

Falkirk Autism Strategy

2013-2023



Autism impacts on the whole life experience of people and their families; they need to be supported by a wide range of services such as social care, education, housing, employment and other community based services. A holistic, joined-up approach is necessary.

Scottish Strategy for Autism, Scottish Government 2011

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Foreword

Falkirk's vision is that through each stage of life, and in particular during periods of transition, every individual with Autism in Falkirk will have access to services and supports which provide them with the opportunities necessary for them to fulfil their potential.

This Strategy sets out how we will work towards this ultimate goal. Our methods and approach are guided by our core values of Partnership, Performance and Public Service, and our aims and ambitions for Falkirk (as stated in the Falkirk Council Corporate Plan 2013-16):

- Further developing a thriving, sustainable and vibrant economy;
- Continuing to improve the health, safety and wellbeing of our citizens and communities;
- Increasing our efforts to tackle disadvantage and discrimination in all its forms; and
- Enhancing and sustaining an environment in which people want to live and visit.

In preparing this 10 year Strategy we spoke with parents and carers, professionals and service providers, both about the positive work already taking place in Falkirk, and the areas they feel are a priority, both for service improvements and further service development. These consultation findings have assisted us in setting our local priorities, which also align clearly with the goals of our Community Planning Partnership.

We are very grateful to everyone who has contributed to the consultation. As we work towards improving pathways, services, and supports, and ultimately outcomes for people with autism, we will continue to do this on a multi-agency basis alongside families and service users. It is our intention to continue the conversations already started about service development and re-design using the Public Social Partnership approach which has facilitated our work to date.

Falkirk Community Planning Partnership

September 2013

1 Introduction

1.1 Autism Spectrum Disorders

- 1.1.1 Autism Spectrum Disorder (ASD) is a lifelong developmental disability that affects how a person communicates with and relates to other people. For the purpose of this document, the term ASD encompasses the whole spectrum of conditions, including, Asperger's Syndrome and high functioning autism. ASD can impact on people in very different ways, although people with ASD will experience difficulties in three main areas – see 9. *What is Autism?* on page 20

1.2 Strategy Development

- 1.2.1 Fundamental to the development of the Falkirk Autism Strategy has been the desire to improve the experiences of those with ASD. As such, it reflects the hopes and concerns, experiences and ideas of families and professionals working in the field, gathered over the past year, in particular through a series of consultation workshops (see 8. Engagement on page 18). We will continue to work together using this multi-agency approach.
- 1.2.2 The strategy goals align with other key strategies and plans, such as Falkirk Council's Corporate Plan 2013-2016 and our practice and approach is guided by the values and principles underpinning Getting it Right For Every Child (GIRFEC), The Curriculum for Excellence and 'The Same As You' (see 10. *Law and Policy Drivers* on page 23 for more information). Our goals also reflect many of those highlighted in the Scottish Government's Autism Strategy, including; a clear focus on the person with autism, the life journey, the care pathway, access to information, services and support, and involving children and adults with autism, parents, carers and families.

1.3 Overall Goals

- 1.3.1 Over the life of this Strategy, our goals are that:
- a Children and adults with Autism Spectrum Disorders are empowered to become Effective Contributors, Successful Learners, Confident Individuals and Responsible Citizens within an inclusive society
 - b Families are empowered to support, promote and encourage the development and well-being of children and adults with ASD;
 - c Parents and carers are supported to value and maintain their own wellbeing in the caring role;
 - d Services and agencies work together in partnership to provide seamless services and support for children and adults with ASD in their life journey.

1.3.2 We will do this by:

- a Actively empowering parents through a strategic approach to parenting support;
- b Ensuring Autism Friendly approaches are integral to mainstream and universal services;¹
- c Ensuring individual and family needs are assessed within a staged approach to assessment and intervention;
- d Ensuring that individual bespoke packages are offered where children and adults require this;
- e Enabling and ensuring that partners work together at all levels, from the strategic and managerial to the practitioner level, to ensure that the experience of children and adults is positive, promotes resilience and fosters independence through their life journey.

1.4 Goals within Two Years

1.4.1 For the first two years our Autism Strategy has six key goals:

- i To fully embed the values, principles and practices of Getting it Right for Every Child (GIRFEC) and The Same As You (SAY) in our work with all families ensuring that practice is inclusive for children and adults with ASD;
- ii To provide learning and development opportunities for both children's and adult workforces, raising awareness and promoting Autism Friendly practice that links directly to service improvements;
- iii To seek to empower parents and families so that they can make decisions about the support they are offered;
- iv To ensure that assessment and diagnosis:
 - a is centred on the service user and in partnership with parents and carers
 - b initiates within universal and mainstream services
 - c is coordinated, in multi-agency pathways for assessment and diagnosis consistent with SIGN guidelines;
- v To ensure that individual needs are identified through universal assessment approaches, with an emphasis on generic additional provision being able to effectively support children and adults with autism;
- vi To ensure that specialist services continue to develop effective practice and disseminate this practice to partners and services.

