

Towards an Edinburgh Autism Strategy -

Edinburgh Autism Plan for people with autism who do not have a learning disability

November 2013

www.edinburgh.gov.uk/autismplan



HEALTH AND SOCIAL CARE



Foreword

Autism is a lifelong developmental disability. People with autism experience difficulty with social communication, social interaction and social imagination.

The Scottish Strategy for Autism 2011 set out the Government's vision for autism services in Scotland. In 2010, the City of Edinburgh Council (CEC) set out plans for services for people with autism who have a learning disability. In Edinburgh, we have identified that there are significant gaps in provision for people with autism who do not have a learning disability. This Edinburgh Autism Plan is about getting the right service at the right time to promote the independence and resilience of people with autism and their carers. It considers the needs of adults, young people moving into adult services, and children, focussing on people with autism without a learning disability.

Six priority areas are identified for service improvement:

- **Development of a care pathway** – getting the right services at the right time
- **The wellbeing of children and young people with autism**
- **Housing** – better support on housing matters and the right kind of housing
- **Employment** – increased support in finding and sustaining employment
- **Individual outcomes** – improvements in people's quality of life
- **Better training / awareness of autism** – increased training and awareness of autism in services and for carers.

We consulted on the plan between May and July 2013. There was significant support for the plan and the service improvements proposed.

We have already made a start at developing and improving services available for children, young people and adults with autism in the city. A key theme in the plan is increasing awareness and developing practice in mainstream services. We are heartened that people from a range of services have volunteered to become Autism Champions.



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Contents	Page
Purpose of Plan	4
What is Autism	4
Prevalence	5
Children’s Autism Services	6
Adult Autism Services	8
Gaps in adult service provision	9
- Moving to a care pathway	
The right services at the right time	11
- Autism Matched Care Model	
Housing Issues and Actions	13
Employment and Proposed Actions	13
Outcomes for People with Autism	15
The wellbeing of children and young people with autism	16
Training and Awareness/ Autism Champions	16
Financial Implications	18
Recommendations	19

Appendix 1 Edinburgh’s performance for adults and young people’s services
& Scottish Government Autism Targets

Appendix 2 Edinburgh Current position for children and young people

Appendix 3 Edinburgh Autism Plan Group members

Appendix 4 Autism Champions remit

Appendix 5 Spend on Autism by Social Care excluding care packages

Appendix 6 Children and Families expenditure (excluding children’s Social Care)

Purpose of the Plan

1. The plan aims to provide a context for the development of a strategic direction for improving outcomes for people with autism and their carers.
2. The Council has already set out plans for services for adults with autism and a learning disability within the wider learning disability strategy¹. Against this background, our self-evaluation identifies significant gaps in provision for people with autism who do not have a learning disability. Taking this into account, the plan focuses upon services for people with autism who do not have a learning disability.
3. To optimise improvements in outcomes of people with autism, the plan places particular emphasis on timely interventions that promote the independence and resilience of people with autism and their carers.
4. The plan includes reference to both adults and children. Whilst there are some common themes across all age groups, the legislative and organisational context is quite distinct for adults and children's services. In children's services, provision and priorities are set within the wider framework of the integration of planning and provision for children and young people with additional needs within the context of Getting It Right for Every Child.

What is Autism?

5. Autism is a lifelong developmental disorder more commonly referred to as Autism Spectrum Disorder (ASD). It affects people differently, with some individuals being able to live independently and others needing very specialist support. However, everyone with autism will experience difficulty in the following three areas of functioning, sometimes referred to as the triad of impairments:
 - Communication – both verbal and non-verbal, e.g. difficulties with use and interpretation of voice intonation, figures of speech, facial expressions and other communicative gestures;
 - Reciprocal social interaction – this includes the ability to understand what someone else might be thinking in a real-time situation and to understand the need for social 'give and take' in conversation and overall interaction;
 - Restrictive, repetitive and stereotypical routines of behaviour – which may be very restricting for their family, friends and colleagues but may also be psychologically distressing or inhibiting for the individual with autism.

(Note: the American Psychiatric classification of autism is being revised and includes a proposed change to simplify the definition of autism).

The Scottish Strategy for Autism²

6. This Strategy, which was published in 2011 by the Scottish Government and COSLA, has a vision that people on the autism spectrum are "*respected, accepted and valued by the communities and have confidence in services to*

¹ Edinburgh Joint Learning Disability Capacity Plan.
2010 – 2020/25: Outcome of Consultation December 2010

² The Scottish Strategy for Autism, Scottish Government 2011 www.scotland.gov.uk

treat them fairly so they are able to have meaningful and satisfying lives. One of its ten indicators for best practice is the development of a local autism strategy. It sets out 2, 5 and 10 year goals with the first two years focussing on access to mainstream services". The current position in Edinburgh in relation to the two-year goals and to the best practice indicators are attached at appendix 1 for adults and 2 for children. Taking into account our performance in these key areas, this plan sets out the current priorities for improving services in Edinburgh.

7. The Scottish Government has made funds of £13.4 million available nationally to organisations across Scotland to develop new services and specifically £35,000 to each local authority to develop and publish a local autism plan. Projects in Edinburgh have been fortunate in securing some short-term funds to develop a range of children's and adult autism services.
8. This is a time of significant development for autism services in Scotland, as the National Strategy is rolled out, new services and approaches are being developed and researched, including a "menu of interventions". In due course, the evaluations of these developments will help inform resources across Scotland and in Edinburgh.

Prevalence

9. The estimated prevalence of all people with autism in the Edinburgh population is 1:100, which equates to 4,850 people (Knapp 2009). As explained above, this plan is about people with autism who do not have a learning disability and it is estimated there are 2,400 people in this group in Edinburgh.
10. Historically, autism has been under-diagnosed so many adults do not have a diagnosis. The situation is improving with diagnosis being made in childhood.
11. Receiving a diagnosis in childhood and having more effective interventions at that stage is likely help people with autism lead more positive lifestyles. This may in turn reduce long-term dependency on services.
12. Late assessment means that some people have struggled significantly through their lives without their specific needs being recognised or addressed. Young people and adults with autism may therefore experience a variety of secondary problems as a result, which come to the attention of services due to a different presenting problem e.g. homelessness, substance misuse, eating disorders.
13. National research also shows evidence of inadequate recognition and treatment of coexisting mental and physical problems. Over a 20 year period, there has been a five-fold increase diagnosis in the number of 9 to 10 year old children with autism (Knapp 2009). The reasons for this increase are not known; certainly the expertise for the diagnosis of children is now more available than it was 20 years ago, but there may be other factors. This trend has become increasingly evident within children's services in recent years and encouragingly the mean age of diagnosis has also been reducing, enabling earlier intervention.
14. The Council currently knows of approximately 850 children aged 0 – 18 years with autism in educational establishments. This number reflects the national prevalence figure and is significant for planning future transition and adult services for people with autism.

