

Renfrewshire Autism Strategy

2014-2017

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Executive Summary and Recommendations

The term 'Autism' refers to a spectrum of developmental disorders affecting how a person communicates with and relates to the world around them. The disorder affects the understanding and use of communication, awareness of social behaviours and interactions, and flexibility in thinking and behaviour. It is estimated that autism affects between 1% and 2% of the population.

National policy on autism is currently driven by the Scottish Strategy for Autism, published in 2011. The Keys to Life, published in 2013, is the Scottish Government's 10 year strategy for learning disabilities. It also refers to people with autism but only in respect of those who also have learning disabilities. Alongside this there are a significant number of policies and pieces of legislation which impact on people with autism and how services should be delivered.

There are a variety of difficulties in trying to identify accurately the number of people affected by autism, and in addressing the specific health and social needs of this group. However, there is considerable evidence of the common co-morbid conditions associated with autism, and an increasing body of best practice in understanding and meeting the needs of people on the spectrum.

The last two decades have seen a shift in the balance of care and this has had an impact on people with autism. Services and supports for people with autism (both with and without a learning disability) are increasingly available within the communities where they live, and additional supports are present within more of our mainstream services. Examples of this include education, where specialist units and additional supports are in place within mainstream schools. This has resulted in a reduction in the need for residential and special needs schools. In the adult world, the increased provision of supported accommodation, the development of autism-friendly day services, and the increased recognition of autism within adult education and employment have all contributed to creating more opportunities for people with autism to lead relatively independent lives.

Based on changes in national and local policy, and through consultation with service users, carers and other stakeholders, a number of clear priorities for autism services in Renfrewshire have begun to emerge. These cover issues such as improved communication and co-ordination between agencies; better access to information for people with autism and their families; greater public and professional awareness of autism; clearer pathways through services; planning structures which focus on outcomes for the individual and which are evidence-based; and smoother transition processes for service users as they move through key life stages. Using these priorities, we have developed within this strategy eleven key recommendations to improve autism services in Renfrewshire as follows:

Recommendation 1: Establish an Autism Working Group to oversee service developments and take forward actions identified within the strategy.

Recommendation 2: Improve data recording and information sharing in relation to autism and the Renfrewshire population, so that this information can inform future planning.

Recommendation 3: Adult health and social care services should undertake a review of pathways to assessment and diagnosis to ensure processes are clear and information on pathways is more easily accessible.

Recommendation 4: Develop and implement an information strategy for autism, the first phase of which would focus on public and third sector agencies, with the second phase focusing on the general public.

Recommendation 5: Ensure practitioners across health and social care services have a basic understanding of the nature of autism and have the opportunity to access further specialist training.

Recommendation 6: Review the current transition arrangements between Children's Services and Adult Services to ensure they are effective, fit for purpose, and appropriate to the assessed needs of young people identified as being on the autistic spectrum and who will require ongoing support into adulthood.

Recommendation 7: Develop improved transition arrangements to support adults as they move through key life stages.

Recommendation 8: Take into account the updated policy on Additional Support for Learning, and work with key agencies including Education and Leisure Services, health and social work, to develop specific actions on support for children and young people with autism.

Recommendation 9: Consider options for the provision of information services to people with autism and their families.

Recommendation 10: Adopt an outcomes approach to the planning and delivery of services and supports based around identified needs of the service user, in consultation with service users and carers.

Recommendation 11: Investigate options for different models of service delivery including, for example, the possibility of developing shared services where this is both appropriate and cost-effective, and the potential to develop innovative practice.

Section 1: What is Autism?

1.1 Autism is a lifelong developmental disorder which affects how people relate to the world around them. It is described as a spectrum disorder or condition because it affects people differently, with some individuals able to live independently, while others will require very specialised support. The severity and functioning of people with autism is wide-ranging, from people who are severely impaired by the condition to those who are minimally affected. Conditions on the spectrum include Asperger's Syndrome, often deemed high-functioning, and atypical autism, also referred to as Pervasive Development Disorder Not Otherwise Specified. For people with autism, the presentation of the condition can fluctuate over time in response to changing circumstances.

1.2 All people with autism will have in common a difficulty in three areas of functioning. This is sometimes referred to as the triad of impairments and means people may experience problems with the following:

Communication: understanding and using verbal and non-verbal communication effectively – this can include social behaviours such as turn-taking, timing and an inability to understand the significance of gestures or facial expressions.

Reciprocal social interaction: understanding social behaviour which affects the ability to interact with other people – this can include difficult in expressing feelings or understanding other people's feelings

Restrictive, repetitive and stereotypical routines of behaviour: thinking and behaving flexibly, which may be exhibited in restricted and/or repetitive activities – this can include difficulty understanding or predicting other people's behaviours and intentions.

1.3 Prevalence rates detailed in the Scottish Strategy for Autism indicate that 1% of Scotland's population has some form of autism. However, it is considerably more prevalent in males; the same study found prevalence of 1.8% in males compared with only 0.2% in females, a ratio of 9:1 in terms of gender. Recent reports have suggested that the true prevalence may be closer to 2%¹ due to under-diagnosis, particularly in females, but this is still to be demonstrated. Section 2 considers the prevalence of autism in Renfrewshire in more detail.

¹ Birmingham City Council (2012) 'Adults with Autism and the Criminal Justice System' Available online

The National Policy Landscape

- 1.4 The nature of autism is such that many different services and policies will be involved in the care and support that people with autism receive. Policies and practice within education, health and social work have particular relevance. The first two, being universal services, may work with people at all points on the autism spectrum. Involvement with Social Work, which is based on an assessment of need, is likely to take place in cases where there is also an additional need, such as a learning disability, mental health issue or physical disability. Evidence indicates that, compared with the general population, people with autism are more likely to experience these types of difficulties.
- 1.5 In addition to specific policy documents on autism, including the Scottish Strategy for Autism (2011) and The Keys to Life (2013) it is important to consider more generic policy relating to services with a duty to provide support. The key legislation and policies include:
- ***The Scottish Strategy for Autism:*** Published in 2011, the national strategy sets out a clear vision for individuals living with autism, underpinned by the principles of dignity, privacy, choice, safety, realising potential and equality. It contains 26 recommendations and has clear goals to be met over a ten-year period. Within this local Renfrewshire strategy we will set out what we intend to do to support these goals and meet those recommendations that are relevant in the Renfrewshire context.
 - ***The Keys to Life – Improving Quality of Life for People with Learning Disabilities:*** This 2013 Scottish Government policy document looks to build on the progress made in the ten years following the publication of *The Same as You?*(2000), the Scottish Government’s previous 10 year national strategy for learning disabilities. It contains 52 recommendations which cover areas such as specific health conditions, lifestyles, independent living, tackling stereotypes, interaction with criminal justice services, and managing complex care needs. The Keys to Life includes people with autism but only in respect of those who also have a learning disability.
 - ***The Same as You?:*** Published in 2000, *The Same As You?* reviewed services for people with learning disabilities and autistic spectrum disorders in Scotland. It set out a vision that no one with learning disabilities should be in long-term hospital care, and should have the same opportunities as others to live as independently as possible in the community. It referred to services for people with autism, including those who did not have a learning disability. It laid out a 10 year change programme to enhance the choices available to children and adults with a learning disability and/or autism, with the aim of improving access to formal assessments and providing better support to people to enable them to live fuller lives.