1.5 Goals within Five Years

1.5.1 Within 5 years the Strategy goals are:

- i to incorporate learning from the GIRFEC approach into adult oriented services;
- ii to make available learning and development opportunities in more specialised practice areas to staff working within universal services;
- iii to ensure that adult and children's services are more coordinated in their approach, thus supporting those affected by ASD throughout their life journey.

¹Autism friendly means being aware and sensitive to the social and environmental factors that can affect people with ASD, and modifying methods of communication and physical space to better suit the needs and strengths of the individual.

1.6 Leading the Strategy

- 1.6.1 It will be the responsibility of the Multi-Agency Autism Strategy Group to ensure the implementation and review of the strategy. The Group will report to Falkirk Children's Commission and the Community Planning Partnership (SG, R1) as well as to Directors and Chief Officers of the respective agencies and services involved.
- 1.6.2 The purpose of the group is to develop co-ordinated services for those with ASD and to steer the implementation of the strategy, by setting clear project milestones. Its scope will include:
- a identifying and addressing gaps in current services;
 - b Fostering interagency cooperation to improve the experience for service users;
 - c Recommending, where required, the commissioning of new services and supports, in partnership with children, young people and adults with ASD, parents, carers and families;
 - d Making recommendations in relation to creative approaches to commissioning.
- 1.6.3 This will ensure that the needs of children and adults with autistic spectrum disorder are considered fully within the complete range of the service delivery across agencies and services in Falkirk.
- 1.6.4 To support a continuing improvement approach, the Autism Strategy Group will monitor and regularly evaluate progress towards our goals.

1.7 A Life-long Challenge

2.1.1 People with ASD experience challenges throughout their lives, and there is therefore a need for sensitive support from diagnosis onwards to minimise stress. Particular periods of change present additional challenges, such as the move into formal education, transition into adulthood and change related to loss of carer support in later life. Evidence-based practice has already identified elements of good practice for promoting effective transitions for this population, which are also found to have positive effects on the experiences of the wider population.

2.1.2 While a key driver is to ensure that the needs of children and adults are well catered for within universal and targeted approaches to transition there is a specific requirement to consider in more detail the needs of those with ASD as transitions can be particularly challenging and stressful for both the individuals and their parents, carers and families.

1.8 Care Pathway

2.2.1 The care pathway describes the process of referral, assessment, diagnosis and subsequent provision of services and supports tailored to the needs of the child, young person or adult with autism.

2.2.2 Assessment and diagnosis may happen at any stage of life, although with improvements supported by greater understanding of the spectrum of conditions, more children and young people are being diagnosed at an early stage. Timely referral for specialist assessment and diagnosis, and access to appropriate supports in universal as well as specialist services are all known to have a positive impact on the life chances and outcomes for people with ASD.

2.2.3 Parents, professionals and agencies identified transitions as a key area in the discussions leading to this strategy, and this is reflected in the Strategy goals, which seek to provide smooth and seamless provision through the life journey.

3 What is Working Well

3.1 Building on Success

- 3.1.1 Falkirk has an established track record of multi-agency work, and the development of new and innovative approaches. CVS Falkirk and District (the umbrella body supporting, developing and representing the interests of the third sector), is routinely involved in service planning and delivery, and the Public Social Partnership approach, piloted and subsequently adopted in Falkirk, means that services are developed and delivered in partnership with agencies and service users. The principles of the Partnership approach have been applied in the work to develop this strategy, and this is the framework for taking the work forward. This provides a strong foundation for continuing to meet the needs of children and adults with ASD through provision in universal and specialist services.
- 3.1.2 There are already in existence a wide variety of services for those affected by autism and increasing willingness to co-ordinate and develop more seamless delivery of services.
- 3.1.3 Where there has been identified good practice this has been built on and disseminated.

3.2 Effective Practice, Example 1: Additional Support Needs Base

- 3.2.1 The Additional Support Needs (ASN) base in Grangemouth High School was established in 2007 in response to an identified need for specialist education provision for a growing number of secondary age pupils. The ASN base complements provision of specialist education in Denny High School in the Northfield base, which provides education for up to 18 children with language and communication difficulties and in particular children with ASD. The children have tailored programmes to suit their individual needs with a high level of support from staff. As a result many more children are able to enjoy their education within Falkirk, which in turn allows them to enjoy positive post-school destinations.
- 3.2.2 Good practice was in evidence due to the planned and coordinated nature of creating the provision, anticipating need and creating a resource to meet the need. It is part of a continuum of education provision, supporting children with ASD in mainstream through to more specialist provision.