Developing an Autism Plan for Edinburgh (for people without a learning disability)

15. This plan is informed by:

- The National Autism Strategy 2011 - A Review of Progress in Edinburgh – see appendix 1 and 2
- Good practice in place in Edinburgh and elsewhere
- A multi-agency programme of self-evaluation and service improvement in Children and Families services
- Work led by NHS Lothian to develop a “matched care model” for autism
- Views of the Edinburgh Autism Plan Group - its focus has on been on adults and young people with autism without a learning disability. Its members include people with autism, carers, NHS Lothian, the Council, housing, care and supported employment providers. A membership list is attached at appendix 3.
- Comments made during the Edinburgh Autism Plan consultation with children and adults with autism and their carers and professionals. Notably the final plan includes an additional priority on “the wellbeing of children and young people with autism”. This priority has been added to reflect the comments made during the consultation and the need for improvement identified by children’s services.

Children’s Services

16. The current position in Edinburgh in relation to the two-year goals for children and young people is attached at Appendix 2. This plan sets out the priorities for improving services for children and young people in Edinburgh.
17. The Edinburgh Autism Plan Group, which focuses on adults and young people in transition without learning difficulties, has been meeting since June 2012. However, a group focussing on an autism plan for children and young people has recently convened and this work is still in the process of development.
18. Edinburgh has a significant number of well-evaluated and established services for children and young people and is currently consulting on and developing services in a number of areas. This consultation is gathering the views of parents, carers, young people and a wide range of professionals supporting children and young people on the autism spectrum. Researchers have engaged in dialogue with the Additional Support Needs Forum.
19. As well as being informed by our understanding of autism and its implications for the experiences of children and young people, our approach is informed by a range of policies and legislation such as
 - The United Nations Convention on the Rights of the Child
 - The Equalities Act
 - The Adult Support for Learning Act
 - Getting it Right for Every Child
20. Children and Families will work in collaboration with all key partners to develop a Children and Young People’s Autism Plan for Edinburgh by the end of 2016. The

plan will be informed by information gathered as part of the above consultation and development work commissioned by the Council. This focuses on support for all children and young people with autism from birth to aged eighteen, both with and without a learning disability.

21. Amongst professionals in our community, we have practitioners with high levels of expertise who are well informed about research at a national and international level. Strong multi-agency links exist across autism support services in Edinburgh. These services comprise of Additional Support for Learning services (including visiting teacher support, psychological services, support co-ordinators and staff in specialist educational placements), health professionals (including speech and language therapists, occupational therapists), paediatricians in community child health, child and adolescent mental health services (CAMHS) and social work professionals.
22. All planning for children and young people with additional needs is delivered through an integrated framework supporting the implementation of 'Getting It Right for Every Child'.
23. Key principles informing practice across Edinburgh focus on ensuring that effective provision:
 - Is proactive and anticipatory
 - Is proportionate, fit for purpose and timely
 - Builds resilience and capacity in and between individuals, families and schools
 - Is inclusive
 - Is individualised
 - Is equitable and sustainable
 - Is focused on achieving seamless support through transitions
 - Makes the best use of resources
24. In addition to mainstream services, children and young people and their families can access supports that are available to those with a wide range of additional support needs, e.g. Child Inclusion: Research into the curriculum (CIRCLE), learning and education resources, the Visual Support Project, and the Edinburgh Guarantee (post school transition support). These are not detailed in this document.
25. Some children and families benefit from support from commissioned services such as Sleep Scotland, Lothian Autistic Society, Play Schemes and Barnardo's Intensive Behaviour Support Service (BIBS). An enterprising third sector contributes significantly to the resources available. These include The Yard, Tailor-Ed and Lothian Autistic Society.
26. Diagnostic assessment for children and young people is readily available through CAMHS and Community Child Health. A draft pathway for Edinburgh has been created within the past year. Developments within this area will be taken forward within the wider structures of NHS Lothian.

Adult Services

27. Each year, an increasing number of adults are diagnosed with autism, and children who have already been diagnosed with autism move into adult services. This puts extra demands on advice and ongoing support services. People have suggested we need to improve co-ordination across services and improve information, advice and the autism care pathway.
28. Edinburgh is fortunate to have some good quality services for adults with autism who do not have a learning disability. Edinburgh services include
 - NHS Lothian's Adult Autism Diagnostic Service – includes an adult autism co-ordinator, who is also the lead clinician, and a number of clinicians providing sessional input
 - The Health and Social Care's Aspire service (part of the Transition Team) – a social work service for young people with autism in transition
 - Autism Initiatives' One Stop Advice Shop at Number 6, which is part funded by the Council, and provides advice, mentoring, social groups and signposting to other services
 - PASDA (Parents of Autistic Spectrum Disorder Adults) which represents carers of adults with autism
 - Into Work providing support to people with autism in employment
 - A range of short-term projects funded from the Scottish Autism Development Fund
 - Supported accommodation, including one dedicated service for people with autism without a learning disability, and generic services supporting other people with autism
29. The Council and/or NHS Lothian fund some of these services but others are dependent on short term external funding.
30. The group identified five priority areas that could improve the outcomes of adults with autism in Edinburgh:
 - Identification of gaps in adult service provision and development of a care pathway³ for autism.
 - Housing issues – access to housing in “safe” areas, skilled housing advice and support.
 - Employment opportunities, including pre-employment support and maintaining people in work.
 - Individual outcomes which are relevant for people with autism.
 - Improved access to training and raising awareness of autism across care, support and advice services.

³ www.clinicalgovernance.scot.nhs/section2/pathways.asp

Each of these areas is considered in detail below and has informed the proposed model of care and care pathway.

Gaps in adult service provision – moving to a care pathway.