- ***Education (Additional Support for Learning) (Scotland) Act 2004 (revised 2009)***: The 2004 Act introduced a new framework for children requiring additional help with their learning. It promotes collaborative working between all relevant agencies to ensure that children have the support necessary to maximise their potential. Renfrewshire Council Education and Leisure Services have a clear policy on how this is implemented locally.
- ***Scottish Intercollegiate Guidelines Network (SIGN)***: These refer to clinical guidelines for the assessment, diagnosis and subsequent interventions for children and young people with autism and were produced in 2007. They cover the 0-18 age group and stress the importance of early diagnosis to maximise the opportunities for children to fulfil their potential with support from appropriate interventions. These guidelines also emphasise the importance of multidisciplinary, multiagency working.
- ***Adult Support and Protection (Scotland) Act 2007***: This legislation makes clear the duty to protect vulnerable adults, particularly those who may be susceptible to harm or abuse from others as a result of a disability, mental illness or other condition which may impact on their ability to protect themselves. Renfrewshire Adult Protection Committee is the multi-agency body which oversees adult protection arrangements locally.
- ***Commissioning Services for People on the Autistic Spectrum***: This document, published in 2008, provides policy and practice guidance and promotes the use of an outcomes-focus in commissioning services for autism. It offers a list of measures which indicate the quality of services.
- ***Getting It Right For Every Child (GIRFEC)*** is the overarching policy which focuses on joint working to ensure the needs of children, particularly vulnerable children, are met and positive outcomes are achieved. The policy sets out best practice, including the identification of a Lead Professional for children identified as needing support from more than one agency, and the creation of a single 'Child's Plan' to be shared by all appropriate agencies. The latter has since been enshrined in the Children and Young People (Scotland) Act 2014.
- ***Social Care (Self-Directed Support) (Scotland) Act 2014***: This places a duty on local authorities to offer self-directed support (SDS) to all service users and is intended to ensure service users have as much choice and control over the support they receive as possible. SDS allows for four options. Option 1 is a direct payment, where the service user receives a payment based on their assessed needs and arranges their own support. Option 2 is where the service user chooses the type of support and the provider they would like and the local authority arranges it. In Option 3, the service user asks the local authority to choose and arrange services. Option 4 is to have a mix of these three types of arrangement.
- ***Public Bodies (Joint Working) (Scotland) Bill***: This Bill received Royal Assent in April 2014 and comes into force on 1 April 2015. It requires local

authorities and health boards to deliver integrated health and social care services for adult services, with an option to include other areas of service. In Renfrewshire, the Council's Children's Services will not be part of integrated services. This is the most significant piece of legislation affecting the way in which health and social care services are governed, managed and delivered.

- ***The Children and Young People (Scotland) Act 2014:*** There are a number of provisions which may impact on the delivery of services and support for children with autism. These include the requirement to develop joint plans for Children's Services; the duty to identify a 'named person' for each child; and the requirement for a 'child's plan' to be initiated in every case of targeted intervention. The Act also moves some elements of GIRFEC from policy to statute, as noted above.
- ***Proposed New Carers Legislation:*** The Scottish Government is currently consulting on proposals for new legislation aimed at improving outcomes for carers, including young carers and the people they care for. Although the legislation is not yet in place, it is anticipated it will have an impact on services in the future.

1.6 In Renfrewshire, the Learning Disability Joint Planning and Performance Implementation Group (JPPIG) currently holds the responsibility for development and practice in the field of autism. In order to achieve the best outcomes for people with autism and their families and carers, it is recognised that ownership of the autism agenda needs to be extended beyond learning disabilities services to include the full range of services that people with autism require. This will include the following areas:

- care and support (adults and children)
- health including primary and community healthcare, and mental health
- employment
- education including further education
- transitions
- housing
- community support
- social and leisure
- criminal justice

As the Renfrewshire autism strategy moves forward, the Learning Disabilities JPPIG will continue to take lead responsibility for planning, performance and implementation of the strategy and will ensure that all of the stakeholders are involved in its ongoing development.

Section 2: Autism in Renfrewshire: Identifying Local Needs

2.1 There is no single source of information which gives a definitive or accurate indication of the numbers of people with autism in Scotland or the range of their needs. There are elements within statutory returns to the Scottish Government (e.g. eSAY) which relate to people with autism but these tend only to reflect people receiving services from social work, thereby excluding others with autism who may have a diagnosis but are not receiving statutory services. Consequently, most agencies will only be working with partial information about people with autism who require some level of support. This section presents an estimate of the total population based on expected prevalence. It also considers the needs of the local population in relation to different elements of everyday living and how living with autism can impact on people.

2.2 Prevalence

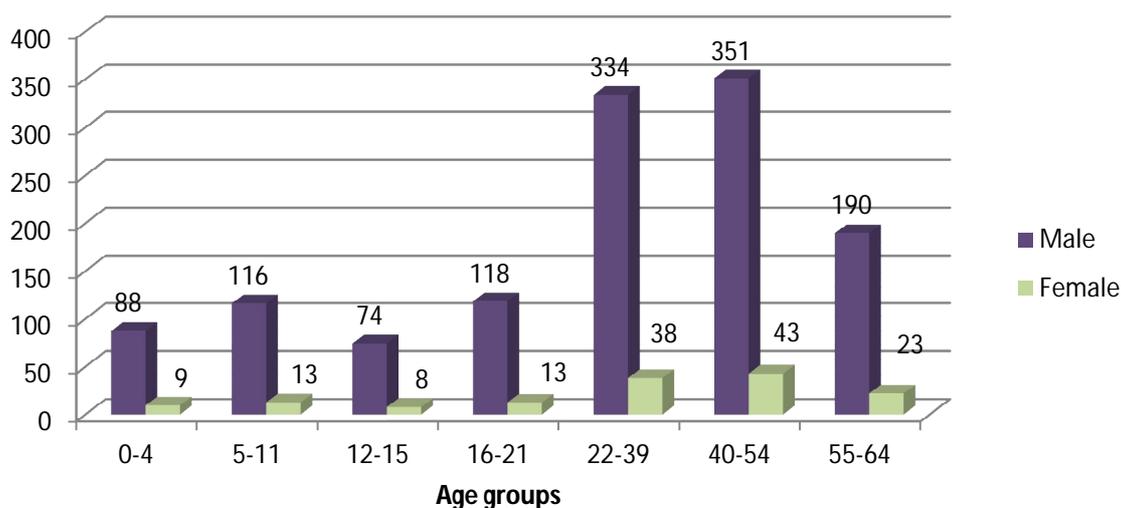
2.2.1 Because many people with autism may be undiagnosed, or may have been diagnosed after leaving the education system but not come into contact with other services, it can be challenging to estimate with any degree of accuracy the number of people in Renfrewshire who have been, or may be, diagnosed as being on the autism spectrum. As previously indicated, research carried out in England by Brugha et al² for the NHS, estimates prevalence at 1.8% in the male population and 0.2% in the female population. Overall prevalence is estimated at 1%. Applying these prevalence rates to 2012 population estimates suggests that there may be just over 1400 people aged under 65 years in Renfrewshire who have autism.

2.2.2 Figure 1 below breaks this down by age group according to the type of services which would apply: pre-school, primary and secondary school ages; the transition group (16-21); young adults; and three adult groups, including the over 55s who will move into Older Adult Services over the next decade. An understanding of the demographics is clearly important when planning for the future.

2.2.3 Data provided by Renfrewshire Council Social Work for the eSAY national database returns identifies 113 adults with autism in 2012. However, this statistical return only takes account of those adults who have been actively involved with social work services in the two years prior to the survey, and mainly applies to people who have both autism and a learning disability.

² Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J (2007) Autistic Spectrum Disorders in Adults Living in Households in England The NHS Information Centre: Leeds

Figure 1: Estimated numbers of children and adults with ASD in Renfrewshire, 2012



2.3 Health Needs

2.3.1 Autism is a spectrum disorder and health needs will vary with the individual. However, there are a number of common co-morbid conditions associated with autism. These include anxiety, Attention Deficit Hyperactivity Disorder (ADHD), gastrointestinal disorders, sensory problems, epilepsy and bipolar disorder. There is a strong evidence base that indicates individuals with autism are more likely to present with behaviours that services can find challenging. The Scottish Autism Strategy highlights that access to services for people with autism can often be compounded by other health-related criteria. This is particularly the case for individuals with autism who do not have a learning disability and may be less likely to be identified by support services. Because of the challenges in trying to identify people with autism, there is no robust data available on the specific health needs of people with autism in Renfrewshire or indeed across Scotland.

2.3.3 In a survey of service user/carers views on autism services in Renfrewshire, carers highlighted concerns around diagnosis. Some of their comments are set out below:

How could the process of getting a diagnosis be improved?

“It [the diagnostic process] can always be improved by speeding up the time it takes to get results. It is a very emotional and upsetting time for parents and waiting is always difficult but I appreciate it cannot always be done quickly.”