3.3 Effective Practice, Example 2: Autism ‘Handy Hints’ leaflets

- 3.3.1 This series of leaflets were developed by the Social Work Paediatric Occupational Therapy service in response to an identified information gap. The leaflets offer practical ideas to parents and carers on managing a child or young adult with ASD or sensory issues. The leaflets, available in hard copy and on the Council Website (see *11. References and Resources* on page 25), have attracted national and international interest. It has been

suggested that there may be no other such resource available. Feedback from professionals in the field and from parents is outstandingly positive and has led to an international link which is contributing to developing a modern social work service in eastern Asia.

3.4 Effective Practice, Example 3: Activity Scheme

- 3.4.1 The Summer and Easter Activity Schemes provides opportunities for young people with a wide variety of disabilities to access main stream provision with the support of an Activity Worker. Children and young people are able to participate in 'normal' activities. Families receive a break from caring and the scheme also assists young adults with transition issues such as individual travel, making choices and keeping safe. In response to need, a specific Autism Group has been established for those with the most complex autistic needs. Feedback from families and young people is extremely positive and has contributed to the development of the Scheme, and helped to avoid young people being accommodated. The scheme has also recently begun exploring ways of developing new technology to increase independence including piloting the use of iPads in gaining the views of young people including those with ASD.

3.5 Effective Practice, Example 4: Person Centred Transition

- 3.5.1 Using the PSP approach to inclusive planning and commissioning, multi-disciplinary adult services from social work and health worked with families, service users and care providers to successfully support four young men with complex ASD to make the transition into their new homes in the Falkirk area. Two of these young men had lived out of area in autism specific residential schools since children and two of the young men had spent years as inpatients in an assessment and treatment hospital. Person Centred Planning was a key element to 'getting it right' and developing a model of support uniquely tailored to individual need whilst ensuring the strengths and gifts of each young man were acknowledged and built upon to develop independence and capacity for growth. Assistive technology has been integral to supporting this and continues to be a positive experience for the young men using it.

3.6 Effective Practice, Example 5: Training

- 3.6.1 In 2012-13, Educational Psychologists delivered 6 different training programs on Autistic Spectrum Disorders, ranging from twilight/awareness-raising to an 8 week module with teachers developing practice in schools delivered by a multi-agency team. They were identified through needs analysis for the audience and indicated positive evaluation
- 3.6.2 The progression of learning and development for professionals on Autism will be considered within the wider frameworks of professional learning and development for Forth Valley.

3.6.3 Throughout the work to develop our Autism Strategy and begin to plan the re-design of services and provision, several areas for improvement have been identified. These broadly align with national gaps and areas for improvement

4 Areas for Further Development

4.1 Transition Planning

- 4.1.1 Families and carers identified transitions as particularly challenging. While the transition into adulthood holds particular challenges due to the move from children's services, where it is perceived that a wider range of supports are available, other transitions were also identified as resulting in stress and anxiety for both carers and service users; for example, the move from pre-school to primary school, and the move from primary to secondary school, and the move into the world of work.
- 4.1.2 Parents and carers, professionals and service providers all identified the need to better anticipate and support transitions. While there are examples of good transition practice such as the Daldorch project (*see 3.5. Person centred*, page 7) our current planning and practices need attention if we are to achieve more consistency in anticipating, planning for and supporting individuals, families, parents and carers through periods of transition, which by their very nature require change and adaptation.
- 4.1.3 The same attention is required to practice around unexpected or unanticipated changes, such as when a sudden onset of poor health on the part of a parent or carer affects their ability to maintain their caring role. At these times acting in a timely and coordinated way to reassess needs and put supports in place is vital.
- 4.1.4 In essence any change is difficult for those affected by ASD and services and professionals need to be particularly sensitive and responsive at such times. In particular, families and carers identified the lack of training and work opportunities and of tracking of adults once they leave the post school college phase. The move on from relationships with staff in children and families services and the need to develop relationships with new individual, agencies and professionals is recognised.
- 4.1.5 Many of these transitions can be planned for and key to successful transition is well planned and prepared-for moves, involving all appropriate individuals and agencies.

4.2 Assessment and Diagnosis

- 4.2.1 There is a widely held view among parents and carers - shared by some professionals - that having a diagnosis opens up access to services that are otherwise not available. During the consultation process, parents and carers were particularly keen that services were developed in line with assessed need, rather than diagnosis.
- 4.2.2 Early, effective and knowledge-based assessment is vital, as are regular updated assessments as individuals' journey through life. This area and how it might be taken forward will be explored in more depth within the Public Social Partnership process.