31. *Accessing health and social care services* – a key feature of people with autism is difficulty with communication and expressing themselves and their needs. The assessment of a person with autism without a learning disability is challenging as their needs are often hidden and their impact can depend on the circumstances. Families and people with autism tell us that professionals often miss or fail to understand the disabling impact of communication difficulties when carrying out assessments. Someone who may appear competent can have difficulties because of their inability to communicate or understand social situations others take for granted.
32. *Diagnosis* - In line with the national strategy, we need to develop easy access to diagnosis and post diagnostic support with coordination to assist people to access social care services and networks.
33. Currently, a person's GP has to make a referral through to the Community Mental Health Team, who will in turn make a referral to the NHS Lothian Specialist Diagnostic Autism Service. Access to a diagnosis is variable across the city. Carers talked of little support with understanding a diagnosis. We have identified a need review the arrangements for diagnosis of autism and to target training for GP's and community mental health teams in understanding autism and effective interventions.
34. *Advice & Support post diagnosis* - The range of people's needs and the support they will require post diagnosis will vary immensely. Most people with autism without a learning disability will have low or moderate care needs and their requirements will be mainly around communication, building a social network, promotion of independence, employment, housing and maintaining stability. A few will however have critical or substantial needs and will require 24 hour support and supervision.
35. Access to post diagnosis advice and support is variable across the city. There is a need to develop clear guidance about the level and type of intervention, advice, support and to build in the option of a review meeting post diagnosis. This would ensure that people know/are able to make contact with relevant support services. We know that only around half of the adults diagnosed with autism in Edinburgh make contact with the Number 6 advice and information service.
36. *Young People in transition* - the Council's Aspire team bridges the transition from children to adult services. The transition route is complicated, as the age of transition to adult services is not the same in all services. We recognise that there is an established referral route for Council schools to this service and links are being made with local private schools. The challenge for this service is late diagnosis of autism, which sometimes happens just at the stage of transition. People told us that transition is particularly difficult if the young person had a late diagnosis or had not been attending school, as there would have been no transition planning.
37. *Mental Health Services* - A multidisciplinary approach for young people with autism could possibly provide a more effective intervention for providing flexible

support and/or improved access to ongoing mental health services, behavioural support and practical interventions.

38. Some teenagers with autism stop attending school and become socially isolated and withdrawn at home, where the family relationships can be very strained. There is a need for practical intervention for families including training/mentoring to understand autism and to find solutions for difficult home situations and reduce aggression at home. Alongside this, services for children and young people need to identify improved ways in which to enable young people to remain in school education.
39. People with autism have voiced concerns about NHS mental health services not understanding people with autism and not having appropriate therapies to address their needs. Nationally, research is being undertaken to determine psychological interventions that can assist people with autism.
40. *Flexible support with life changes* – People with autism struggle with minor and major life changes. People may require assistance with developing strategies to cope with change. The National Autism Strategy highlights the need for flexible support which people can dip in and out of through their lives as required. One proposal is to have a local autism co-ordinator who can advise in this way.
41. *Information and Advice/ Developing Social Networks* - the One Stop Shop Number 6 provides advice and assistance for people with autism without a learning disability through 1:1 advice, mentoring and as a base for social networks. The service is well used and the one stop shop model is being rolled out across Scotland as part of the National Autism Strategy. Each year approximately 70 additional people in Edinburgh use this service; as a result the capacity of Number 6 to respond is severely stretched. A need was identified to put more information online about the range of social supports, events and training available in the city and to extend the range of advice and support available to people in the city.
42. *Carers* - All carers have the right to have their own care and support assessment. Short Breaks can assist both the carer and person with autism, in most circumstances individually tailored packages work best.
43. Once a person has a diagnosis, their carer(s) often need help with understanding the diagnosis, in particular how to communicate effectively with a person with autism and where to go to get help and advice.
44. Many adults with autism still live at home with their families or families are heavily involved in supporting them in daily living. Parents of Autism Spectrum Disorder (PASDA), a local charity that supports carers of adults with autism. Carers in Edinburgh and PASDA identified a need for training and support for carers who have adult children living at home who are isolated and at times aggressive.
45. *Isolation and Loneliness* – People told us they hugely value the few social activities that are organised by/for people with autism. They stressed that the value of specific social activities in preventing/reducing isolation to be recognised in the plan

The right services at the right time – Autism Matched Care Model

46. We need to be clear what Edinburgh's autism matched care model is. This will be underpinned by the completion of an Integrated Care Pathway for autism:

Referral ► Diagnosis ► Initial Supports ► Ongoing Supports

The care model in children's services operates on common principles within the Edinburgh pathways for Getting It Right for Every Child. One important difference from the adult model is the presumption that where need is identified initial supports will be put into place in advance of diagnosis.

47. We need to be clear what Edinburgh's autism matched care model is. This will be underpinned by the completion of an Integrated Care Pathway for autism:
48. The model will need to pay particular attention to the care pathway at points of transition from child to adult and adult to older people's services.
49. Values that will underpin the matched care model are:
- Promoting independence and personalised supports
 - Improving communication round the person with autism
 - Helping people with autism manage change
 - Supporting carers
 - Increasing capacity in mainstream services
50. Work has begun on several aspects of the integrated care pathway:
- We are building awareness in frontline services about understanding autism and how to access health and social care services. This is being addressed through the Autism Champion Initiative and development of an Edinburgh autism awareness booklet and e-learning module (referral).
 - Promotion of the Scottish Autism Alert card (when it is published) – A card that people with autism can carry which tells others what to expect when they meet a person with autism, including notes for criminal justice professionals (referral).
 - Frontline services, including GPs, Police, Accident and Emergency and Social Care Direct are aware of indicators of autism, how to communicate effectively with people with autism and understand the care pathway. When developed, information about the Integrated Care Pathway will be available on Refhelp, NHS Lothian's referral guidelines (referral).
 - There has been an in principle decision that adults will get an autism diagnosis and support via mental health services (diagnosis).
 - Collation of summary of effective psychological interventions and therapies (diagnosis/ initial support).
 - Ensuring Lothian's Best Practice Transition Protocol is adopted by all child and adolescent mental health services across Lothian and adult transition services (diagnosis)