“Different departmental communications needs to be improved. I felt like I was the go-between....passing on info that could have been put in a simple email.”

“Reduce the time it takes to get assessed and have more information on support, as a couple of leaflets is [sic] not enough.”

2.4 Educational Needs

2.4.1 Children with autism are entitled to additional help with their learning. This may be provided in mainstream school or in specialist education. Prevalence rates suggest that there are around 200 children of school age in Renfrewshire who may require additional support linked to autism and its impact. In a very small number of cases, children may be placed in residential schools which cater for more complex needs.

2.4.2 Placements in residential schools for children with autism have fallen considerably over the last decade. This is partly attributable to the increased level of provision to support people with autism in mainstream schooling or in local Additional Support Needs (ASN) schools. There are currently no children from Renfrewshire attending autism specialist residential schools. Five children with autism who are looked after and accommodated attend special educational needs schools as day pupils.

2.5 Employment Needs

2.5.1 As with the other needs referred to in this section, it is difficult to identify specific employment issues for people with autism in Renfrewshire because of a lack of data about the population. The latest eSAY return (see 2.2.3) indicates that only 2 people with autism are in employment, and a further 5 are in training for employment. This group of individuals tend to have a higher level of need and most also have a learning disability.

2.5.2 Local employability services indicate that they support a small number of people with autism. Some are participating in a specialist autism service but

others are working with the mainstream service. A more detailed scoping exercise will be necessary to fully identify needs and demand in this area.

2.6 Housing Needs

- 2.6.1 The most recent eSAY return for Renfrewshire states that there are currently 20 people with autism living in supported accommodation in the Renfrewshire area, and 74 people living in mainstream housing, mostly with a family carer. There are a further 7 people living in a care home setting and 1 person receiving continuing care and treatment in an NHS inpatient facility. These figures refer almost exclusively to people with both autism and a learning disability and, as such, cannot be taken to accurately reflect the numbers of people with autism who require housing support or more specialised forms of housing.
- 2.6.2 Carers of children with autism will often identify the need for their children to have particular features or adaptations within their home. This may include the requirement for a large, quiet, safe and enclosed garden area that is reasonably remote from neighbours. Research tends to support the benefits for some children with autism of expending large amounts of energy through exercise. This can be noisy and lead to complaints from neighbours.
- 2.6.3 Conversely, many people with autism report that they are extremely sensitive to noise and can have great difficulty with, for example, coping with the noise of upstairs neighbours walking on the floor, or neighbours playing music. In some areas (e.g. Springburn Housing Association in Glasgow) housing has been built with additional sound proofing in ceilings, floors and walls, making it better suited to meet the particular difficulties faced by some people on the autism spectrum.
- 2.6.4 Discussions have been ongoing with Renfrewshire Housing colleagues about these issues in terms of the extent to which such needs can be built into the Local Housing Strategy.

2.7 Social and Leisure Needs

- 2.7.1 I Exist, a study by the National Autistic Society in 2008, reported that over half of adults with autism surveyed found it hard to make friends and that 80% felt that social support would make them feel less isolated. The nature of autism is such that it can make family life and relationships more challenging³.

³National Autistic Society Scotland (2008) We Exist: A Bill for Autism, A Bill for Scotland

- 2.7.2 As referred to at 2.6.2 studies have also shown that exercise can be highly beneficial for people with autism, both in terms of reducing the impact of behaviours often associated with autism (for example, anxiety, depression, aggression, hyperactivity) and in preventing weight gain, since there is some evidence to suggest that people with autism are at increased risk of being overweight⁴.
- 2.7.3 For people with autism and learning disabilities, Renfrewshire Learning Disabilities Service provides a range of comprehensive day opportunities. Adults attending can access a wide range of activities which will promote health and wellbeing and social integration. The recent collocation of Milldale and The Mirin within ON-X and Lagoon Leisure centres offers the adults attending an excellent outlet to experience the benefits of physical activities by using the range of activities and equipment available.

2.8 The Criminal Justice System

- 2.8.1 There has been some debate amongst professionals as to the numbers of people in the criminal justice system who have autism. However, it has proven difficult to confirm this with any statistically significant data. Autism Midlands have reported, on the basis of a small study, that between 4% and 7% of prisoners in HMP Birmingham show features of autism, with prison staff estimating the rate to be 5.5%⁵. Difficulties in identifying accurate figures generally arise from a lack of diagnosis, and from those in the criminal justice system often presenting with other issues such as substance misuse, mental health problems, learning difficulties and learning disabilities.
- 2.8.2 In overall terms, it is recognised that for certain individuals there may be a connection between their offending behaviour and autism. For some there may be certain factors which predispose an individual with autism into the criminal justice system, such as social naivety; poor empathy; misinterpretation of social cues; and vulnerability to social grooming.⁶ This emphasises the importance of recognition of autism traits by professionals within the criminal justice system, and of a multi-agency approach to addressing the issues arising.
- 2.8.3 Renfrewshire Criminal Justice Social Work team produces over 1000 reports per year for courts, and works with an estimated 700 individuals subject to orders in the community. The service has identified that, of the current cases,

⁴ Dawson, G & Rosanoff, M (2009) Sports, Exercise and the Benefit of Physical Activity for Individuals with Autism Published online by Autism Speaks

⁵ Birmingham City Council (2012) 'Adults with Autism and the Criminal Justice System' Available online

⁶ Wilson, C, University of Cambridge, at British Psychological Society Conference on Autism and Criminal Justice System, 2013

only 5 people have a clear diagnosis of autism. However, given the study reported at 2.8.1, there may be some value in examining the issue in more detail within the criminal justice system to identify if the condition is indeed more prevalent than initial figures suggest.

2.9 Support for Carers

2.9.1 A recent survey undertaken as part of consultation over the Renfrewshire Autism Strategy highlighted some of the issues impacting on those who care for people with autism. These include concerns about a general lack of autism awareness in society, about the safety and security of the person they care for, financial worries, and access to services.

What do people who use services tell us?

Caring Responsibilities

“Child care is very complicated because of his additional needs and the lack of approved children care providers in local area”

“School holidays and childcare have restricted my ability to gain suitable employment. An understanding of the issues facing carers and a desire to support carers is something that I have found missing in previous employers and in most of my attempts to gain suitable employment.”

“Caring for someone with autism is really difficult. There have been times when I have felt completely isolated, frightened and misunderstood, and I have had to change how I think and behave in order to be able to adapt and meet the needs of my child.”

Section 3: Autism in Renfrewshire: Current Provision

- 3.1 As set out in Section 1, people with autism have needs which are recognised as being on a spectrum, ranging from very low level needs to complex/intensive care needs. As such, services and supports for people with autism cover a broad range of need, though statutory services tend to be focused towards higher levels of needs. While it is not always helpful to focus on services available rather than needs to be met or outcomes to be supported, it is useful to consider the nature of current provision for people with autism.
- 3.1.1 Recommendation 10 of the Scottish Strategy for Autism states that agencies and services should develop a 'Menu of Interventions' including advice, therapeutic interventions and counselling for children, young people and adults with autism that are appropriate and flexible to individual need. A multi-agency working group, including parents and carers, drew up the resulting Menu of Interventions described in Appendix 1, which aims to provide a guide to interventions and supports required by people on the spectrum across their lifetime and ability span.
- 3.1.2 In Renfrewshire, it is intended to map services more fully using the Menu of Interventions described in Appendix 1, and to use this as the basis for the ongoing development of autism services by education, health, social work, or voluntary services.

Services for Children

3.2 Health Services for Children

- 3.2.1 The Children & Adolescent Mental Health Service (CAMHS) is a specialist service covering a wide spectrum of needs. The ASD referral process is managed by CAMHS, though assessment and diagnosis of autism in children is carried out on a multi-disciplinary basis. Referrals for assessment and diagnosis typically come from GPs, educational psychologists, health visitors and community paediatricians. CAMHS has indicated that their diagnosis rate following referral is around 40%, suggesting that although there is insight and awareness of the condition amongst professionals, further work requires to be done with referrers to recognise some of the specific aspects of an autism presentation. The CAMHS team will signpost children to other services where there is a confirmed diagnosis. The child would then have their needs met as per legislation on Additional Support Needs.