4.3 Early Support for Parents

- 4.3.1 Parents of children diagnosed with ASD highlighted the need for early support from a key professional with whom they could develop a good relationship. This concept of a key worker/named person was reflected by both parents of children and adult carers as crucial to how well supported they felt, and to their capacity to manage the challenging stages of life, development and transition. Where such a relationship was in place, the journey and parental capacity was improved; where it was not, the journey was difficult and stressful.

4.4 Information

- 4.4.1 Parents highlighted the need for information to be provided in a variety of forms and repeated at different stages. Good and easy to access information is important to families and those affected by ASD. It is recognised that currently there is no coordinated and easily accessible information locally within Falkirk, though systems are being developed e.g. the Family Information Service which could provide a framework for an information base.
- 4.4.2 Improved information (SG, R10) about local services for people with ASD, parents, carers, and families, is required. Within this, clear information can be included on the processes and expected timescales from referral, assessment and diagnosis, including points of possible delays, for people with autism, parents, carers and families. In relation to this we look forward to the results of the national mapping exercise conducted by the Scottish Government, which will provide a sound beginning for this work.

4.5 The More Able

- 4.5.1 Falkirk recognises that there are limited specialist services and support available for adults with ASD and that young adults can often fall below the criteria for accessing services if they do not have a learning disability. This has been highlighted in a number of areas and professions, and is a key area for further work both locally and nationally.

4.6 Parents, Carers and Families

- 4.6.1 Families vary in their ability to manage trauma and cope with other challenges. Universal and targeted services have a key role to play in building capacity among families and individuals with ASD, helping to sustain children and adults with ASD as well as vital family/support systems in the community. Sometimes parents are themselves undiagnosed and this can complicate communications, managing expectations and responding appropriately to circumstances. Building capacity through support, training and increased awareness is essential.

4.7 Learning and Development

- 4.7.1 Training and development of the Children's and Adult workforce is a vital element in building the capacity and confidence of professionals and staff in both mainstream and universal services. Some excellent work is already being done, and we will look to extend awareness-raising, Autism Friendly training, and to develop further specialist training for practitioners working in ASD services, and in doing so continue to improve service delivery. Key to this is developing the use of Person centred planning to support holistic outcomes and build capacity.

4.8 Communication

- 4.8.1 Effective communication is a vital element in multi-agency working. Poor information exchange and coordination between professionals, and lack of clarity about roles and responsibilities, can have a negative impact on both timely access to the care pathway, services and support, and on the experience of children and adults with ASD, and parents, carers and families.
- 4.8.2 Sensitivity around communication should extend to careful consideration of the needs of parents and carers, children and adults with ASD in formal settings such as meetings. These can be daunting, particularly where there are many attendees.

4.9 Wider Developments

- 4.9.1 We will follow with interest the Scottish Government's proposed:
- i Discussion (SG, R3) around identifying ASD lead officers, and any proposals and guidance for rollout across Scotland;
 - ii Review of the current Scottish Intercollegiate Guidelines Network (SIGN²) guidance for children, and in particular how any revised guidelines can be used to improve services and support for adults with Autism in Falkirk;
 - iii Discussions (SG, R23) in relation to diagnostic processes for adults and children, with particular reference to any implications for practice, pathways, including any review of the quality diagnostic standard (SG, R25);
 - iv National waiting lists assessment (SG, R21), to better understand the nature of delays, to provide some form of baseline against which to measure progress towards more timely assessment and access to diagnostic services in the Falkirk area, and to draw on any revised guidance.

²Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders: A national clinical guideline (1998) Scottish Intercollegiate Guidelines Network (SIGN) <http://www.sign.ac.uk/pdf/sign98.pdf>

4.10 Self Directed Support

- 4.10.1 Falkirk has embraced Self-Directed Support and is actively preparing for the implementation of the new legislation in both adult and children's services. The opportunity to build on family and individual strengths and provide tailored support in line with assessed need and in accordance with the priorities and wishes of families and individuals fits well with the areas identified by parents, carers and professionals we consulted. Current pilots in children's and adult services include those affected by ASD and will inform work to take forward this strategy.

5 Conclusions

- 5.1.1 Ultimately, the goals we set out in this Strategy are all intended to better support the life journey of people with ASD, in order that:
- i People with ASD experience seamless support throughout their lives, and in particular through periods of transition and change;
 - ii Through a whole family approach we support and sustain parents, carers and families;
 - iii Targeted, coordinated and effective multi-agency service delivery meet the needs of people with ASD in Falkirk throughout their lives;
 - iv Local authority and partner agency procedures and plans work together to provide seamless support through important life stages and transitions;
 - v Existing local multi-agency assessment pathways operate smoothly for all age groups and stages, improving access and experience for people with ASD in both specialist and universal services.
- 5.1.2 Falkirk's Autism Strategy will, over the next 10 years, provide the structure and focus to take forward these goals building on existing good practice, learning from new research and the views and feedback from those affected by ASD.
- 5.1.3 This plan will be developed and regularly reviewed, feeding back into the Community Planning Partnership, and the principles of PSP will continue to underpin our work and ensure the involvement of service users, families and key agencies and stakeholders.