- Improvements to support in the first year after receiving a diagnosis are proposed through additional resources to the One Stop shop to follow up and review people in the first year. There is scope to develop this area further (initial support).
- Online and face to face autism advice, information and a mentoring service is to be available in the city. A one stop shop is established for adults, but it struggles to meet demand. Web information on Edinburgh services is to be developed (initial and ongoing support).
- The Council's Aspire team and Local Area Co-ordination team now provide social work assessment and support for young people with autism who are in transition (initial and ongoing support).
- Increase capacity in mainstream and mental health services through the promotion of Autism Champions, to improve/develop quality of services such as social work, housing, job centres and the police by building skills and knowledge for staff teams.
- Support initiatives to prevent isolation and loneliness by exploring ways to ensure funding is sustainable for these organisations (ongoing).
- Development of key performance indicators to monitor performance of the matched care model (all)

Housing Issues Identified

51. It is difficult to access housing in "safe" areas, skilled housing advice and support.
52. Adults with autism face particular difficulties with both securing appropriate housing and maintaining a tenancy. Differences in sensory perception can make many environments difficult to bear, limiting the availability of suitable accommodation. Private lets are often the only realistic option in the short-term, but can often be too insecure (i.e. unpredictable), to contemplate, leaving people with autism in constant fear of being given notice on their tenancy.
53. Safety is a major concern. Neighbour disputes can be very traumatic for adults with autism, and they are sometimes seen as the difficult neighbour, rather than the victim of anti-social behaviour, due to a difficulty in communicating their side of the story. Sensory differences are often ignored and they are seen as unreasonable or fussy when trying to report noise issues. Adults with autism have stressed that they would feel more secure if they were living in autism-specific housing, similar to the model used by Autism Initiatives at Blackfriars Street.
54. Management of a tenancy for adults with autism can be problematic. Some people experience real problems in dealing with the landlord or any workmen entering the property. This often stems from the workers lack of understanding of autism and the need to prepare people when entering their home (in particular, the need to be aware of the reason for this and for the visit to occur at the allotted time). Sometimes adults with autism will need support to maintain their tenancy. A small amount of support can be crucial to enable

them to live independently, but time needs to be taken to build a relationship of trust before this support can be effective.

Housing proposed actions

55. *Increasing capacity in mainstream services* – In line with the national strategy, we see a need to ensure that a wider range of mainstream services/networks can support people with autism. Our proposal to increase this capacity is to promote Autism Champions across the mainstream services, such as social work services, housing advice services, job centre and the police.
56. *Autism Awareness Training* – provided to all staff dealing with CEC housing issues, in particular housing officers, Edindex (Edinburgh housing allocation system) staff, housing benefit officers, repairs direct staff and community safety officers. In addition, an advice sheet should be made available for staff within these departments, with some basic guidelines and contacts if they are dealing with someone with autism.
57. *Autism champions* – there should be dedicated autism champions within housing services. Some Community Safety Officers have already volunteered.
58. *Autism Flagging system* – We have added a box to the Edindex form to allow adults with autism to be identified if they wish and specific accommodations made (e.g. a repair can be allocated for a specific time, rather than a full-day slot).
59. *Supported housing* – CEC and its local housing associations should investigate setting up supported housing for adults with autism and no learning disability. Particular attention could be made to sensory differences at the design stage.

Employment

60. Adults with autism can experience a range of difficulties in obtaining and keeping a job. The difficulties in obtaining and keeping a job can arise from a lack of appropriate information, advice and support for adults with autism.
61. In Edinburgh, there are two major providers for employment support for adults with autism:
 - Number 6 is a one stop shop for adults with autism without a learning disability. A range of information, advice and support services are provided, including 1:1 advice and support on employment issues. This includes support with the application and interview process as well as support and advice with difficulties that may arise in the workplace. Between April 2012 and October 2012, Number 6 provided 178 sessions comprising of 1:1's, appointments and group sessions on employment and education issues.
 - IntoWork provides supported employment services to 75 people with autism. It uses the 5 stage supported employment model to support people into employment – job readiness, vocational profiling, job search, employer engagement and on/off the job support.

62. Supporting people with autism into work can require support for a considerable period. IntoWork have successfully obtained funding from the Scottish Autism Strategy. This will fund a worker who will be able to work with people for up to a two year period in preparing for and finding employment.

Employment Proposed actions

63. *Autism champions* – to increase knowledge and specialism in autism there should be dedicated autism champions in a range of employment related functions including careers advice, job centres, and HR advisors in the Council and NHS Lothian.
64. *Information on welfare benefits* - there will be an impact on people's benefit situation when considering possible employment options. Number 6 and FAIR have provided joint welfare benefits service since 2012. This should continue as many people with autism will be subject to welfare benefit reviews in the next two years and will need assistance with communicating their needs.
65. *Work experience* – these can be very beneficial experiences for people with autism in preparing for, or as part of the transition to, employment. The Council, in partnership with other local organisations, is developing two specific projects that will provide experiences for people disabilities including people with autism:
- *Project Search* – City of Edinburgh Council and NHS Lothian will explore methods of increasing the number of people with autism in the organisations. Project Search is a program which provides training and education leading to employment for people with disabilities. Project Search is based on a partnership approach that includes a business, a training organisation and a supported employment organisation. This model will be developed for people with disabilities, including autism, in the Council. It is anticipated that the first intake will take place in summer 2014 and the project will be a partnership between, the Council, IntoWork, Edinburgh College and NHS Lothian.
 - Edinburgh Guarantee Plus - modern apprenticeship opportunities are secured for young people without disabilities.
66. *Jobcentre Plus* – Jobcentre Plus is an important agency in assisting people to find appropriate employment. We suggest autism awareness training continues for new staff and that annual refresher courses are established in Edinburgh centres.
67. During the consultation on the plan, managers working in the Council spoke of the need for training on how they can support employees with autism in the workplace. Consideration should be given to how the Council can support employees with autism at work. This might include training for managers on supporting people with autism in the workplace and for employees with autism, for example on autism awareness and managing anxiety at work.
68. *Volunteering experiences* – these can be very beneficial experiences for people with autism in preparing for, or as part of the transition to, employment. The Council and NHS Lothian should consider how to provide/promote experiences for people with autism.