3.2.2 The PANDA Centre, based in the Royal Alexandra Hospital, is a specialist community paediatric service which works with children with developmental additional support needs, including pre-school children. Where a child has additional developmental needs, PANDA would provide services to meet individual needs.

3.2.3 Within NHS Greater Glasgow and Clyde there is an Early Intervention Team, which may be accessed in respect of young children where a diagnosis of autism is confirmed.

3.3 Pre-school, Primary and Secondary Education

3.3.1 Depending on the level of need, children with autism within Renfrewshire can be supported in mainstream school or attend one of several schools dedicated to children with Additional Support Needs (ASN).

3.3.2 Pre-school children can access specialist provision at the Hollybush Children's Centre, Mossvale Nursery School and the Preschool Assessment & Development Centre. The local authority's three Additional Support Needs schools – Clippens, Kersland, and Mary Russell - have provision for pupils with autism. Within mainstream schools, there are specialist bases within two primary schools (St Paul's Primary and St Anthony's Primary) and three secondary schools (St Benedict's High, Castlehead High and Park Mains High) where children with autism can receive supports. A review of Additional Support Needs provision is currently underway. In a small number of cases, the local authority may commission a placement from a specialist provider in the field of autism, such as the National Autistic Society Scotland and Scottish Autism, although the need to use such resources has diminished over the years as local services have developed greater expertise in supporting children with autism.

3.4 Children with Disabilities

3.4.1 Children with a diagnosis of autism can access social work services through Renfrewshire Children with Disabilities Team. The main eligibility criterion for the team is that the child's disability should be permanent and substantial. The child's needs are assessed through the multi-disciplinary Integrated Assessment tool. This leads to the formulation of a Child's Plan which is based around the GIRFEC [Getting It Right For Every Child] outcomes model focusing on areas such as the child's safety, health, nurturing and inclusion. A small number of children may have needs which result in a specialist residential or day placement being necessary, but the vast majority of children and their families receive services locally. This includes respite or short

breaks, which provide support for the children to reach their full potential and for their families to have a well earned break from their caring role.

- 3.4.2 The Flexi-care Service, which is part of the Renfrewshire Learning Disabilities Service (RLDS), is based at Spinner's Gate Resource Centre in Paisley. Flexi-care works with both young people and adults and supports people who have a learning disability and people who have a dual diagnosis of autism and a learning disability.

3.5 Transitional Arrangements

- 3.5.1 Where a child is identified as requiring additional support at the point of progression into adulthood, relevant services will convene an Extended Support Team to assess future needs and put plans in place. This process commences two years before the anticipated school leaving date. The transition from children's to adult services is carefully managed in a three-stage process outlined in Figures 2 and 3 below. The three stages are:

Stage 1:	Identification and information sharing
Stage 2:	Assessment of Continued Need
Stage 3:	Transfer from Children's Services to Adult Services

- 3.5.2 This transitions process focuses on the multi-agency transition planning that is required when a young person's support needs move from specialist additional support needs (ASN) provision or occasionally from ASN provision within mainstream education, to Adult Social Work services. As with other Renfrewshire young people, the identification, monitoring and provision of additional support needs for pupils is managed through the Integrated Assessment Framework (IAF) and the extended support framework of each educational establishment. The transitions process may also be applied to young people who receive case management in mainstream Children and Families Social Work Teams within Renfrewshire and who are assessed as requiring ongoing support packages from Social Work Adult Services. This may include children with autism who do not have a learning disability.
- 3.5.3 The transition from school to post-school in this context is jointly managed and co-ordinated by the educational establishment and Social Work Services. Thus for each young person involved in the process the school has a named senior manager (a support co-ordinator) who is responsible for ensuring that the establishment meets its duties under the ASL legislation. Where a need for ongoing support into adulthood has been identified, social work will identify a named worker to manage their involvement and responsibilities.

- 3.5.4 Multi-agency Transition Panels will ensure an overview of the plans for young people moving from children's to adult services. There will be two Transition Panels, one covering the transition of young people who meet the criteria for referral to the Renfrewshire Learning Disability Service, and one covering the transition to Adult Services for young people with a physical disability or with social, emotional and behavioural needs. The Panels will consist of representatives from Education, Health and Social Work.
- 3.5.5 The Transition Panels will meet quarterly and will ensure that all aspects of the young person's transfer to adult services have been considered and appropriate plans put in place accordingly. All lead professionals completing Integrated Assessments in respect of young people involved in the transition process will be expected to attend the relevant Panel as required to outline the main elements of the Assessment.
- 3.5.6 The Transition Panels will ensure that any resource issues arising from the transition process are resolved timeously and that young people and their families are informed and included in respect of the assessment and resource allocation processes. The Transition Panels will be responsible for assigning priority to the plan for young people where there is a waiting list for access to services or resources. Information will also be derived which supports planning around future need and resource management.
- 3.5.7 To ensure accurate financial projections are made concerning care packages required by young people making the transition to adult services, the Coordinator for Learning Disability Strategy and Development (RLDS) will ensure that details of all such packages discussed at the Transition Panels are sent to the Social Work Finance Service Manager.
- 3.5.8 The transitions process for a) children with a learning disability and b) without a learning disability who require services into adulthood is represented in diagrammatic form in Figures 2 and 3 below.

Renfrewshire Transition Process: Learning Disability

Stage 1 - Identification and Information Sharing

Identification of young people likely to require continued support as Adults- By age 13 and no later than end of S2

Once young person identified- Extended Support Team Case Conference (ESTCC) meeting arranged. Meeting to include SW/Health. Parental consent to be obtained to pass information to other agencies.

EST CC to identify planned school leaving date and makes transition info available to young person/parents

If young person not known to SW, with parental consent Education to contact SW and allocated Social Worker to become involved in transition process

In cases where commissioned service may be required, commissioning staff should be involved. Consideration should also be given to Self Directed Support

Stage 2 – Assessment of Continued Need

Stage two commences immediately following completion of stage one for young people leaving school at 16 years. For young people leaving at 18 years stage two to commence two years before leaving date i.e. in final term of 4th year at school

By end of S3 integrated assessment to be completed which will include a child's plan reflecting initial transition plans.

If appropriate, initial discussion with parents regarding Adults V Incapacity (AWI) legislation to take place at this stage

Planning for transition should move to a transition planning meeting to take place no later than two years before expected leaving date. (Education & Health staff to be included in Transition Planning meeting)

Transition planning meeting to consider young persons needs line with GIRFEC-safe healthy active achieving nurtured respected responsible and inclusive

Education and SW to agree about what agency should chair the planning meeting

Transition planning meeting to identify appropriate RLDS. Allocated SW to be responsible for referral to RLDS

Stage 3 – Transfer from Children to Adult Learning Disability Services

RLDS worker to be identified no later than 6 months before transfer to RLDS with joint work being carried out in the 6 months prior to the transfer to RLDS

Final Transition planning review: ensuring all services required for the young person have been identified and accessed. To take place no later than 3 months prior to school leaving date.