6 Scottish Government Strategy for Autism

6.1 The Ten Year Plan

Foundations; 2 year goals	Whole Life Journey; 5 year goals	Holistic, Personalised Approaches, 10 year goals
<ol style="list-style-type: none"> 1. Access to mainstream services where these are appropriate to meet individual needs. 2. Access to services which understand and are able to meet the needs of people specifically related to their autism. 3. Removal of short-term barriers such as unaddressed diagnoses and delayed intervention. 4. Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis). 5. Implementation of existing commissioning guidelines by local authorities, the NHS, and other relevant service providers. 	<ol style="list-style-type: none"> 1. Integrated service provision across the lifespan to address the multi-dimensional aspects of autism. 2. People with ASD have access to appropriate transition planning across the lifespan. 3. Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas. 4. Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism. 	<ol style="list-style-type: none"> 1. Meaningful partnership between central and local government and the independent sector. 2. Creative and collaborative use of service budgets to meet individual need (irrespective of what the entry route to the system is). 3. Access to appropriate assessment of needs throughout life. 4. Access to consistent levels of appropriate support across the lifespan including into older age.

6.2 Best Practice Indicators

1. An Autism Strategy, developed in partnership with PSP, people with ASD and professionals and incorporated in key policies and plans, reflects local needs;
2. Training and development informs staff and improves understanding amongst professionals about ASD;
3. Easy access to useful, practical information about ASD, local services and local action improves communication for all stakeholders;
4. ASD Training Plan improves knowledge and skills of those who work with people who have ASD, ensuring support by properly trained staff;
5. Data collection and reporting improves local knowledge of how many people with ASD are receiving services, and informs service planning;
6. A multi-agency care pathway for assessment, diagnosis and intervention removes barriers and improves the support for people with ASD;
7. A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement;
8. Effective, coordinated, multi-agency service delivery demonstrably meets the needs of people with ASD;
9. Multi-agency procedures and plans support individuals through major transitions at each important life-stage;
10. A self-evaluation framework ensures best practice implementation and monitoring.

7 Falkirk Autism Strategy: High Level Plan

Theme	Intentions and actions
7.1 Foundations <i>Targets for August 2015</i> <p>Our focus in this phase of activity is on improving access to and the experience of mainstream services and care pathways by addressing delays, improving post-diagnostic support, and raising workforce awareness of ASD and Autism Friendly practice.</p> <p>Working with the PSP approach, we will look to develop improved services to better respond to the individual needs of children and adults with ASD and their families and carers.</p>	
Values, principles and child-centred practices	<p>Implement the Named Person role as detailed in the Children and Young People (Scotland) Bill.</p> <p>Align the Pre-Five Community Assessment Team (PREFCAT) process with GIRFEC.</p> <p>Review existing children and young person's multi-agency framework for assessment and diagnosis of ASD.</p>
The care pathway, services and support	<p>Analyse the current pathway for assessment and diagnosis in adult services and formulate appropriate actions to streamline this.</p> <p>Engage Adult Service Providers to explore the post-diagnostic support currently available and identify future developments.</p> <p>Analyse and evaluate the range of provision currently available within the area using the mapping exercise and existing consultation outcomes.</p> <p>Develop a Service Menu to provide information on services providing post-diagnostic support in the Falkirk area.</p>
Empowering parents and families	<p>Pilot and embed the Early Bird training³ and approach into Falkirk's menu of support.</p> <p>Pilot self-directed support approach with families affected by autism and analyse the outcomes.</p>
Training and development	<p>Provide Autism Awareness training and signposting information for universal children's and adult service providers.</p> <p>Provide targeted, specialist ASD training for Health Visitors and education staff to improve early monitoring and detection.</p> <p>Ensure that Named Persons have an appropriate level of training and understanding of ASD and approaches, and knowledge of the services and support available to equip them for the role.</p> <p>Share and promote good practice across the partners and services they provide.</p>
Autism Strategy Group Commissioning, Partnership	<p>Continue to use the PSP approach and principles in developing services to individuals and families affected by autism.</p>

³ EarlyBird is for parents whose child has received a diagnosis of an autism spectrum disorder (ASD) and is of pre-school age (not yet of statutory school age). The programme aims to support parents in the period between diagnosis and school placement, empowering and helping them facilitate their child's social communication and appropriate behaviour in their natural environment. It also helps parents to establish good practice in handling their child at an early age, so as to pre-empt the development of inappropriate behaviours.
<http://www.autism.org.uk/our-services/residential-community-and-social-support/parent-and-family-training-and-support/early-intervention-training/earlybird.aspx>