Outcomes for People with Autism

69. When defining outcomes, it is important to recognise that what has been traditionally viewed as a 'positive' outcome may not necessarily be the case for an adult with Autism. Indeed, while it is widely acknowledged that areas such as living independently in your own home, having strong social networks and a job are common measures of positive outcomes in adult life, for some adults with autism such generalisations may be unhelpful. Our opening premise must be that there is no single definition of what constitutes a positive outcome and that subsequently, it is the particular needs and wishes of each individual that determines its success. This is in itself a challenging statement both for commissioners of services and service providers that will require changes to traditional ways of thinking and innovation in terms of new approaches – both of which are vital if we are to truly make services responsive to the needs of adults with autism.
70. Outcomes for children and young people are defined in terms of the Wellbeing Indicators with the National Practice model for Getting it Right for Every Child⁴; “We want all our children and young people to be fully supported as they grow and develop into successful learners, confident individuals, effective contributors and responsible citizens”. We believe they should be:
- Safe – protected from abuse, neglect or harm
 - Healthy – experiencing the highest standards of physical and mental health and supported to make healthy, safe choice
 - Achieving – receiving support and guidance in their learning – boosting their skills, confidence and self-esteem
 - Nurtured – having a nurturing and stimulating place to live and grow
 - Active – having opportunities to take part in a wide range of activities – helping them to build a fulfilling and happy future
 - Respected – to be given a voice and involved in the decisions that affect their well-being
 - Responsible – taking an active role within their schools and communities
 - Included – getting help and guidance to overcome social, educational, physical and economic inequalities; accepted as full members of the communities in which they live and learn
71. Autism services for adults funded by the Council report on outcomes applied to all support services. The result of this approach is that these outcomes do not address the particular needs/wishes of adults with Autism. It is proposed that Friedman’s (2005) Conditions of Wellbeing Outcomes are utilised for evaluating services supporting Adults with Autism:

⁴ <http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright>

- Being healthy
- Staying safe
- Enjoying & achieving
- Making a positive contribution
- Achieving economic wellbeing

72. Development of outcomes and key performance indicators to monitor performance of adult services will be undertaken as part of the work with NHS Lothian on the matched care model.

The Wellbeing of Children and Young People with Autism

73. The wellbeing indicators set out in 71 above apply equally to all children and are addressed taking into account each child's strengths, needs and family circumstances. Whilst we recognise that the needs of children with autism are diverse and find unique expression in each individual, there are areas of concern that are typical to autism that need to be taken into account in child planning. In particular, it is especially important to recognise the inter-relationships between the child's life at home and in the community and their life in early years and school education. It is also important to recognise that the impact of a child's or young person's autism may be 'hidden' or find expression in indirect ways.

74. Well balanced, integrated and 'autism aware' planning provides the most effective framework for promoting the wellbeing of a child or young person with autism. To enable this we are developing resources to support effective 'autism aware' planning with involvement from the child or young person, parents/carers and professionals. We are also working with our partners to support better opportunities for learning, inclusion, fun and friendships for children and young people in learning, in the wider life of schools, in play and leisure and the wider community life.

75. This improvement framework will be developed and extended as part of the wider strategy for children and young people with an Autism which will be developed through the Edinburgh Children's Partnership.

Promoting Awareness and Training and the Autism Champions Initiative

76. This improvement framework will be developed and extended as part of the wider strategy for children and young people with autism which will be developed through the Edinburgh Children's Partnership.

77. There is evidence that basic awareness training on autism can improve significantly people's ability to communicate with people with autism. We are developing Edinburgh focussed training materials on understanding autism, including an information booklet and e-learning module.

78. We have begun to map out education and training requirement of practitioners. In partnership with NHS Lothian, we will develop a tiered education and training programme to underpin the matched care model, including detail on required competencies, skills and learning outcomes. This will be informed by work being undertaken at a national level.
79. We plan to establish a multi-professional, Lothian wide team with responsibility for delivering the education and training programme.
80. World Autism Day is now celebrated internationally on the 2nd of April. Cities have demonstrated their support by lighting up significant building such as the Eiffel Tower and the Empire State building in blue. It is recommended that the Council and its partners celebrate the next world autism day and that a programme of events is developed. This would be an excellent opportunity to promote awareness of autism and publicise work being undertaken in the city.
81. Raising awareness of autism and training of families on how to communicate with a person with autism has been demonstrated to significantly improve people's quality of life. We need to ensure that families have access to this type of training on an ongoing basis.
82. The Government has a project considering accreditation for autism trainers; this will inform the development of a pool of local autism trainers.
83. Getting it Right for Every Child provides the framework for a structured approach to leadership, training and awareness across services for children and young people. Opportunities for shared training will also support better transition between the worlds of children's and adult services.

Autism Champions

84. A key development of this plan will be the development of the Autism Champion Initiative. The role of an Autism Champion would be to
 - build knowledge, understanding and skills in teams about working effectively with people with autism
 - contribute to the development of good autism practice in the city
 - promote autism awareness, influence and interest throughout statutory agencies including Health and Social Care (H&SC), NHS, the Job Centre, police, Services for Communities and Housing Associations.
85. Autism Champions should be promoted both in social work teams and in main stream services such as housing, Revenues and Benefits, police and employment services and in social work and mental health services assessment and treatment services. The first group of champions have volunteered and will meet for the first time in October 2013.
86. Autism Champions would be part of and supported by a multidisciplinary practitioner group. Ongoing support for Autism Champions will be provided by the Council. An outline role and purpose for an Autism Champion is attached at appendix 4.

Financial Implications

87. The Scottish Government allocated the Council one-off funding of £35,000 to develop an Autism Plan for Edinburgh. The funding is being used to:
- develop the plan
 - roll out the Autism Champion Initiative
 - develop new training resources - including an Edinburgh Understanding Autism, elearning module, autism development work in schools and training and coaching for carers.
88. The Council's investment in adult autism services for people without a learning disability is small in comparison to the identified needs. £115,450 was invested in 2012/13 on Number 6 One Stop Autism Shop & Aspire social work transition service), this included a grant of £35,000 from the Government. In 2013/14, funding of £238,450 has been identified (this includes £70,000 short term funding from the Government) to develop the plan and for service improvements and to ensure that existing quality autism services are sustained. See Appendix 5 for more detail on spend.
89. In Children and Families, the biggest area of expenditure for children with autism who do not have a learning disability is in additional support at school. In 2012/13, additional support costs for this population amounted to £4,765,350. Broadly this represented a 50/50 split between specialist provision and additional support in mainstream settings. The highest concentration of additional support in mainstream settings is in the early years, where 34% of all additional support is for children with autism. In primary schools, 16% of support to mainstream schools is for children with an ASD and in secondary the proportion increases again to 23%. Expenditure in Children and Families social work is additional to the above.
90. Given the financial constraints on the Council, it is likely that many of recommendations will have to be achieved through service redesign or reprioritisation of budgets. However, the plan requires a greater focus on raising awareness, partnership approaches and improved co-ordination of services - these initiatives do not necessarily require additional funds. In addition, partnership working provides opportunities to align community and private sector resources and attract third sector funding.
91. There are significant areas of the plan still under development e.g. plans for post diagnostic support, options for supported housing, evaluation and feasibility of long term funding of local autism pilot projects, improvements in schools and family support. A detailed costed action plan will therefore be completed in 2014, once the national funding situation is clearer and the adult autism care pathway has been completed.