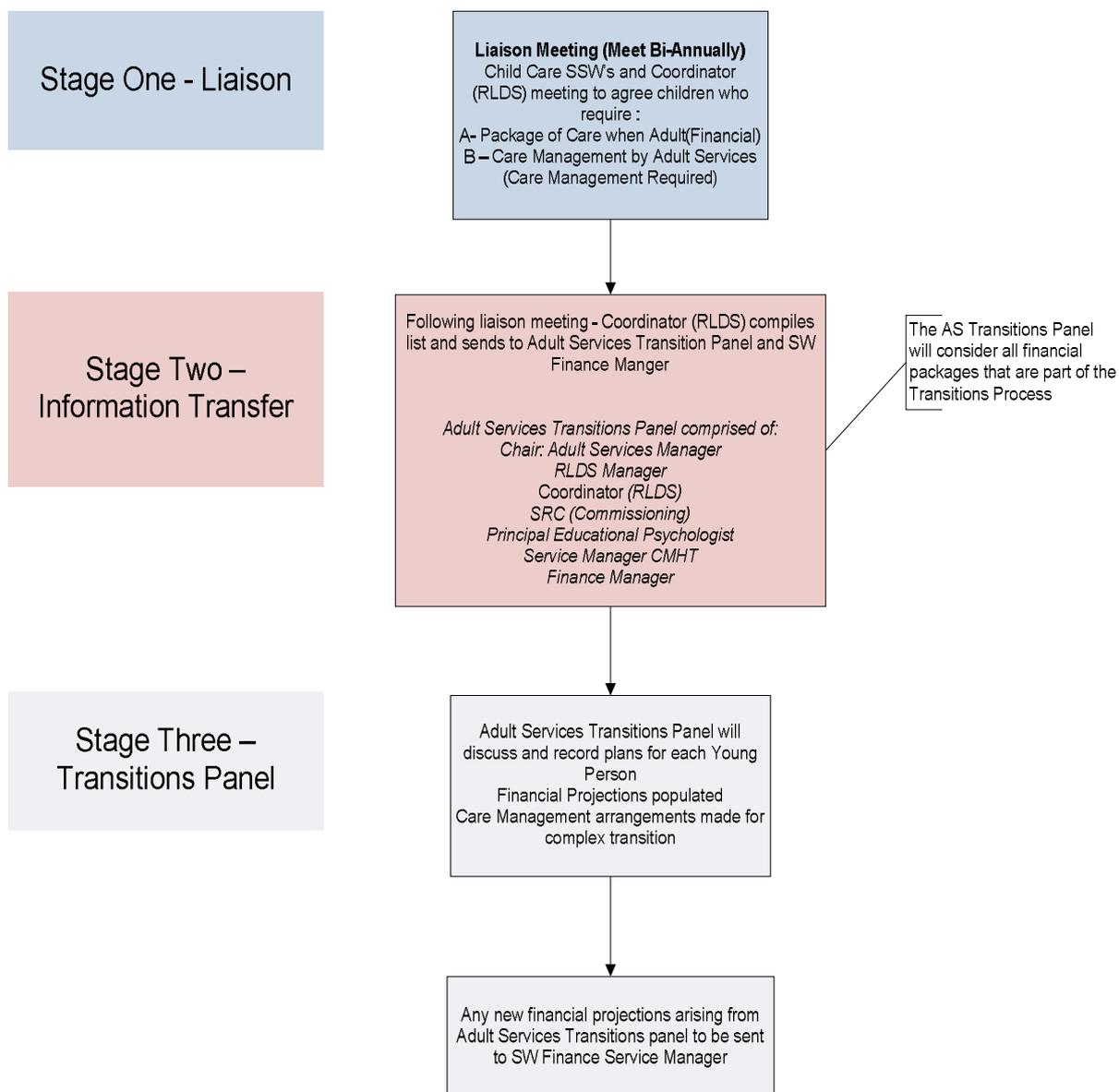
Formal transfer of case responsibility to/RLDS will take place on young person attaining 18 years of age or on leaving school.

Monitoring of the Transition Process

Transition Panel to ensure an overview of Plans for young person moving from Childrens Services to RLDS including Resource allocation. The transition panel should have reps from SW, Education and Health

Co Ordinator (RLDS) to feed finance projections to Finance Manager & Adult Services Transitions Panel

Renfrewshire Transitions Process – Adult Services (Non Learning Disability)



Services for Adults

3.6 Further and Higher Education

3.6.1 Within Renfrewshire, tertiary education is provided at the campuses of West College Scotland (further education) and the University of the West of Scotland (UWS) (higher education). West College Scotland operates a Learning Plus team, who work with students with any disability or additional need that may affect their learning. Support will vary depending on the particular needs of the individual. UWS operates a similar support through its

disability service and was supporting 30 students with autism in 2013/14⁷. People will also attend further and higher education opportunities outside Renfrewshire.

3.7 Employability

- 3.7.1 A supported transitions programme, run in partnership with Enable, funds a support worker for young people with autism within mainstream schools. Support is offered in their final year of school to help secure a positive destination and work experience opportunities. There is no specific targeted employment support for people with autism; the needs of young people with autism are being met within the existing employment support service.
- 3.7.2 A partnership approach to employability support for people with additional support needs (including autism) is currently being developed in Renfrewshire. In addition to this, Project Search is being implemented for adults with learning disabilities with the service due to begin during 2014/15. Renfrewshire Learning Disability Service is also developing a programme offering training and employment opportunities in horticulture.

3.8 Autism and Learning Disability

- 3.8.1 For adults with diagnoses of both autism and a learning disability, services will be co-ordinated by Renfrewshire Learning Disability Service (RLDS), a fully integrated health and social work service. Access to its services is on the basis of assessed need. Those people eligible for services are provided with a person-centred plan which outlines the supports needed to achieve the best outcomes. Staff within RLDS, including clinical psychologists, psychiatrists, learning disabilities specialist nurses, and speech and language therapist, have been specially trained in assessment and diagnosis of people with autism, and have developed considerable expertise in effective practice and interventions in this field. Ongoing training is available to the wider RLDS staff group to enable them to provide the appropriate level of support, both pre and post diagnosis.
- 3.8.2 The Intensive Support Service (ISS), based in Spinner's Gate, works with a small number of adults with more complex needs, most of whom have autism at the more complex end of the spectrum. The service provides a therapeutic creative environment enabling service users to undertake a full range of daily activities working towards maximising their independence and wellbeing. The learning environment is supported by using the learning approach of SPELL (Structures, Positive Assessment, Empathy, Low

⁷ Freedom of Information request to UWS, April 2014

Arousal, Links). A range of strategies of interventions are also in place which promote communication, social interaction and flexibility of thought. The techniques adopted in ISS are being developed across all RLDS services. The service has developed a strong supportive relationship with carers while providing a structured yet flexible range of opportunities for the service users throughout the day.

A carer's view of the Intensive Support Service

"The ISS is very important to our son and our family. It has allowed him to be cared for in a safe, secure and supportive environment where he feels he is understood and his needs are met'.

They [the staff] have learned how my son works and developed a great rapport. He loves coming each day"

- 3.8.3 The Anchor Centre supports adults with severe to profound learning disabilities and complex health care needs, some of whom have autism. This service offers a range of opportunities for adults to maintain their health and maximise their level of independence.
- 3.8.4 RLDS Day Opportunities operate from The Mirin and Milldale, offering structured support for adults with a moderate to severe learning disability, some of whom have autism. Both services are based within leisure centres to promote integration within the wider community. The service offers opportunities for adults to access a range of activities to maximise independence and has been cited as an exemplar of good practice in The Keys to Life report 2013.
- 3.8.5 The Community Networks Team, which is also part of RLDS, supports adults with learning disabilities and autism who have comparatively low levels of need and are more able to be relatively independent. The service is based at Spinner's Gate Resource Centre. It offers a wide range of social activities as well as supporting access to education and employment. An example of the employability support available is the tea bar within the Mirin, which is run by service users.
- 3.8.6 In addition to the structured services noted above, support is also offered to adults by the aforementioned Flexi-care Service. Flexi-care facilitates access to a range of social and leisure activities for both adults and young people within their own communities. The service is provided on a basis of assessed needs and aims to promote social inclusion. The service has around 80 trained volunteers who provide support to around 180 adults

accessing the service on a regular basis. The service has been cited within the National Autistic Society's I Exist report as an exemplar of good practice.

