provide a clear vision of the change that is possible.

6.2 Specific Themes Arising from the Data

6.2.1 Support for Challenging Behaviour

It is clear from all of the information in this report that one of the main issues for this group is the presence of challenging behaviour and the impact challenging behaviour has on service breakdown or hospital admission. It is worth emphasising that challenging behaviour is understood as a communication from the individual and as product of the environment they live in and of the support they receive. It is not a diagnosis, and although it is associated with certain conditions and syndromes, it is not innate to the individual, but rather an expression of their unmet need.

In the delayed discharge group, 83% had current and/or historical challenging behaviour, and challenging behaviour was reported to be the reason for 57% of admissions. In the out-of-area group who were priority to return, 82% had current and/or historical challenging behaviour; these figures increase when considering

people who are also autistic. Individuals with learning disabilities who have challenging behaviour therefore make up a significant percentage of those who are priority to return or who are delayed in hospital. This indicates that this is a specifically challenging behaviour focused issue, and that improving support for this group must have a significant emphasis on addressing challenging behaviour.

The implication from this is that effective and appropriate methods must be adopted across the sector in order to support individuals who have challenging behaviours. Positive Behavioural Support (PBS) is regarded as best practice in this area, but this report has found that PBS is not routinely used across social care settings, and in fact many social providers have no skills or expertise in PBS. This means that for both service providers and for family carers it is necessary to build better skills and resilience in dealing with challenging behaviour, and to develop expertise in PBS. As the majority of adults with learning disabilities in Scotland now live in the community, it is likely that a significant focus for developing these improved behavioural skills, must be on social care providers, as they are the key support agents for people with learning disabilities and complex needs.

The fact that challenging behaviour is such a significant factor also points to the need for earlier intervention with young people with learning disabilities who are at risk of developing challenging behaviour. In both the delayed discharge and out-of-area groups, over 80% of individuals had historical challenging behaviour, meaning that these are very likely to be individuals who would have benefited from early intervention around their behavioural support needs.

Finally, the fact that challenging behaviour is such a key issue, means that there is a need for effective and timely access to expert intervention, both to prevent crisis, and to help deal with crises when these arise.

6.2.2 Support for Autism

Although this report is focused on learning disability and is framed in a learning disability context, it is clear that coexisting autism is a significant factor. Data show that nearly half of the priority to return group, and over a third of the delayed discharge group were autistic, and that those who were autistic were more likely to have challenging behaviour, more likely to be placed out-of-area in crisis, and likely to be in more expensive placements. Individuals with both a learning disability and autism can therefore be regarded as those for whom there is the most pressing need to provide more effective support.

6.2.3 Lack of Local Services

The data showed that 77% of the group who were priority to return were placed out-of-area due to lack of specialist services locally, either because these did not exist or had no capacity. This indicates a lack of local provision for people with challenging behaviours. It may be that in times of crisis, or when services are required at short notice, HSCPs find it easier to move the person than to develop new services locally, perhaps because these situations usually occur in very small numbers per year and one person at a time. The longer-term impact of using out-of-area placements is that local specialist services are not developed, resulting in a vicious circle of out-of-area placements.

Cross authority or regional commissioning would potentially help address this issue; there is also a need to have a focus on longer-term planning in relation to commissioning for this group.

6.2.4 Support for Family Carers

Support for family carers in relation to people with complex needs is not sufficient, and in some areas is felt to be significantly lacking. Family carers reported both a lack of direct support services for their family member, particularly in times of crisis, and also a lack of support to them as carers, particularly in relation to access to specialist behavioural training, advice and guidance. This is not a new finding, as a range of research over the years (for example Wodehouse & McGill, 2009) has demonstrated that family carers report problems in accessing services, lack of respite provision, exclusion from services, and ineffective strategies in dealing with challenging behaviour. All of these have also been noted as factors in the feedback from family carers during this project.

6.3 What Makes Good Support

Throughout the work of this project, an aim was to come to an understanding of what good support for people with learning disabilities and complex needs should look like. To this end, a range of conversations took place with stakeholders, both professionals and families; good practice guidance from a range of sources was reviewed; and research evidence was considered, in order to take an evidence-based approach.

The result was the identifying of a number of key elements which are essential in providing good quality support for this group, and these are described below.

6.3.1 A Person-centred Approach

All support provided to people with learning disabilities should be person-centred, in order to most effectively meet a person's outcomes and provide them with the life choices and opportunities that they wish. This imperative becomes even more important when considering the group which is the focus of this report. Due to their additional support needs and often challenging behaviours, people with learning disabilities and complex needs have very specific support requirements which will make it even more important for services to be truly person-centred. For example in the need to adopt a range of communication methods, rather than utilising mainly verbal or written communication; or in the designing of bespoke environments that can best meet the person's individual sensory needs, rather than just using available housing stock.