Equalities Impact

92. An Equalities Impact Assessment has been undertaken and includes feedback received as part of the consultation process. The assessment can be viewed at https://orb.edinburgh.gov.uk/info/200849/equalities/463/equality_and_rights

Environmental Impact

93. Some people with autism have heightened sensitivity to sound, light, touch and smell. The environment and even small changes to it therefore can be a particular issue for people with autism.

Recommendations

1. Children and Families will work with key partners to develop a Children and Young People's Autism Plan for Edinburgh. This will be demonstrated by increasingly autism friendly environments across services for children delivered through:
 - A published framework for effective and consistent use of appropriate strategies which will impact positively on the well-being of children and young people with autism
 - Use of an autism framework within the Integrated Child Planning Process
 - A strategic programme of autism awareness and training across Children and Families' Services including an advanced training programme for targeted staff
 - An audit of existing services for children and young people with autism with a view to identifying priorities for improvement.
2. Improve service planning and develop shared training to support better transition between children and adult services to be demonstrated by:
 - Getting It Right Transition Planning allowing for collaboration of adult and children services to plan for next steps
 - Transition groups running for young people of school leaving age addressing skills of independence and social awareness
 - Increased number of students supported in 5th and 6th years at High School offering opportunities such as the JET programme, collaboration with agencies such as Enable and Caledonia Youth to support skills of independence and relationships.
3. Completion of an Integrated Care Pathway for young people in transition and adults with autism as outlined above.
4. CEC and local housing associations seek opportunities for supported housing for adults with autism and who do not have a learning disability and promote autism awareness training amongst front line staff.

5. People with autism are actively encouraged to participate in proposed employment initiatives in the City; Project Search, a model to assist young people with disabilities gain employment and Edinburgh Guarantee Plus.
6. The Council puts in place strategies to can support employees with autism at work, such as training for managers on supporting people with autism in the workplace and for employees with autism for example on autism awareness and managing anxiety at work.
7. A refresher autism awareness training for Jobcentre Plus staff should be run annually.
8. CEC considers how to provide/promote volunteering experiences for people with autism.
9. Welcomes the Autism Champions Initiative and notes that an Edinburgh Autism Awareness booklet and an elearning Autism Awareness module for staff has been developed.
10. The Council supports training for carers and notes that the Council, in partnership with PASDA, (a local support services for carers of adults with autism) has commissioned training for carers to build family's skills in supporting people with autism.
11. Ensure current information and advice, information and mentoring services in the city for adults with autism are sustainable and consider ways to increase these services in the city.
12. The Council and its partners celebrate World Autism Day on 2nd April 2014 to promote awareness of autism in the city.
13. Edinburgh Autism Plan group will reconvene to consider the on-going monitoring and governance of the Edinburgh Autism Plan. Its membership will be reviewed to ensure representation from key stakeholders.
14. A costed action plan for this strategy is developed in 2014, once the national funding situation is clearer and the autism care pathway has been completed.
15. This plan is submitted to the Government in November 2013.

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Appendix 1

National Autism Strategy – Edinburgh Current Position for Adult Services

Scottish Strategy's 2 year goals	Current position Edinburgh	Plans
Access to mainstream services where these are appropriate to meet individual needs	Some training been done in Job Centres and Police Autism awareness included in Police Officer Induction	Promote Autism Champions in mainstream services
Access to services which understand and are able to meet the needs of people specifically related to their autism	Provision of Number 6 One Stop Shop and dedicated Social Work Transition service "Aspire" for young people with autism. Hard to access appropriate mental health services Local Area Coordination Team working with people with autism.	Promoting knowledge and understanding of autism amongst front line workers and community mental health teams
A local Autism Strategy developed '	Plan in place for adults relate to services for people with a learning disability and autism	Plan for adults with autism and no learning disability being developed.
Removal of short-term barriers such as unaddressed diagnoses and delayed intervention	Recognition of need to develop integrated care pathway and awareness of autism and relevant services amongst GP's and Community Mental Health Teams.	Development of an integrated Lothian care pathway for adults without a learning disability being developed.
Access to appropriate post-diagnostic support for families and individual (particularly when there is a late diagnosis).	Post diagnostic support for adults variable, no systematic follow up.	Proposals being developed for post diagnostic support/co-ordination by NHS and the Council.
Implementation of existing commissioning guidelines by local authorities, the NHS and other relevant service providers. (Government guidelines 2008/03/27085247/0	Some specific services commissioned	This plan is informed by the guidance.
Access to training and development to inform staff and improve the	Range of courses available for practitioners and managers.	Understanding autism emodule under development and training

understanding amongst professionals about ASD		booklet.
A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication.	PASDA Directory Number 6 website	Consider ways to link the various information resources and include Autism Network Scotland information. CEZ Autism Webpage to be developed.
Process for data collection on people using services	Various agencies collect data	Develop protocol to improve data collection across agencies.
Multi-agency care pathway for assessment, diagnosis and intervention – removing barriers	Carried out by learning disability services	Agreement reached diagnosis to be undertaken in mental health services and training needs identified.
Framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.	Carers and service user representation on the Edinburgh Autism Plan Group. Wide consultation on draft plan May-July 2013. Extensive consultation on planning services for Children with Disabilities	Group of people affected by autism, carers and multi agency stakeholders to monitor implementation of this plan. Extensive consultation exercise held May-July 2013

Appendix 2

National Autism Strategy- Edinburgh Current Position (Children and Young People)