- 3.8.7 Over the last 15 years there has been a significant shift in the balance of care from long term residential and hospital care to care in the community through the provision of appropriate supported accommodation, and increased investment in community-based staff to care and support adults to assist them to meet their particular needs.
- 3.8.8 Within Renfrewshire there is an emphasis on supporting people to live independently where possible, or with family carers. For those people who require support to live in their own communities, a Supported Living Model is in place which provides the adult with a tenancy/occupancy agreement, promoting rights and responsibilities. For some, the model will comprise individual properties with access to staff; larger properties providing 2, 3 and 4 person shared living opportunities with on-site staff; or core and cluster properties linked to a shared staff resource. The use of assistive technology such as Telecare is being gradually increased. This is proving increasingly useful in promoting increased levels of privacy and independence while maintaining the safety and security of the individual.
- 3.8.9 In Renfrewshire, several new housing options have been developed to provide suitable accommodation for adults with learning disabilities, and these have been designed so as to accommodate people with autism. Examples of this include:
- **Six-person Cluster Flats** - a purpose built property which provides six adults with their own individual flat with internal access to a common hallway, shared staff area and secure garden area. The property has been specifically designed to enable the provision of support to adults whose behaviours and communication would challenge mainstream accommodation including excessive noise and inappropriate behaviours. The design recognises the need for individual space, whilst providing the adult with a safe and secure environment. The property has been designed to enable the staff team provide highly individualised care plans promoting robust personal plans from a shared flexible staff resource.
 - **Group Living** - A number of highly successful small group living situations have been developed offering a more shared environment including the refurbishment of a property to provide a shared environment for five adults. The internal design recognises the need for personal and shared space offering fully accessible en suite facilities with shared lounge areas from which the staff team provide individualised care plans promoting robust personal plans from a shared flexible staff resource.

- **Supported Tenancy Model designed to be autism-friendly** – This is a new housing development in Paisley specifically designed to take specific account of the needs of adults presenting with autism and/or other complex communicative needs. This property is for eight adults to share 2 four-person properties with access to an on-site staff team to provide highly individualised care plans within an environment which can be adapted and altered to meet individual need. This development has enabled some young adults who were supported in out of area residential establishments to return to their local community.

3.8.10 In all of the above there are key elements of design which have been incorporated to ensure the properties can assist the support team to enable social inclusion and appropriate independence for the individuals.

3.8.11 In recognition of the need to provide support to carers, RLDS offers respite or short breaks by providing adults with autism access to residential respite. Respite is targeted at supporting carers by providing care and support outwith the family.

3.8.12 Weaver’s Linn Respite Centre in Paisley is a 10-bed residential establishment providing a programme of care for the full spectrum of needs associated with adults with learning disabilities, some of whom will have autism. The service is based around meeting the assessed needs of both the adult and the carer and has gained considerable expertise in enabling the adults and their families to receive the much needed break within a local service.

3.8.13 Some adults with autism receive respite within residential units provided by the third and independent sectors. Some of these placements are within specialist out of area units. However, in Renfrewshire we have been working to increase the number of places available for respite within the local area. This includes more provision at Weaver’s Linn Respite Centre for people with autism and learning disabilities. In this way we aim to improve our capacity to provide local respite care rather than have to place people distant or remote out of area specialist autism respite placements.

3.9 Health Services for Adults

3.9.1 Health services have a leading role in the diagnosis of autism. Ideally, people with autism will have been diagnosed in childhood and will, in consequence, have access to a range of supports such as assistance with their language skills, communication, including social interaction, assistance with life skills development, and dealing with relationships. In recent years,

with increased awareness of autism, considerable improvements have been made in the assessment and diagnosis of autism in children, meaning many more people are identified as having autism during childhood which in turn has contributed to the improvement of transition arrangements between children's and adults' services.

- 3.9.2 Over recent years, although there have been considerable improvements in the knowledge and understanding of autism leading to increased levels of diagnosis in childhood, we recognise that there remains a group of adults who may have autism but have not had access to assessment. As a result, we recognise there are some individuals who may have unidentified needs and will require to be signposted towards services that can undertake an assessment and post diagnostic supports.
- 3.9.3 Assessment and diagnosis of adults who have a learning disability is undertaken by the Renfrewshire Learning Disabilities Service (RLDS) which operates as a fully integrated community based health and social work service for adults with learning disabilities including those who also have autism, providing a single point of entry to a comprehensive range of health and social work services.
- 3.9.4 Renfrewshire Learning Disability Service has relatively clear routes to assessment and diagnosis for adults who have learning disabilities who may present as having autism. This assessment can be provided by professionals (see 3.8.1) within the service who have undergone appropriate accredited training. Assessment is on a multi-disciplinary basis. RLDS can then facilitate access to the appropriate range of supports available to adults with learning disabilities and autism.
- 3.9.5 Post-diagnostic support is then offered by the larger RLDS locality team and may include one to one work with the individual, training for care staff and families and referral to appropriate team members or supports if unmet needs have been identified, e.g. day opportunities, other health care workers, respite.
- 3.9.6 For adults with autism who do not have a learning disability, referrals may be made to the NHS Greater Glasgow and Clyde Adult Autism Team. They are based at the Yarrow View Centre in Yoker, Glasgow, and are a specialist NHS service which will carry out full assessment and diagnosis for autism. Referrals to this team are via the individual's own GP, although other services, such as the Renfrewshire Adult Community Mental Health, may facilitate contact with the Adult Autism Team and subsequently work closely with them on post-diagnostic support.

3.9.7 Support to individuals after they have had a diagnosis of autism is clearly a very important area, particularly in assisting them to come to terms with the impact of their condition on their life. In section 1.2 the triad of impairments was referred to in terms of difficulties that a person with autism may experience in:

- communication
- reciprocal social interaction
- restrictive, repetitive and stereotypical routines of behaviour

In some cases, interventions may be at a fairly low level of awareness raising and advice-giving to help the individual to achieve greater awareness of themselves, and be given advice about coping mechanisms in social and work environments.

3.9.8 People with autism often have difficulties with cognitive and behavioural flexibility, sensory processing and regulating their emotions. In addition to interventions specifically aimed at reducing behaviours that challenge, services should also aim to offer psychosocial interventions for both the core symptoms of autism. This might be in the form of groups focused on social interaction, and interventions which address the difficulties commonly experienced by those with autism, e.g. anger management, problem solving and personal safety skills (National Institute for Health and Care Excellence (NICE) Clinical Guidelines 142, 2012).

3.9.9 Research findings to date suggest that approximately 10-20 % of people with learning disabilities present with behaviours that are found challenging to services (Emerson, 2000)⁸. McClintock, Hall and Oliver's (2003)⁹ analysis of risk factors associated with challenging behaviour showed that individuals with a diagnosis of autism were significantly more likely to show self-injury, aggression and disruption to the environment. Challenging behaviour, when severe, has been shown to have a negative impact on the individual, and can result in admission to specialist, and costly, residential service provision for many years (Emerson 2000). Matson and Rivet (2008)¹⁰ reported that the frequency of behaviours which challenge services increased with severity of autistic symptoms. NICE recommend that behaviours which challenge should be assessed considering physical disorders, mental disorders and environmental factors. NICE propose that a psycho-social

⁸ Emerson, E. 2000 Developmental disability and behaviour. Gillberg, C. & O'Brien, G. (eds.). London: MacKeith Press

⁹ McClintock, K, Oliver, S and Hall, C (2003) Risk markers associated with challenging behaviours in people with developmental disabilities: a meta-analytic study *Journal of Intellectual Disability Research*, 47, 405-416

¹⁰ Matson, J L and Rivet, T T(2008) The effects of severity of autism and PDD-NOS symptoms on challenging behaviours in adults with intellectual disabilities *Journal of Developmental and Physical Disabilities*, 20, 41-51

intervention based on behavioural principles, informed by a functional analysis, may then be undertaken (NICE CG142, 2012; The Matrix, 2011).

3.10 Housing

- 3.10.1 In Renfrewshire, there are 19 places in specialist housing provided by the third sector for adults with high levels of need. One unit provides a shared environment for five individuals, two linked properties each provide a shared environment for four individuals, and one property provides six individual flats with a shared staff and secure garden area. These units have been designed to support people whose needs may preclude them from mainstream housing to live in the community as independently as possible.
- 3.10.2 Many of our service users live in mainstream accommodation, but some of which may have had minor adaptations carried out to help their particular condition, or the tenancy will be located in an area better suited to the individual's needs, As highlighted in section 2.6, it is recognised that there is a need to develop a broader range of housing options for individuals whose needs would not be appropriate for mainstream housing. It is therefore essential that close attention is paid to the design of accommodation so as to encourage social inclusion while also providing an environment to assist the staff team to promote opportunities for the individual to gain the level of independence of which they are capable
- 3.10.3 People identified with particular community care needs where housing is an important factor may be referred to the Community Care Panel, a joint Housing and Social Work panel which assesses the housing and support needs of people who need support to live in the community. Housing Support teams will also assist people with lower levels of need, and housing staff will work closely with colleagues in social work and health services to reduce risk to individuals and find housing solutions to problems.