6.3.2 Environments which Support Communication

Challenging behaviour is best understood as a means of communication, a method for the individual to communicate their needs and attempt to have them met. Given that challenging behaviour is such an issue for this group, communication must therefore be a key element of the solution. The use of a range of augmentative and alternative communication strategies are essential in providing good quality support. For example, *Board Maker* is a visual communication system using pictorial symbols; *Talking Mats* is an interactive resource, that aims to improve the lives of people with

learning disabilities by increasing their capacity to communicate effectively about things that matter to them; and the Picture Exchange Communication System (*PECS*), is a communication aid which teaches the learner to communicate within a social context.

6.3.3 Active Support and Full Lives

Active Support is fundamental to providing effective person-centred support for people with learning disabilities and complex needs. It has a focus on ensuring that people are involved in all aspects of their own lives and that support starts from the premise that regardless of level of difficulty, disability or challenging behaviour, people can and should be supported to be involved fully in their day to day lives. A range of research has been carried out to demonstrate its effectiveness in providing better support and improving quality of life for people with learning disabilities (Mansell and Beadle-Brown, 2012).

6.3.4 Positive Behavioural Support

This report has already commented on the research to evidence the effectiveness of PBS in supporting people with complex needs and challenging behaviours. A comprehensive and person-centred PBS plan is therefore an essential element of good quality support, in order to understand the communicative function behind the behaviour and to outline the proactive strategies to support the person in relation to this. This plan should also contain specific reactive strategies to most safely and effectively support the person when challenging or high-risk behaviours do occur.

6.3.5 Suitable Accommodation

Feedback within this report has indicated that lack of appropriate accommodation is a key factor in the lack of local services for people with complex needs, leading to the use of both hospital and out-of-area placements. For some individuals with complex needs, specialist or bespoke housing may be required. For example, if an individual has particular challenges around property destruction, or if in times of distress, an individual becomes extremely noisy, the use of ordinary housing may be difficult. However, for others, with different types of support needs, it will be possible to adapt ordinary housing to meet their needs appropriately.

Overall, it is clear that developing suitable environments that can meet the needs of this group is an essential element to getting support right. People with very complex and challenging needs, and particularly those with autism, require specific environments which are likely to include aspects of the following:

- An environment which keeps the person safe, particularly a secure outdoor space.
- Significant outdoor space, with potential for outdoor activity and sensory stimulation through physical activity.
- Potential for flexible use of the environment, for example, ability to shut down certain areas, or to allow staff to withdraw and leave the person in a safe space during a challenging incident.
- Environmental adaptations to meet people's needs where sensory integration issues are present.

- Homes with rooms that are bigger than average and allow for safe management of behaviour, including the potential for safe use of restraint if required.
- Services with the capacity for staff space, including the potential for onsite staff support (supervision, debriefing, on-the-job training).
- Homes which are sufficiently linked to the local community, in order to ensure the opportunity for use of ordinary local resources, and also to ensure local availability of sufficient staff.

6.3.6 Skilled and Motivated Staff

Essential in providing good support is having a skilled, motivated and enthusiastic staff team, who have a commitment to the work that they do, and who enjoy working with individuals with complex needs. The ability to see beyond any complex needs to the person themselves is essential, as is the ability to have a degree of empathy and understanding.

Staff are required to have an understanding that challenging behaviour serves a function for the individual and is communicating a need. Staff with knowledge about autism, particularly in terms of how it impacts people and the type of supports that might be required, would also be helpful.

Supporting people with learning disabilities and complex needs is a skilled role, which can be challenging; staff therefore need to be well trained and well supported, and pay scales should reflect the importance of the work they do.

6.3.7 Good Management and Practice Leadership

For any staff team to be effective, they must be supported by skilled managers who motivate their team and provide clear leadership. Within complex needs work in particular, practice leadership is important. Practice leadership is defined as the use of observational monitoring, intensive and regular observation of staff practice, and the use of role-modelling, mentoring, and feedback to staff on a regular basis.

It has been associated with better outcomes for individuals with learning disabilities, for example, increased engagement, and with better support to staff, lower levels of staff stress and more positive work experiences (Mansell & Beadle-Brown, 2012), and is widely regarded as a useful model for services for people with complex needs which require a more significant direct management and leadership presence than may be needed in other services.

Good management also involves providing attention to staff's needs via supervision and post-incident debriefing, thus encouraging reflective practice and emotional support to staff.

7 Conclusions and Recommendations

7.1 Values and Principles

it is important to outline the values and principles on which all of this work is based. All recommendations made in this report should be viewed in the context of the following:

7.1.1 Human Rights

Fundamental to the values on which this report is based is that people with learning disabilities have the same human rights as anyone else, and that these rights are not reduced by the level of their disabilities or the complexity of their needs. It is clear that the experience of people with learning disabilities being unable to receive support to live within their local communities, but instead having to move far from home or even to live for long periods of time within hospital settings, is a denigration of their human rights. Any attempt to move away from the current situation and to create a new dynamic in how support is provided, must recognise that this is fundamentally a human rights issue and must be addressed with the urgency that that context indicates.