Scottish Strategy's 2 Year Goals	Current Position in Edinburgh	Plans
<p>Access to mainstream services where these are appropriate to meet individual needs</p>	<ul style="list-style-type: none"> • Presumption to inclusion in educational establishments • Enhanced provision is established in Primary and secondary schools (both recently reviewed) • Schools are supported to include children with autism by the Edinburgh Autism support services, recognising the need to prevent exclusions and to ensure the entitlement of every child to a school education • Whole staff autism training in primary and high schools • Spectrum multi-disciplinary pre -school support at home and educational establishment through to the end of Primary One • Edinburgh Leisure support for inclusion • Recognised need to improve access to social, leisure, evening and weekend activities and opportunities • Equalities Act (2012) - materials prepared for all schools to support implementation of this guidance • Increased access to an appropriate curriculum in S5 and S6 	<ul style="list-style-type: none"> • Whole staff default autism training for educational establishments • Strategic professional development framework • Identified autism lead (Autism Champion) in educational establishments • Equalities Act (2012)- All schools to receive guidance to support compliance • Implementation of reflective tool to support the planning processes for pupils with autism
<p>Access to services which understand and are able to meet the needs of people specifically related to their autism</p>	<ul style="list-style-type: none"> • The Edinburgh autism support services are well established • Specialist schools and provisions are skilled in supporting pupils with autism • Primary and Secondary autism specific after-school clubs are established and have been positively evaluated • Specialist playscheme provision is available • Playboxes Project- targeted support developing joint attention, 	<ul style="list-style-type: none"> • Establishment of a range of supports and opportunities to promote wellbeing and social competence • Partnership working between City of Edinburgh ASL Services and Capability Scotland to create an extension of the Primary Club model • Improved access to support

	<p>play and interaction in young children with autism</p> <ul style="list-style-type: none"> • Social Communication Groups run collaboratively by Edinburgh autism support services • Close working between NHS Lothian and City of Edinburgh aims to make effective local provision available for children and young people who have autism and a learning disability and who require intensive behavioural support • Exploration of programmes and supports to promote the development of social understanding and competence e.g. PEERS Programme • Dedicated Social Work transition team 'Aspire' support young people into positive destinations • Third sector provide a wide range of activities, groups and clubs 	<p>available, including during weekends and holidays</p> <ul style="list-style-type: none"> • Close working between NHS Lothian and City of Edinburgh aims to make effective local provision available for children and young people who have autism and a learning disability and who require intensive behavioural support.
<p>A local Autism Strategy developed</p>	<ul style="list-style-type: none"> • Consultation and development work, commissioned by City of Edinburgh, is underway 	<ul style="list-style-type: none"> • Edinburgh Autism Plan for Children, with and without a learning disability, to be developed
<p>Removal of short-term barriers such as unaddressed diagnoses and delayed intervention</p>	<ul style="list-style-type: none"> • Evaluation identified overall areas of strength in paediatric diagnostic services • A draft pathway for diagnostic assessment of children and young people has been devised • Waiting times for some diagnostic services are increasing and giving rise to concern • Intervention is not diagnosis dependent • Spectrum multi-disciplinary support offered to families at point of recognition of need • New multi-disciplinary ASAP (A Single Access Point) system in place to ensure the provision of equitable and timely support • Introduction of 27-30 month checks by Health Visitors • Plan to include M-CHAT assessment training for Health Visitors 	<ul style="list-style-type: none"> • Increased focus on multi- disciplinary training • Improved integration of diagnostic services (CAMHS and Community Child Health) within the integrated child planning framework • Sustained trend towards early recognition of need and diagnosis

	<ul style="list-style-type: none"> Recognised need for raised autism awareness in universal services 	
<p>Access to appropriate post-diagnostic support for families and individual (particularly when there is a late diagnosis)</p>	<ul style="list-style-type: none"> Standardised and appropriate information provided to all families at point of diagnosis Spectrum early- years multi-disciplinary team support families pre and post diagnosis Multi- disciplinary post diagnosis Family Follow Up meetings (5-18) piloted and positively evaluated Integrated child planning and collaborative working delivered through Getting It Right Parent Workshops offered by the Edinburgh autism support services Parent workshops offered by Kindred and Health Professionals Families have access to PEEP, Triple P, Incredible Years, Raising Children with Confidence Autism specific parent courses are available, e.g. Hanen (Talkability and More than Words), Williams and Wright CAMHS and BIBS (Barnardo's Intensive Behaviour Support) outreach services Support for families available through third sector, including NAS, LAS and Scottish Autism Siblings' groups offered by Barnardo's and Action Group 	<ul style="list-style-type: none"> Family Follow Up meetings will be offered to all families of newly diagnosed primary and secondary aged children in mainstream schools Clear and consistent information to be given to families to explain Getting It Right Child Planning process and multi-disciplinary roles Extended availability of existing parent programmes Consistent and effective use of a single child's plan across all services and practitioners
<p>Implementation of existing commissioning guidelines by local authorities, the NHS and other relevant service providers. (Government</p>	<ul style="list-style-type: none"> Strategic commissioning priorities are currently being aligned with the priorities of the children's partnership 	<ul style="list-style-type: none"> Finalised priorities will reflect the needs of children and young people with autism and the commissioning guidelines

<p>guidelines 2008/03/27085247/0)</p>		
<p>Access to training and development to inform staff and improve the understanding amongst professionals about ASD</p>	<ul style="list-style-type: none"> • Edinburgh autism support services offer a range of general and targeted training programmes • ‘Understanding the Impact of Autism’ (University of Strathclyde) module offered to approximately thirty City of Edinburgh staff over two years • Edinburgh Autism Network formed (following on from a multi-disciplinary PGC Autism course run in partnership with University of Strathclyde) • Edinburgh Autism Network plan and arrange training and information sharing events for multi- disciplinary professionals • East of Scotland Professional Interest Group (ESPIG) provide a forum for the sharing of current research • Research on the impact of Playboxes method undertaken by a multi-disciplinary team • Training in Playboxes method delivered to over 300 staff • Emotions Talk resource developed and widely used • Regular ADOS peer review meetings established 	<ul style="list-style-type: none"> • A default training course and progressive training framework to be devised for all staff in City of Edinburgh educational establishments.
<p>A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication</p>	<ul style="list-style-type: none"> • Autism Network ‘Practical Supports’ Directory produced for professionals • Support and information available from Lothian Autistic Society, National Autistic Society, Scottish Autism, Tailor-Ed, Kindred, Fair, Vocal and Enquire 	<ul style="list-style-type: none"> • Families and professionals to be signposted to information and supports through Family Follow Up meetings following diagnosis and, as appropriate, through contact the Edinburgh autism support services • Planned information sharing event for parents and professionals.
<p>Process for data</p>	<ul style="list-style-type: none"> • SEEMIS- Education 	<ul style="list-style-type: none"> • To establish a reliable data set for