3.11 Social and Leisure

- 3.11.1 The RLDS Flexi-care service plays a key role in addressing the social and leisure needs of young people and adults with learning disabilities, some of whom will have autism. It provides a wide range of opportunities to over 200 service users, including activity groups, befriending services and Going Places groups. The service is supported by its network of trained volunteers. The service is highly regarded, both within the community and nationally, and has received recognition including numerous awards for excellence.

3.11.2 Renfrewshire Leisure Ltd (RLL) has worked in close partnership with RLDS to create two purpose-built day services that are located entirely within the new On-X leisure facility in Linwood (Milldale) and the Lagoon in Paisley (The Mirin). Although RLL do not provide specific classes or activities for people with autism, it is clear that they make a considerable contribution to improving access to a range of healthy living activities and to assisting in the integration of people with autism into sports and leisure services. There are strong links between RLDS and Renfrewshire Leisure because of the collocated services at the Mirin and Milldale and RLL staff have undertaken training in supporting customers with learning disabilities and/or autism. A range of the activities provided daily are supported jointly by RLL and RLDS staff.

A Carer's View of the Flexicare Service

"Flexicare is like an oasis in our family's hectic week, my son can't wait to take part in the fun and activities. The activities are tailored to his needs and the staff team promote his strengths and encourage him into areas he finds difficult. The rest of the family get a few hours of peace and quiet and chance for a catch up".

3.12 Criminal Justice

3.12.1 Locally, criminal justice services are provided by Police Scotland, by Renfrewshire Council Criminal Justice Social Work Service, by the Scottish Court Service, and by the Scottish Prison Service.

3.12.2 As noted at section 2.8, there can be difficulties in identifying autism in people within the criminal justice system because they will often present with other issues. Staff do not currently receive specialist training to recognise behaviours associated with autism, which may be masked by mental health issues or substance misuse. Unless a service user who has received a diagnosis of autism chooses to share this with services (which they are not obliged to do), services may not be aware of their condition. Health services would normally require patient consent to share this information.

3.12.3 The Scottish Strategy for Autism makes reference to criminal justice in respect of the need to learn about current developments and ensuring the needs and wishes of those on the spectrum are taken into account in future programmes. The Keys to Life, however, dedicates a whole section to Criminal Justice and makes 5 recommendations aimed at greater recognition of the needs of people with learning disabilities within the system. Through this activity, it is likely that the issue of autism in the criminal justice system will receive greater recognition. A senior nurse from RLDS who is specially

trained in autism is currently seconded to the Scottish Prisons Service with a remit to identify and increase awareness of people with learning disabilities and/or autism in the prison population.

3.13 Carers

3.13.1 Where someone with autism relies on the support of a carer (usually a family member) it is important that the carer has access to support, advice and information and that they are involved in the planning of support for the person with autism.

3.13.2 Carers have the right to a carer's assessment and Renfrewshire offers a carers self-assessment as a means of determining carers needs in their own right. In a Renfrewshire Carers' Consultation Survey carried out to support the development of the Renfrewshire Autism strategy, 16% confirmed they had a carer support plan and a further 24% indicated they would like one.¹¹

3.13.3 As previously mentioned, respite or short breaks is a service which is frequently seen as essential to the continuation of family life and the ability of the family to continue in their caring role, as identified in section 2.9. Appropriate respite can be accessed via children and adult services on the basis of assessed need.

3.13.4 In addition to the statutory support provided to carers, there is an active local parents group, supported by the National Autistic Society (NAS), which provides social groups and peer support to parents and carers of people with autism. Renfrewshire also has a Carers Centre, based in Paisley, which acts as a one-stop shop for information, support and advice.

3.14 Areas for Development

3.14.1 In order to develop a fuller understanding of the population of people with autism in Renfrewshire, it has been identified that further work is required in the following areas:

- Mapping services and supports in Renfrewshire against The Scottish Strategy for Autism's Menu of Interventions (recommendation 10 – see appendix for details), including those commissioned through the independent and third sector.
- Gathering information on number of diagnoses of autism in childhood and comparison with national figures and expected prevalence.
- Services/supports for people with autism who do not have a learning disability, including support into employment and specialist housing provision

¹¹ Online survey carried out in 2013 to identify carer views on a range of issues related to autism services

- Scoping demand for autism services in older people to determine whether services are appropriate to their needs
- Consider options for developing a broader range of housing provisions to take account of the particular needs of people with autism
- Ensuring clear referral pathways for people diagnosed with autism in adulthood
- Awareness raising within the Criminal Justice system as to potential links between autism and offending, identifying appropriate interventions and ensuring support within the court and prison systems
- Ensure that services are prepared for the implementation of future legislation to support carers

Section 4: Identifying priorities in interventions and supports for people with autism

4.1 The provision of specific services for people with autism varies depending on eligibility criteria and assessed need. Legislation relating to education provision is clear as to the need for additional support for children with autism, and consequently schools in Renfrewshire provide support in mainstream schools and in Additional Support Needs (ASN) schools. Similarly, there are a number of specialist services within learning disability services for higher levels of need in the estimated 40% of people on the autism spectrum who also have a learning disability. There is greater variation in provision for those children and young people with a lower level of need. There are also challenges in identifying the population, particularly amongst adults who may never come into contact with statutory services.

Priority: Improving co-ordination between services and supports available to people in Renfrewshire with autism

4.2 Because of the wide range of needs of people with autism, there is no single agency which provides for all of these needs. The majority of provision is delivered by Renfrewshire Council Education and Leisure Services, Renfrewshire Learning Disability Services and the commissioned services provided by the third and independent sector in the form of supported accommodation or residential care. However, it is recognised that there are many other partners in Renfrewshire providing formal or informal support for people with autism and their carers.

4.3 In order to co-ordinate services and supports more effectively, to take forward the development of an overarching strategy for autism, and implement an action plan to address gaps in provision, it is proposed to establish a working group with a specific remit for autism. This group would also consider options for identifying a local 'lead' for autism. This will sit alongside Recommendation 3 of The Scottish Strategy for Autism which aims to 'explore the benefits of ASD lead officers' and 'establish how roll-out across Scotland might best be achieved'.

Recommendation 1: Establish an Autism Working Group to oversee service developments and take forward actions identified within the strategy.

Priority: Identifying the population and sharing information appropriately

4.4 Due to improved awareness, increasingly a diagnosis of autism is made during childhood, meaning that more children and young people are getting additional

support where required. However, there are likely to be significant numbers of people with autism, particularly adults, who are not in regular contact with statutory services. Having a clearer picture of the number of people affected by autism would support services in planning more effectively for the future, identifying gaps in provision and ensuring capacity in services is sufficient to meet needs.

- 4.5 In instances of higher-level need and/or co-morbidity, information sharing is increasingly not a barrier, particularly in services such as RLDS and the Adult Community Mental Health Team (CMHT) where services are provided on a joint team basis by Renfrewshire Council and Renfrewshire Community Health Partnership under a single management structure.
- 4.6 In instances of lower-level need, it is recognised that services may often lose contact with individuals once they leave the school system. Whilst this need not be a concern in many cases, as people with autism would not necessarily have an ongoing need for support, a lack of information could be an issue for those people who encounter future difficulties relating to their disorder where services are not aware of their diagnosis. This also makes it more difficult to plan and develop future services.

Recommendation 2: Improve data recording and information sharing in relation to autism and the Renfrewshire population, so that this information can inform future planning.

Priority: Diagnosis

- 4.7 The national picture shows that diagnosis of autism in children is improving. Pathways to assessment and diagnosis may be clearer for children because they are all involved with universal services and staff working with children have greater awareness of autistic traits. However, evidence indicates that the referral pathway for assessment of adults appears to be less well defined, particularly where there is an absence of co-morbidity and regular involvement with any statutory service.

Recommendation 3: Adult health and social care services should undertake a review of pathways to assessment and diagnosis to ensure processes are clear and information on pathways is more easily accessible.