7.1.2 Maximising Choice and Control

All recommendations within this report are based on a commitment to maximising the control people with learning disabilities have over their own lives, and the opportunities they have to make choices. This commitment does not change when people have severe learning disabilities, complex needs, or communication difficulties. In the context of this report in relation to out-of-area and hospital placements, individuals having choice about where they live and who they live with, are particularly relevant.

7.1.3 Prevention and Early Intervention

Challenging behaviours are a key characteristic of people with learning disabilities who are described as having complex needs. All research evidence and practice-based knowledge demonstrates that challenging behaviours develop at an early age, usually in childhood. It is therefore imperative to have a focus on early intervention for children with learning disabilities, particularly those with additional support needs such as autism or significant communication difficulties, as these are the group most at risk of developing challenging behaviours.

7.1.4 A Whole Life Approach

Traditionally, services to people with learning disabilities have been siloed into adult services, and child services, with little interaction or joint working between the two. This applies to policy as well as service provision, throughout different agencies and services. Finding support solutions for people with complex needs will require a whole life approach, with a fundamental commitment to closer working between adult and child services, and a focus on future planning from an early age.

7.2 Theme One: Strengthening Community Services

It is clear that a simple focus on discharging people from hospital will not reduce overall numbers, if these individuals are replaced by new admissions. A key element therefore to the successful reduction of use of hospital beds, and to the reduction of out-of-area placements, is for the strengthening of services within the local community. There must be a focus on strengthening the capacity of the community to develop good quality, safe and resilient services, with the right kind of accommodation and staff with the right kind of skills, in order to reduce the need for hospital admission and out-of-area placements, and to reduce the length of admissions when these are necessary.

7.2.1 Crisis Support

An important requirement in having strong community services is that these services are able to deal with crises; to manage them when they occur and bring the situation back to a period of stability, where any longer-term support issues can be addressed. Developing stronger and more resilient community services that can be supported to work through crises without the need for admission to hospital or use of an out-of-area placement is fundamental to reducing the use of these placements over the long-term. Health and Social Care Partnerships (HSCPs) should consider making crisis support available to community services in order to strengthen and maintain these services. This is likely to require specialist support across a range of systems, involving close collaboration between services and agencies.

This crisis support could be provided in a number of ways, depending on local arrangements, and it may be possible for HSCPs to work together to develop this type of service, especially for the smaller HSCPs. It would require the ability to provide staff at short notice, who are skilled in working with people with challenging behaviours and other additional needs, such as communication difficulties or autism.

One option for this type of crisis support is that it could come from the local assessment and treatment unit, where inpatient health staff could be seconded on a short-term basis to provide crisis support to community placements. The costs for these staff would need to be considered, and could potentially be met by the HSCP for specific periods of time to bolster a struggling service.

Another option is that this support could be provided by integrated learning disability teams; this may have the advantage of providing staff already known to the individual. Any change in role from for learning disability teams would need roles and expectations defined differently, and would also require additional training to develop expertise to provide this type of crisis intervention. There may also be a role here for other HSCP resources to be used to provide support, or even specifically commissioned third sector teams.

Crisis support could also be provided by specially developed Intensive Support Teams. For some HSCPs this may be seen as the most appropriate model, and it is a model that is reported to have been successful in some areas in the past.

Whatever the model of the service, the input provided should be multi-disciplinary, with an emphasis on providing direct support, rather than being limited to advice,

training, or consultation. Access should be 24/7, with the ability to provide direct support either in the family home or other settings such as social care services, schools, respite facility, or other community setting. The purpose of this support would be to provide a local alternative to admission to hospital, and must therefore be flexible and available outwith office hours.

The model of support provided should be Positive Behavioural Support (PBS), and the support must have the ability to respond to a sudden escalation of behaviour with a range of proactive and reactive strategies, including the ability to respond to the most physically challenging and high-risk behaviours.

7.2.2 Flexible Support Responses

In addition to strengthening community services in times of crisis, this report has also highlighted the need for more flexible support responses to be used in community settings, in order to avoid the use of out-of-area placements or hospital admission. This could be approached in a number of ways depending on local circumstances, but it is recommended that HSCPs take a flexible and creative approach to problem-solving individual situations in order to provide local alternatives to admission to hospital or out-of-area placements.

Flexibility in budgets, via a contingency fund, would allow for bespoke, person-centred decisions to be made locally. This type of flexibility could allow for creative options to be quickly explored at times of crisis, for example, to take someone away on holiday instead of being admitted to hospital, or if a family carer falls sick, then they are accommodated elsewhere, while support staff move into the family home to support the individual, thus minimising disruption to the person and minimising the potential for challenging behaviour leading to crisis and placement breakdown. Although it is acknowledged that budgets may be tight, there are some HSCPs which are already successfully adopting this type of approach in for specific situations.