collection on people using services	<ul style="list-style-type: none"> • The Special Needs System (SNS)- NHS • SWIFT -social work • Challenge to collate this data and maintain accuracy of a database 	children and young people in Edinburgh with a diagnosis of autism to support getting it right for every child.
Multi agency care pathways for assessment, diagnosis and intervention-removing barriers	<ul style="list-style-type: none"> • Getting It Right established as pathway to intervention • Draft pathway for diagnostic assessment (0-18) shared with key stakeholders • Identified need to further develop current diagnostic pathway • Autism ACHIEVE Alliance national research outcomes available to inform planning 	<ul style="list-style-type: none"> • Diagnostic assessment pathway will be agreed and finalised with key stakeholders.
Framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement	<ul style="list-style-type: none"> • Extensive consultation process underway • Focus Groups held involving young people, parents, education staff, health professionals and social work (2013) • Individual interviews carried out with children and young people and parents • Kindred led ASL forum 	<ul style="list-style-type: none"> • Planned ongoing consultation with children, young people and their families. • Effective involvement of children and parents in child planning.

Appendix 3

Edinburgh Autism Plan Group Members

Helen Morgan, City of Edinburgh Council, Health & Social Care
Jayne Kemp, City of Edinburgh Council, Health & Social Care
Mary Alexander, City of Edinburgh Council, Health & Social Care
Ian Waitt, City of Edinburgh Council, Health & Social Care
Richard Ibbotson, Autism Initiatives
Matthew Day, Number 6, Autism Initiatives
Karina Williams, Parents of Autism Spectrum Disorder Adults (PASDA)
Jane Neil-Maclachan, NHS Lothian
Karen Gracie, Scottish Autism
Rick Murray, Places for People
David Bain, Into Work
Mary Rhodes, City of Edinburgh Council
Ian Waitt – City of Edinburgh Council
Tom and Patricia Campbell, Carers
Chris Griffiths, Carer
Mark Keenan, Edinburgh and the Lothian's Aspergers Society
Chris Brodie, City of Edinburgh Council, Children & Families

Appendix 4

Edinburgh Autism Champions Remit

Purpose

- To build knowledge, understanding and skills in teams about working effectively with people with autism
- To contribute to the development of good autism practice in the city
- To promote autism awareness, influence and interest throughout statutory agencies including Department of Health and Social Care (H&SC), NHS, Job Centre, Police, Services for Communities and Housing Associations.

Ask of a champion

- Keep abreast of developments in autism services in the city
- Share learning and commit to building knowledge & skills in their respective teams
- Have an interest in working with people with autism
- Develop a good understanding of autism and how to communicate effectively with people with autism
- Highlight areas of good practice and areas that need development
- Advise / sign post other team members about, effective communication, the care pathway and appropriate services/advice and information as required.
- Attend initial day session for autism champions
- Attend autism champion briefing meetings on a quarterly basis
- To know how to access relevant autism training and information about autism services

Selection

Staff to volunteer to do this with agreement of manager. They would need to make a commitment.

What is the manager committing to?

- Initial autism awareness training – 1 day
- Session on Edinburgh services/policies and how to access them and/or half day at Number 6 to learn about services they offer.
- To attend quarterly 2 hour information sharing sessions on autism

Implementation

First stage - To develop awareness in H&SC assessment teams and in Council and Housing Association housing services. (Possibly NHS Community Health Teams too.)

Second Stage - To develop awareness in Other Council Departments and wider range of statutory agencies.

Resources required to make this happen

Information pack – understanding autism, effective communication, CEC care pathway, Edinburgh services and supports

Access to regularly updated online information on autism services / policies / care pathway in the city and how to access them – to be developed

Initial Autism awareness training - Jane Neil-Maclachan & Number 6 Support for quarterly information session for autism champions

Appendix 5 - Spend on autism by Health and Social Care - excluding care packages

Activity	Funding source	12/13 spend	13/14 income	13/14 spend	14/15 spend
Additional H&SC staff hours to develop resources	Scottish Government Autism Plan Grant	0	£35,000	2,594	0
Additional H&SC staff hours to develop the plan	"			1409	0
Social Stories 2 x training sessions	"			700	0
Development of plan, venue and resource costs.	"			800	0
Training of peer trainers & development of other training materials	"			4000	
Edinburgh World Autism Day Events - 2nd April 2014	"			2000	
Contribution to C&F temporary autism development worker & H&SC development work				23497	
Champions Training Initial Training Days x 2, venue cost	H&SC workforce planning budget	0		?	?
1 specialist 1:1 advice, information and mentoring worker new post at Number 6	Demography & service redesign 14/15*	0	15000	15000	22500
Carers Positive Behaviour Support Training by Richmond Fellowship jointly funded with PASDA	Demography & service redesign 14/15*	0	5000	5000	5000
Number 6 , Information and Advice, Mentoring Service	CEC Grant	23000	23000	23000	23000
Number 6 budget deficit 13/14 & ensuring core advice ad information service is sustainable in the future	Pressures Budget & service redesign 14/15*	0	15000	15000	30000
LAC extended to young people with autism	Disabilities Budget - service redesign	0	30,000	30000	30000
Project Search - employment support worker	Blindcraft / P&C autism budget	0	23,000	23000	0
Aspire Team	Disabilites Budget & Scottish Government Grant (35,000) for 13/14	92447	92447	92500	92500

**Appendix 6: Autism Plan for services for people with autism who do not have a learning disability.
Children and Families estimated expenditure (excluding children’s Social Care)**

Services and schools	Estimated expenditure (£)
Kaimes School	1,192,800
Language classes	569,000
Secondary resource provision	346,800
Psychological services	230,750
Speech and language therapy	337,200
VTSS	732,800
Audit funding to mainstream schools	116,3000
Commissioned specialist provision	293,000
Total	4,865,350