Theme	Intentions and actions
7.2 Whole Life Journey <i>Targets for August 2018</i> Building on foundation work, our intention is to properly incorporate the values, principles and practice which underpin GIRFEC, SAY and the Curriculum for Excellence (CFE) capacities into all services, extending co-ordination of multi-agency service delivery for children and adults with ASD, and providing more specialised training to build capacity in mainstream and universal services	
Values, principles and child-centred practices	Increase personalisation for people with ASD using policy frameworks for adults and children, including GIRFEC, SAY and CFE capacities, person centred planning, and self directed support, <i>providing a seamless journey through services</i> . Integrate the 'One Person; One Plan' principle into all services, ensuring Plans are individualised and person centred.
The care pathway, services and support	Embed the one-stop approach into planning and resource allocation. Establish and map all existing processes at all stages and formulate appropriate actions to streamline these. Develop a post-diagnostic support model integrating into this the one-stop shop approach. Look at the development of an adult multi-agency assessment and diagnostic pathway.
Good practice Training and Development	Extend availability of specialist learning and development opportunities to staff in universal services. Seek examples of good practice and promote these through guidance and Continuing Professional Development with Falkirk Council, NHS Forth Valley, voluntary sector agencies and other relevant stakeholders.
Strategy oversight Service development and design	Maintain the Autism Strategy Group. Continue to use the PSP approach and principles in developing services to individuals and families affected by ASD.
Theme	Intentions and actions
7.3 Holistic, Personalised Approaches <i>Targets for August 2023</i> 10 years from now, we hope to be in a position to confidently say that children and adults with ASD in Falkirk feel empowered and included, that families, parents and carers are able to both promote and support the wellbeing of those they care for, and are themselves supported and cared for as carers. Underpinning all of this, service provision provides seamless support throughout the life journey	
Children and Adults with Autism Spectrum Disorders	Review and maintain the focus on the life journey and wellbeing outcomes for children, young people and adults. Look at the development of an adult multi-agency assessment and diagnostic pathway.
Creative solutions	Embed the one-stop approach into planning and resource allocation. Within the Integrated Children's Services Plan and the Health and Social Care Integration agenda, maximise opportunities to restructure budgets to meet the needs of all individuals requiring additional support.
Needs-led Assessment	Falkirk Integrated Assessment Framework's principles and adult single assessment principles should be reviewed and honed and considered for application across the lifespan, including older people.
Parents and Carers	Parents, carers and families, to sustain their own health and wellbeing, are supported and enabled to care for themselves.

Appendices

There are four appendices:

1. Engagement
2. What is Autism?
3. Law and Policy Drivers
4. References and Resources

8 Engagement

8.1 Consultation

- 8.1.1 The hopes and the concerns of parents, carers, professionals and service providers in Falkirk, which feature throughout this Strategy document, bear striking similarities to the issues highlighted in the various other sources we have considered in preparing our strategy, and in particular those issues identified in the Scottish Strategy for Autism (Scottish Government, 2011).

8.2 What we did

- 8.2.1 The Autism Group co-ordinated a series of consultation and service design conversation⁴ events in 2012 involving groups of parents and carers, professionals and service providers, as well as a joint session at which the stakeholder groups came together. Using a variety of methods to encourage participation, we asked five questions:
- i What is working well in Falkirk?
 - ii What is missing?
 - iii Where are we getting it right for people?
 - iv What key questions do you want posed to commissioners and planners?
 - v How would you like to be involved in the Public Social Partnership (PSP) approach going forward?
- 8.2.2 The sessions, with good levels of interaction and high levels of interest in being involved in the process, were very positive. People appreciated the opportunity to spend time together, to hear other perspectives and to reaffirm a commitment to getting it right for children, young people and adults with ASD in Falkirk.
- 8.2.3 The success of this Strategy will depend on the continuing participation of those parents and carers who expressed an interest in maintaining some involvement, and on engaging people with ASD, advocacy and community groups.

8.3 What we found

- 8.3.1 **Parents** and carers tell us they want⁵:
- i To carry on the conversation around the design and development of services that better meet the needs of and build on the strengths and assets of children, young people and adults with autism, parents, carers and families;
 - ii To be kept informed through feedback from this and other meetings;
 - iii People with autism to be involved in the Public Social Partnership and the next stage of the process going forward;
 - iv For other agencies e.g. third sector, the police, to be part of the design conversation.