Another option could be to develop the provision of short-term respite or 'places of safety'; these could perhaps be developed on a regional basis, to allow cost-sharing and flexibility of use. This would provide assessment if needed but primarily would be to give the full-time carers a break. This could also be used on a proactive basis, before things become fully at crisis point.

Intensive short breaks services may also prevent family placement breakdown, with an aim to keep children in their family homes and communities on a long-term basis. This would deliver intensive support for the child, provided by staff skilled and experienced in supporting people with challenging behaviours, and would give parents a break in order to better continue their caring role over the long-term.

7.2.3 Support for Family Carers

Although this project focused on adults from 16 upwards, there are a number of themes that have emerged in relation to children and young people; one of these is the need for increased support for family carers, particularly in relation to behavioural challenges and how best to work through these in a family setting. The NICE guidelines for people with learning disabilities (NICE, 2018) also recommend

increased support for families and carers to reduce the need for people to move away from their homes and communities for care, education or treatment.

This is something that HSCPs should be considering in order to have the right support available. This support may take a number of forms; it may include help to keep people at home via respite, therapeutic short breaks, direct support in the home, and the provision of an out-of-hours support service. It may also include providing information and support for family carers via family networks, peer support, carer forums and advocacy.

Support for family carers may also be provided via offering opportunities for training, particularly in areas such as PBS, communication, mindfulness, and the safe use of physical interventions.

More availability of support from learning disability specific CAMHS services, would support a preventative approach aimed at reducing challenging behaviour at an early age, and would be helpful in terms of impact on future services, as well as on long-term outcomes for the individuals concerned. Early intervention is recognised as the most effective way of preventing long-term breakdown of family and service placements. There is a range of evidence available through good practice documents and also via research, that early intervention PBS in particular may prevent school exclusions, family breakdown, out-of-area schooling, and hospital placements.

7.2.4 Strengthening Social Care Providers

Social care providers are a key element of addressing the issues of hospital and out-of-area placements for people with learning disabilities and complex needs. If these providers can be supported to become more successful in supporting people with complex needs, regardless of behavioural crisis or escalation of challenges, then service breakdown will become much less common. In order to achieve stronger social care providers there are a number of factors to consider.

Recruitment and retention issues within social care are widespread and well-known, with many HSCPs and provider organisations commenting on the challenges they face in recruiting and retaining the number and quality of staff required. Many providers report this to be particularly difficult for complex services where the work may be more challenging, with higher risks to staff and greater skills required in terms of the support provided. This issue is currently being considered via a COSLA/Scottish Government working group.

There may be a need to consider whether remuneration needs to be more reflective of more complex work, and to explore options for how this could be achieved. There could also be consideration of how social care providers evidence the training, support, and management oversight that they provide to their staff who work within complex services, as research indicates that staff who feel well-supported and receive effective practice leadership provide a better service, and are more likely to be able to work successfully with those individuals who have complex needs.

7.2.5 Risk Register

Better local monitoring of those at risk of admission, by people who know the person, who can make decisions, and have access to funding may assist in preventing admission, particularly where these people have some flexibility in how they problem-solve at a local level.

HSCPs, working with service providers, community health teams and families, should have local risk management strategies in place to identify those who are at risk of placement breakdown leading to hospital admission or out-of-area placement. This could be achieved via a risk register process. This should mean regular reviews and a link in to the development of crisis contingency planning, in order to avoid placement breakdown, and should be effective in providing better anticipatory care planning. Risk of admission should be viewed by HSCPs as a critical event in a person's life, resulting in prioritised care management.

7.2.6 Recommendations in Theme One: Strengthening Community Services

Recommendation 1: HSCPs should develop options for access to crisis services for people with learning disabilities and complex needs, with a view to providing direct support to service provider or family placements which are at risk of breakdown.

Recommendation 2: HSCPs should consider the role of flexible support responses, to be used when placements are experiencing significant difficulty. The need for these should be informed by the use of risk registers to identify individuals at risk of out-of-area or hospital placement.

Recommendation 3: HSCPs should ensure that greater consideration is given to family support for the family carers of people with learning disabilities and complex needs.

7.3 Theme Two: Developing Commissioning and Service Planning

The planning and commissioning of services for people with complex needs has been one of the significant themes in this report and there are a number of important conclusions in relation to commissioning.

7.3.1 Co-production Commissioning

Commissioning should be approached in a spirit of co-production; that is, commissioners working together with family carers to design services, a partnership approach between families and professionals; creating a team around the person, incorporating both multi-disciplinary professionals and family, so that people who know and care about the individual specify the care and support plan on which commissioning is based. This is essentially a person-centred approach to commissioning that focuses on outcomes for the individual, recognising that designing the right support for people is not about imposing a one size fits all solution, but is about listening to what each individual needs to live their own life, and building support based on those needs. It is a commitment to working in partnership with the people who use services and their families, in order to create a catalyst for

change, in the belief that everyone is an expert on their own life and that everyone has something to contribute.