Priority: Awareness raising and training

- 4.8 Raising awareness of the nature of autism and the impact it may have on individuals is a central factor in improving outcomes for people with autism.

Within Renfrewshire, there is specific training available for staff working directly with people with autism, but there is also a need for broader awareness-raising targeted at staff across a range of services who may come into contact with people who have autism, or show autistic traits, so that they and the agencies they represent can become better prepared to manage the care needs of people with autism.

- 4.9 It is therefore recommended that a two tier approach is taken to raising awareness and training. The first involves general awareness-raising, with the second level targeted at services which directly support people with autism.

Recommendation 4: Develop and implement an information strategy for autism, the first phase of which would focus on public and third sector agencies, with a second phase focusing on the general public.

Recommendation 5: Ensure practitioners across health, education, housing and social care services have a basic understanding of the nature of autism and have the opportunity to access further specialist training.

Priority: Transition planning

- 4.10 There is already a process in place for transition from Children's Services to Adult Services, with planning beginning two years before a child leaves school. For children with autism who are identified as requiring additional support, the transitional arrangements will ensure their care plans reflect their needs as adults. This will include access to appropriate staff from key services who will co-work the case and assess the ongoing needs for the person into adulthood. For children with autism aspiring to move into higher/further education or employment, it is recognised that further specialist provision is required to give them the types of support they need if they are to benefit from these resources.
- 4.11 Transition arrangements have tended to focus on children moving into adult services. However, it should also be recognised that there are adults with autism who are currently in receipt of services but who require to move into different services as their needs change. This may also apply to adults moving into older people services. The process therefore needs to consider future needs across the entire age range and not be confined to children into adult transitions.

Recommendation 6: Review the current transition arrangements between Children's Services and Adult Services to ensure they are effective, fit for purpose, and appropriate to the assessed needs of young people identified as being on the autistic spectrum and who will require ongoing support into adulthood.

Recommendation 7: Develop transition arrangements to support adults as they move through key life stages.

Priority: Educational Support

4.12 Renfrewshire Council has recently consulted on its policy on Additional Support for Learning and will present the findings in the second half of 2014. It is proposed that any specific recommendations in relation to autism should be made following the production of the revised policy.

Recommendation 8: Take into account the updated policy on Additional Support for Learning and work with key agencies, including Education and Leisure Services, health and social work, to develop specific actions on support for children and young people with autism.

Priority: Information services for people with autism and their families

4.13 Six areas in Scotland are piloting 'One-Stop-Shops' (OSS). These were created using additional funding made available at the launch in 2011 of the Scottish Strategy for Autism. OSS offer a single point of contact for information and advice relating to autism. They are currently being evaluated by the Scottish Government. Depending on the success of the pilot and the lessons learned, limited resources may be made available to roll-out the OSS model to other areas of Scotland. Renfrewshire currently has no access to an OSS so the prospect of a resource such as this becoming available would be attractive. Under the current pilot, it should be noted that each OSS covers more than one local authority area (e.g. one covers the whole of Ayrshire) and each OSS is managed by a Third Sector organisation.

Recommendation 9: Consider options for the provision of information services to people with autism and their families.

Priority: Planning, commissioning and models of service delivery

4.14 In the last three years, health and social care services across Scotland have been moving towards a strategic commissioning approach to service planning. This involves undertaking a needs assessment for the sector of the

population for which services are being planned, and putting in place long-term joint plans which are regularly reviewed. These long-term plans require to be undertaken in consultation with stakeholders and should reflect a focus on outcomes for service users, carers and the wider community. They should reflect the full spectrum of needs within Renfrewshire. Plans are currently in development for a number of care groups to produce a commissioning plan and this approach should be extended to include autism services in Renfrewshire. Long-term commissioning plans for care groups within Adult Services are expected to be completed by the end of 2014/15.

- 4.15 One of the benefits of a strategic commissioning approach is that the consultation and needs assessment may identify different models of service delivery, since the focus has shifted to be on the outcome achieved rather than simply putting a formal service in place that meets immediate needs. This is also the ethos behind self-directed support, which is now enshrined in social care legislation. In addition to supporting people with autism to direct their own support, agencies are being encouraged to look at alternative ways to provide services. This may include the development of shared services.
- 4.16 Also, as part of the above strategic commissioning approach, there is the need to address the particular care requirements of a very small number of people with autism and learning disabilities who require very high levels of care due to behaviour that can challenge services. Such cases tend to be extremely expensive. Renfrewshire is working alongside partners in other authorities and NHS as part of an initiative to develop a national framework agreement for procurement of specialist residential care. It is unlikely to be cost effective for any single local authority to develop such a service. However, there may be opportunities to jointly develop a service across authority boundaries.

Recommendation 10: Adopt an outcomes approach to the planning and delivery of services and supports based around identified needs of the service user, in consultation with service users and carers.

Recommendation 11: Investigate options for different models of service delivery including, for example, the possibility of developing shared services where this is both appropriate and cost-effective, and the potential to develop innovative practice.

**Appendix 1: Menu of Interventions (see Section 3)
A Guide to Interventions and supports for people on the autism spectrum**

ASD Challenge	Interventions (to include advice, therapeutic interventions and counselling)
1. Understanding the implications of an autism diagnosis	Post diagnostic discussion (s) and individualised counselling. The provision of good quality education and information packs for individuals, families/carers along with appropriate verbal discussion at time of need. Use of visual props if needed. Signposting to useful websites and forums.
2. Development of effective means of communication	Individualised language therapy assessment. Updated as required. Alternative and augmentative communication systems introduced where required. Work to ensure language system (regardless of form) is used functionally and is therefore effective on an individual basis. Teaching/learning on internet etiquette and supervision.
3. Social communication	Targeted social communication programmes delivered either individually or in a group setting as required and appropriate to the individual to include internet etiquette and promotion of online safety.
4. Developing and maintaining relationships	Work to assess the understanding of relationships and promotion of skills to develop relationships including sexuality issues and intimate relationships. Access to social groups, friendship circles etc.
5. Social isolation for individual with autism	Accessible social groups and opportunities, support in the community. Befrienders. Respect the need to be alone at times. Acceptance by families that friendships can take many forms.
6. Social isolation for family	Family/ Partner/ Carer support, opportunity for respite. Access to autism friendly environments
7. Learning to learn skills	A functional assessment of the person's cognitive abilities and learning style leading to a planned programme both directly with the individual and indirectly with the family, carers etc. Formal psychometric testing may be conducted if appropriate to inform intervention.
8. Predicting and managing change	Timely individual direct work with individuals to teach methods where required. Family/carers /employer guidance/education in these methods. Visual supports; timetables, timers, text alerts, choice boards etc to be used as appropriate.
9. Behaviour and emotional regulation protecting wellbeing	Knowledge development in understanding behaviour in the context of ASD. Individual work with the individual on assessing behaviour, recognising triggers and developing and managing the implementation of strategies to help. Behaviour support plans, cognitive interventions, psychotherapy or counselling as required and indicated by life circumstances e.g. around transitions of all types including bereavement. Work with the individual's family/carers, criminal justice, social work, Police as appropriate. Autism Alert card possession.

10. Restricted and repetitive interests and behaviours	Assessment and positive day to day management on an individualised basis. Treatment by mental health clinician if required.
11. Motivation issues	Structured programmes as appropriate to the individual linking to the other core challenges as required. Career guidance, employer/HE/FE support.
12. Sensory issues	Assessment of sensory difficulties. Identification and implementation of strategies. Environmental adaptation on an individual basis with individual control working towards reducing the impact of sensory sensitivities.
13. Daily living skills	Assessment of core life skills as required across the lifespan and to take account of changing needs at various transitions. Specific individual programmes to teach and maintain these skills where needed. Involvement of families/carers in assessment and Implementation of new learning. Education for families/employers/ care providers/housing dept re practical needs.
14. Co existing conditions- examples	epilepsy, dyspraxia, dyslexia, disorders of attention, sensory impairment, anxiety, sleep disorder, addiction, anger management, depression, self harm, psychosis, personality disorder, OCD, disordered eating patterns etc. These require assessment and treatment/management by appropriate specialist clinician. Joint working is crucial across specialities with a clear case co-ordinating lead identified.