⁴Falkirk Autism Strategy Development Service Design Group, Notes of Meeting, 25th April 2012

⁵Falkirk Autism Strategy Development Service Design Group, Notes of Meeting, 25th April 2012

- 8.3.2 Professionals and service providers tell us they want⁶:
- i To turn discussion into actions;
 - ii To involve parents who have a key role to play in helping to shape what we do;
 - iii To support children and families, building their resilience and capacity;
 - iv To use the resources we have at our disposal more effectively.

8.3.3 Partners in the development of the Strategy

- NHS Forth Valley (including CAMHS, adult psychiatry, SALT, HVs, School Nurses, Paediatrician);
- Falkirk Council Social Work Services (Children and Families and Community Care);
- Falkirk Council Education Services (including Educational Psychology);
- Skills Development Scotland;
- CVS Falkirk and District.

8.4 Autism Strategy Group, 2011-13

- 8.4.1 The Strategy group was initially led by the Change Co-coordinator, who was employed by CVS Falkirk and District on behalf of the Council. This ensured that all relevant people were involved in the development, and provided opportunity for challenge and debate.

- 8.4.2 Consequently, there has been involvement of professionals from adult and children's services within Falkirk Council (social work, education, and educational psychology), NHS Forth Valley (including psychiatric service, speech and language services and paediatric services) and the third sector. Combined with the involvement of parents and carers this has produced a wide variety of material to develop the strategy and a commitment to continue development in an inclusive manner.

⁶Falkirk Autism Strategy: Building a New Approach to Service Design and Commissioning Professionals Engagement Event, 3rd May 2012.

9 What is Autism?⁷

9.1 Definitions

9.1.1 The contents of the Autism section are drawn from three website sources, namely:

- 1 www.scottishautism.org/about-autism/what-is-autism/autism-diagnosis
- 2 www.autisminitiatives.org/about-autism
- 3 www.autism.org.uk/living-with-autism.aspx

9.1.2 Autism Spectrum Disorder (ASD) is a lifelong developmental disability that affects how a person communicates with and relates to other people. For the purpose of this document, the term ASD encompasses the whole spectrum of conditions, including, Asperger's Syndrome and High Functioning Autism. ASD can impact on people in very different ways, although people with ASD will experience difficulties in 3 main areas:

- i Social Communication – verbal and nonverbal communication skills;
- ii Social Interaction – being able to engage with the social world appropriately and establish and maintain relationships with people;
- iii Social Imagination – This is the ability to predict another's thoughts, feelings, behaviour or intentions when these are not in line with routine.

9.1.3 People with ASD can also have restricted and repetitive interests and sensory sensitivities. A person with ASD may have other conditions, affecting their level of functioning. For example: Attention-Deficit Hyperactivity Disorder (ADHD), a learning disability or mental health difficulties.

9.1.4 People with ASD can have difficulties with both verbal and non-verbal language. For example, many people with autism have a very literal understanding of language, and may think people mean *exactly what they say*. They may find it difficult to use or understand:

- body language, including facial expressions;
- tone of voice;
- Jokes and sarcasm.

9.1.5 Some people with ASD may have fairly limited speech that may feature the use of learned or echoed words and phrases, with varying degrees of relevance to the context. Some people with autism may not speak. They will usually understand what other people say to them, but prefer to use alternative means of communication themselves; sign language, visual symbols, such as pictures, photos, or signs to let people know what they want to say. Others will have good language skills, but may still find it hard to understand the give-and-take nature of conversations.

⁷The contents of the Autism section are drawn from three website sources, namely:
www.scottishautism.org/about-autism/what-is-autism/autism-diagnosis
www.autisminitiatives.org/about-autism
www.autism.org.uk/living-with-autism.aspx