The recent NICE guideline on service design and delivery for people with learning disabilities and behavioural challenges (NICE, 2018) contains guidance to help commissioners focus on prevention and early intervention, to enable people with learning disabilities to live in their communities and calls for people to be able to have control over the support they receive and lives they lead. This may involve people with learning disabilities and their families sharing their lived experience of services and the learning for the future that can be gained from their experience; advising on new models of service to be developed locally or nationally; designing performance indicators for quality services; and inspecting or auditing services to advise on their suitability for people with complex needs. This may involve the use of advocates and those skilled in the use of alternative communication systems such as *Talking Mats*, in order to genuinely obtain the views of people whose verbal communication may be limited.

7.3.2 Commissioning for the Future

The evidence from this report suggests that complex support services are often developed in a reactive way, on a person by person basis. A longer-term approach to planning is needed in order to support commissioning for the future, for example tracking complex individuals from an early age, to have a better knowledge about what kind of support need is anticipated, and to be able to proactively plan appropriate services to meet these needs. This may include analysing information from schools and residential schools, in terms of exclusions and behavioural challenges faced in the school environment, as well as information from Children & Families Social Work teams. This includes focused planning for young people coming from school in order to map their future needs, and working with transition teams to achieve better transition support from child to adult services.

This is about understanding what we want from our market and shaping it; planning on the basis of systematic analysis of local data, population profiles, and user experience. This is a collaborative and integrated approach to commissioning across the whole system, to ensure strategic service change and improvement. Part of this may be about bringing together commissioning colleagues to share local knowledge and set local priorities and plan ahead, perhaps working together to commission regionally across local authority boundaries. People with complex needs are a comparatively small group and if HSCPs continue to commission individually, then there is a danger that services will continue to be piecemeal, set up on a one by one basis, with a lack of proactive planning.

It is clear that in many cases the current system focuses less on early intervention and spends more on crisis management. There are in some cases financial disincentives to discharge; over time integration may change this, but so far this does not often appear to be the case.

7.3.3 Skilling up Commissioners and Care Inspectors

Good commissioning requires a whole-system perspective, with an understanding of the population need, of local resources and of best practice. Commissioners should

be commissioning good lives, not just services; and services that isolate individuals from their communities should no longer be commissioned. Commissioners have the opportunity to be leaders of cultural change and to be the strategic leaders in achieving systemic changes in how services are commissioned.

It is recognised that the group of individuals referred to in this report have very complex needs and that specialist knowledge of their support needs can provide a challenge to commissioners, particularly as they are a small group for whom they do not regularly commission services. It may therefore be that training for commissioners to support them with complex needs commissioning would be helpful, as would the opportunity to share experience, skills and learning between commissioning teams across the country.

All commissioning activity should support the development of person-centred services and a sustainable model of care, with the necessary staff support and skills made available, and commissioning should focus on achieving outcomes for the individuals using services. There is a link here with the role of the Care Inspectorate; and it may be helpful for there to be support provided for Care Inspectors who are responsible for inspecting services for people with learning disabilities and complex needs.

This expertise in complex needs being provided to Care Inspectors may also assist in ensuring that social care providers are held accountable for their commitments made during the commissioning process. Creating a stronger link between contract monitoring and the original commissioning specification, with an emphasis on ongoing reviews for individuals with complex needs, may be helpful to support with increased provider responsibility.

7.3.4 Use of Assessment and Treatment Units

There is a need to develop a new understanding of the role and function of inpatient services, which goes hand in hand with development of community supports. Some people will continue to need high-quality inpatient services because of a genuine need for assessment and treatment of their mental health. However, challenging behaviour is not a reason for admission to hospital, and crises in relation to challenging behaviour should be addressed in other more proactive ways as already described.

Where possible, admissions should not be on a crisis basis, but should give the assessment and treatment unit staff an opportunity to get to know the individual at home in familiar surroundings, by working alongside the current provider for a period of time, and to carry out a range of assessments prior to admission, so that they are better placed to help plan and support discharge. Other than in an emergency admission, when admission is being considered, a review meeting should be held with all relevant individuals, including the person themselves if appropriate, and their family. It would be helpful for the discussion to also include a practitioner with expertise in complex needs and challenging behaviour who is not clinically responsible for the individual, in order to have an independent expert voice. Options other than admission should be comprehensively explored.

When an individual is admitted to an assessment and treatment unit, it is helpful if service providers stay involved in the person's support. This is partly to provide continuity of support and reassurance to the individual, but also because loss of placement is linked with a longer stay in hospital. This could involve continuing some aspect of support while the person is in hospital, in order to work towards maintaining the placement, keeping familiar relationships, and more proactively working towards discharge. Funding would need to be made available to support this, and it may need to become part of the contract at time of commissioning.

Discharge plans should be set from point of admission. Discharge for even the most challenging individuals, should be achieved at no more than 12 months after admission; this is to give sufficient time for assessment, time to plan and develop a new service. However, this does not imply that there should not be an aspiration to achieve discharge sooner than 12 months.

As part of the process of discharge for those with challenging behaviour, assessment and treatment units should adopt PBS as their model of support and ensure all staff are trained in its use, and PBS should be integrated into the broader pathway for discharge into community services.

An increased focus on delayed discharge within learning disabilities could be helpful in prioritising this group, therefore separate reporting for learning disability delayed discharge would be helpful.

7.3.5 Discharge/Repatriation Pathway

This report has highlighted the issue that for some people, once they are placed out-of-area or in hospital, there is a sense that they lose contact with local community services, and may appear to be forgotten about. Regular multi-disciplinary reviews should be held while the person is out-of-area or in hospital, perhaps using the Care Programme Approach, or equivalent; these should occur on at least a 6-monthly basis. In addition to family members, this should include all relevant professionals involved in the person's support (attending either in person or by teleconference), both in the current placement and in the funding HSCP. This would bring a level of regular scrutiny and accountability in terms of discharge and repatriation. As with reviews prior to admission, a practitioner with expertise in complex needs and challenging behaviour who is not clinically responsible for the individual, should also be included, in order to have an independent expert voice. The focus of these reviews should be in making the commissioning team accountable, and would give the person, their family and the multi-disciplinary group confidence that work is proceeding towards discharge/repatriation.

Transition out of hospital or back to their local community should be done on a person-specific basis, and best practice suggests that for those with challenging behaviour this should be based on a functional assessment of the person's behaviour and a full PBS plan to support their move back into their local community. Transitions may need to be lengthy and require to be funded appropriately to ensure the best possibility for success. This includes consultation about the physical accommodation, including anyone that the person will share with, as well as an understanding of the type and amount of support required.

It could be helpful for HSCPs to consider the creation of a role in each HSCP to lead on repatriation or discharge; this would assist with bringing a level of focus and attention to these individuals, and would also create a single point of contact for any work on discharge or repatriation. At the moment, there may be a lack of a line of sight for some individuals, where a range of professionals are involved but there is not a clear lead in terms of responsibility for repatriation/discharge. A complex needs repatriation/discharge pathway could also be developed locally by HSCPs and adapted as required for individual needs

7.3.6 Housing Solutions

Lack of suitable accommodation was described as the biggest barrier both for the priority to return group and also for those whose discharge is delayed, with it being the main barrier for around half the individuals in both groups. This indicates a new approach to providing housing is required, with some focused planning on the type of housing and service models that may be necessary to meet the needs of the most complex individuals.

Commissioners should work with local housing providers to plan how to meet the housing needs of individuals with a learning disability and complex needs. They should ensure that a range of housing options and models of service are available, which enable individuals to live in their local communities, close to their family members if they wish and that options are available in terms of whether people choose to live with others, or would be best supported to live alone.

Particular examples of good housing models discussed during the work of this project included modular builds to provide bespoke and robust housing solutions; and core and cluster models, which combine the opportunity for an individual person-specific service, within the security of a larger support team, allowing for back-up and opportunity to rotate staff where required. There was recognition that for some very challenging individuals, individual supported living packages could be a very difficult model to sustain, both in terms of isolation for the individual, and in terms of lack of back-up and emergency support for staff.

Consideration should be given to how joint commissioning plans can address housing for this group, and also whether housing contribution statements specifically for people with complex needs would be a helpful way forward.

7.3.7 Regional Models

In relation to those who are placed out-of-area inappropriately, and are priority to return, it has been difficult to present accurate financial costs for these services, due to incomplete reporting of figures across Scotland. However, even from the information received, it is clear that there are substantial sums of money spent on this relatively small group of complex individuals. Adding together the spending of HSCPs within health board areas, it can be seen that five health board areas are spending over two million pounds per year each, and another four health board areas are spending over a million pounds a year each, on this small group of 109 out-of-area people who are a priority to return. Consideration should therefore be given to alternative models that could potentially produce cost savings over time and would offer better outcomes for the individuals concerned. It may be that HSCPs

within health board areas, or within wider MCN (Managed Care Network) areas, could work together to consider regional solutions for their shared challenges.

This report found 79 people currently supported out of Scotland, of whom 47 were not there through choice and 17 of those who were described as requiring repatriation. This small group needs more focused attention; this is a group who are particularly challenging to support, with over 80% having challenging behaviour and over half being autistic. Although small, they are also an expensive group, with over half costing more than £200,000 annually. Consideration should be given as to whether a better solution could be found by HSCPs working together and rather than commissioning for each of these individuals separately e.g. whether development of a regional resource could not better meet their needs. A regional service may be helpful for those with the highest levels of need, who may require extremely high ratios of support and may benefit for a period of time, from a very robust and secure environment. This would avoid so many individuals being transferred to England due to lack of suitable services within Scotland, and it may also provide financial benefits for individual HSCPs.

7.3.8 Service Models

In relation to models of support, there are currently a range of different models used to support this group, and there are examples of good practice and successful support in each of these models. This report does not therefore recommend a particular model, but recognises that to offer a person-centred service, a range of models may be provided across Scotland, including residential services, individual supported living, core and cluster, and secure settings.

There may also be a need to consider hybrid health and social care models which may be a helpful option for some individuals, providing additional benefits from having health care staff as part to the support team, working alongside social care staff.

Clearly it is important that any models of support are selected on a person-centred basis, not purely as a means for cost savings or economies of scale. Large institutional services should not be seen as the way forward, and in particular former institutions should not be re-commissioned and badged as community living, unless that is what they genuinely provide. Any service model which restricts opportunity for community living should not be commissioned.

7.3.9 Recommendations in Theme Two: Commissioning and Service Planning

Recommendation 4: HSCPs should take a more proactive approach to planning and commissioning services. This should include working with children's services and transitions teams; the use of co-production and person-centred approaches to commissioning; and HSCPs working together to jointly commission services.

Recommendation 5: HSCPs should identify suitable housing options for this group and link commissioning plans with housing plans locally.

7.4 Theme Three: Workforce Development in PBS

Building a workforce competent in PBS is a critical step to improve support services to individuals with learning disabilities, and PBS training is a key element in achieving this. The information in this report indicates that the individuals who are the subject of this report would benefit from PBS-informed services; the group is primarily moderate to severely learning disabled and challenging behaviour is the biggest cause for hospital admission or out-of-area placement. This is therefore a group likely to benefit from PBS input, and a strategic approach to workforce development in PBS should be developed across services in Scotland.

7.4.1 PBS Training & Qualifications

This report found that on the whole, social care providers are poorly trained in PBS and there is a lack of clarity what PBS is, with some providers appearing to equate it with training from restraint providers. A programme of PBS training should be launched across the health and social care sector with a number of levels of training, including accredited and non-accredited. This training should be mandatory for providers wishing to support individuals with complex needs and challenging behaviours. Although there is currently no sector accredited PBS training, the PBS Academy suggested that there should be at least three levels of PBS training to reflect the PBS Competence Framework (PBS Academy, 2015). These levels are: *foundation* (those responsible for providing direct support); *intermediate* (those responsible for facilitating the implementation of PBS, in supervisory or clinical roles); and *advanced* (those responsible for embedding PBS into services and building capacity). In order to systematically introduce PBS into care provider organisations, all three levels of training are required.

PBS training should be sponsored by the Scottish Government, with training made available at reduced costs to social care providers for a period of time, in order to create a critical mass of PBS-skilled practitioners. The Scottish Government should seek partnership with a university in order to develop this training.

7.4.1.1 Delivery of Training

Training must be delivered in a way that promotes generalisation and maintenance, so that PBS skills learned can be used in a variety of contexts over a period of time, and there is a need to intersperse teaching with supported application via a longitudinal training format, which is combined with periods of practice in the service setting and supported by coaching and mentoring.

PBS expertise is essential for those leading PBS: it is important for those delivering training and leading on the implementation of PBS to be themselves professionally qualified and experienced in PBS (NICE, 2018). There is a lack of accredited training in PBS in Scotland, with the result that many Scottish services have very limited skills in providing PBS-informed services. PBS is used more widely in health services, and there has been PBS training at an introductory level delivered to some health staff; however, more in-depth PBS knowledge and experience is limited here also, particularly for those providing direct support.

7.4.1.2 Practice Leadership

There is also a need for practice leadership to take any PBS training from theory to practice. The use of strong practice leaders with a commitment to PBS is an essential support mechanism to successful and comprehensive implementation of PBS. Practice leadership ensures that PBS is genuinely incorporated into direct care staff's practice, so that PBS is embedded within day-to-day ways of working (Mansell & Beadle-Brown, 2012). Practice leadership has increasingly become regarded as an essential part of developing a PBS culture within organisations and practice leaders have a role in facilitating implementation of PBS via coaching, role modelling and providing ongoing support.

The wider literature on implementation science may also be useful to consider here in terms of addressing translation gaps from training to practice. Implementation science promotes the systematic uptake of training into routine practice, and it stresses the role of on-the-job coaching and performance feedback. Within a practice leadership model, those leading on the implementation of PBS should observe staff regularly, model good support, and give feedback. Training in PBS should include teaching around practice leadership, so that participants are taught how to undertake a practice leadership role.

7.4.1.3 Whole-Systems Approaches

PBS is also a whole-systems approach and is most effective when not seen in isolation from the rest of the organisation; in order to be implemented at optimum level, it requires to be embedded into policy and practice, with comprehensive changes made to systems and structures, and with PBS knowledge and practice being introduced across organisations and within services. A range of literature over many years refers to the fact that building PBS capacity at organisational level is essential and PBS training should address capacity building, resulting in systems change, not just change for the individual (Mansell Report, DOH, 1993).

Denne et al (2015) suggested an approach to workforce development in PBS which included the need to create cultural change including policies and operational procedures that promote PBS, and contractual arrangements that require PBS. PBS training would need to be supported by the organisation's culture, infrastructure, policies and procedures. This is about building the capacity of organisations to implement PBS systemically, rather than merely delivering PBS training within a service or organisation where organisational support and buy-in are lacking. Developing local capacity and the competence of everyone involved in the delivery of support to people with learning disabilities is critical to the successful implementation of PBS.

7.4.2 Community of Practice

In order to strengthen the use of PBS throughout services, it would be helpful to establish a Community of Practice in PBS. Communities of Practice are a concept that have successfully been applied to a range of areas and support the promotion of specific approaches. It is felt that Scotland would benefit from a Community of Practice around the implementation of PBS which would be focused on developing national learning resources, coordinating and supporting the implementation of PBS,

offering guidance on policies relevant to individuals that challenge, and providing best practice examples of PBS.

7.4.3 Recommendations in Theme Three: Workforce Development in PBS

Recommendation 6: The Scottish Government should seek partnership with a university to provide PBS training across the health and social care workforce in relation to people with learning disabilities and complex needs.

Recommendation 7: The Scottish Government should support the establishment of a PBS Community of Practice.

7.5 Next Steps

To address the issues outlined in this report will require transformational change across the support systems that are currently in place for people with complex needs. This needs whole-system change, multi-agency approaches, across government, and across sectors. The next steps are therefore pivotal in taking the findings of this report forward from paper to practice. Key to this process is the policy lead from the Scottish Government, and support for a strategic approach to implementation from the HSCPs around Scotland. As a refreshed framework for *Keys to Life* is anticipated, this would provide a means to take forward the implementation of this report.

In order to achieve the transformational change described in this report, there are a number of recommendations which will require to be taken forward by HSCPs, in order to achieve a redesign of systems and services for people with learning disabilities and complex needs. HSCP Chief Officers should consider the findings and recommendations of this report, and nominate a local lead to address the recommendations, and to coordinate these recommendations being adopted into local practice.

It may be that HSCPs wish to work together, to create a local change management working group which could coordinate a range of work based on the themes of this report, i.e. strengthening community services, developing commissioning and service planning, and workforce development in PBS. This group would also be responsible for mapping out a timetable for change, with clear targets and timescales; this is important in order to ensure momentum is sustained. This would involve regular communication, and delivering consistent messages about progress so that all stakeholders know what is happening and how any changes will affect them.

Throughout this process there is a need to continue listen to the sector, to get commitment and create a shared ownership of ideas, through shared understanding of what we are doing and why. Building credibility and trust will be vital, and creating opportunities for dialogue and discussion. HSCP engagement with social care providers will also be essential as it is they who must step up to provide better community-based support which can support individuals with the most complex needs and challenging behaviours. This will require strong leadership throughout service provider agencies.

It is clear that there are many examples of good practice in support for people with learning disabilities and complex needs already in place around the country. There are also some HSCPs who have progressed further than others with their development of support for this group. It would be useful for these HSCPs to share their learning around solutions to common problems with other HSCPs across Scotland, and this could perhaps best be done under the auspices of the Social Work Scotland group. A series of good practice learning events, such as seminars or conferences could be considered, to address relevant topics, for example, commissioning complex services, developing suitable environments, providing local leadership and direction, and overcoming barriers.

Through the implementation of the recommendations outlined in this report, and with the sector working together, the ambition is to ensure better lives for people with learning disabilities and complex needs. In particular, this would ensure that those delayed in hospital settings or who are in out-of-area placements can come home to live in their local communities once more.

8 Summary of Recommendations

8.1.1 Theme One: Strengthening Community Services

Recommendation 1: Develop options for access to crisis services for people with learning disabilities and complex needs, with a view to providing direct support to service provider or family placements which are at risk of breakdown.

Recommendation 2: Consider the role of flexible support responses, to be used when placements are experiencing significant difficulty. The need for this should be informed by the use of risk registers to identify individuals at risk of out-of-area or hospital placement.

Recommendation 3: Ensure that greater consideration is given to family support for the family carers of people with learning disabilities and complex needs.

8.1.2 Theme Two: Developing Commissioning and Service Planning

Recommendation 4: Take a more proactive approach to planning and commissioning services. This should include working with children's services and transitions teams; the use of co-production and person-centred approaches to commissioning; and HSCPs working together to jointly commission services.

Recommendation 5: Identify suitable housing options for this group and link commissioning plans with housing plans locally.

8.1.3 Theme Three: Workforce Development in Positive Behavioural Support

Recommendation 6: The Scottish Government should seek partnership with a University to provide PBS training across the health and social care workforce in relation to people with learning disabilities and complex needs.

Recommendation 7: The Scottish Government should support the establishment of a PBS Community of Practice.

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