- 9.1.6 Some people with autism may have limited motivation to initiate and sustain conversation, while others may have a strong desire to verbally interact although interaction may focus on restricted interests. Some individuals may dominate a conversation that might include *'diverting back to their preferred topic'*.
- 9.1.7 People with autism often have difficulty recognising or understanding other people's emotions and feelings, and expressing their own, which can make it more difficult for them to fit in socially. People with autism may not understand the unwritten social rules which most of us pick up over time, often with little or no conscious thought. A person with autism may stand too close to another person for their comfort, or start what may seem an inappropriate subject of conversation. Difficulties with social interaction can mean that people with ASD find it hard to form friendships.
- 9.1.8 Social imagination allows us to understand and predict other people's behaviour, make sense of abstract ideas, and to imagine situations outside our immediate daily routine. Difficulties with social imagination mean that people with autism find it hard to understand and interpret other people's thoughts, feelings and actions, or cope with new or unfamiliar situations. These difficulties should not however be confused with a lack of imagination, as many people with autism are noted for their creative talents.
- 9.1.9 People with autism have said that the world, to them, seems like a mass of people, places and events which they struggle to make sense of, and this can cause considerable anxiety for some. In particular, understanding and relating to other people, and taking part in everyday family and social life may be harder for them.
- 9.1.10 It can be hard to create awareness of autism as people with the condition do not 'look' disabled: parents of children with ASD often say that other people simply think their child is naughty; while adults often find that they are misunderstood.
- 9.1.11 People with autism may experience some form of sensory sensitivity in one or more of the five senses of sight, sound, smell, touch and taste. Senses are either intensified (hyper-sensitive) or else reduced in intensity (hypo-sensitive). While some individuals may be able to describe the issues that result from hyper or hypo-sensitivity to sensory input, many others cannot clearly articulate their experiences. Sometimes, reactions to sensory input may be interpreted as 'difficult' or 'challenging' behaviour.
- 9.1.12 The world can seem a very unpredictable and confusing place to people with autism, who often prefer to have a fixed **daily routine** so that they know what is going to happen every day, for example travelling to and from school or work by the exact-same route, or eating exactly the same food for breakfast. **Rules** can also be important: it may be difficult for a person with autism to take a different approach to something once they have been taught the '**right**' way to do it.

- 9.1.13 Many people with autism have intense special interests, often from a fairly young age. These can change over time or be lifelong, and can be anything from art or music, to trains or computers. Some people with autism may eventually be able to work or study in related areas. For others, it will remain a hobby.

9.2 The Prevalence

- 9.2.1 There is a lack of accurate information on the number of people with an Autism Spectrum Disorder, or indeed clear information on the number of people currently in contact with services, either locally within the Falkirk area, or nationally.
- 9.2.2 People of any nationality, race, culture, faith or social background can have autism.
- 9.2.3 Based on recent studies, the Scottish Strategy for Autism, 2011 estimates that around **1 in 100 of the population** has a condition on the autistic spectrum; with a ratio of 4-1 male to female, although it should be noted that studies suggest an under-diagnosis among females.
- 9.2.4 The Falkirk population stood at 156,800⁸ in August 2013. Applying the '1 in 100' statistic suggests that some 1,568 individuals (children, young people and adults) in the Falkirk area have ASD.
- 9.2.5 Studies indicate that somewhere between 44% and 52% of people with autism have a learning disability, and around one in three people with a learning disability has an autistic spectrum condition. However, these are only estimates. Without accurate information it is difficult to properly assess the scale of local need, or to deliver or design services to meet those needs.
- 9.2.6 Improving data gathering, analysis and reporting is therefore a priority for Falkirk, as well as other local authorities and the Scottish Government.

⁸ Source: National Records of Scotland: Falkirk Council Area - Demographic Factsheet (last updated 08/08/2013) accessed online August 2013 at: <http://www.gro-scotland.gov.uk/files2/stats/council-area-data-sheets/falkirk-factsheet.pdf>

10 Law and Policy Drivers

10.1.1 Children and Young People/Community Care

- Getting it Right for Every Child (**GIRFEC**) www.scotland.gov.uk/gettingitright
- Children (Scotland) Act 1995
- Children and Young People Bill

10.1.2 Support for Children and Young People

With the aim of raising standards for every child, The Curriculum for Excellence plans to enable every child, including those children and young people with additional support needs, to become a successful learner, confident individual, effective contributor and responsible citizen.

<http://www.educationscotland.gov.uk/thecurriculum/whatiscurriculumforexcellence/index.asp>

10.1.3 Support for Learning

The Education (Additional Support for Learning) (Scotland) Act 2009 sets out a framework for supporting children's learning, with the aim of ensuring all children and young people receive the additional support required to meet their individual needs and help them to become successful learners.

10.1.4 Carers Strategy, Caring Together 2010-2015

Carers are now, and will remain, fundamental to strong families and partnerships and to resilient and cohesive communities. The strategy for carers in Scotland envisions that carers are recognised as equal partners in care and supported in their own right by statutory and voluntary services.

10.1.5 Adults with Autism

Adult Support and Protection (Scotland) Act 2007: Part 1

The Adult Support and Protection (Scotland) Act 2007 (ASP Act) put in place measures to enable greater protection for those adults in Scotland who are most at risk of harm. The Act defines adults at risk as:

- 1 *individuals aged 16 years or over,*
- 2 *who are unable to safeguard themselves, their property, rights or other interests,*
and
- 3 *are at risk of harm, and*
- 4 *Because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than others who are not so affected.*

10.1.6 Employment and Training

A natural aspiration for many individuals with ASD is that they should be able to secure meaningful employment and be able to contribute to the economy of Scotland. Many people on the autism spectrum have both the ability and the aspiration to do some form of meaningful work, but need personalised support to find work and ongoing consistent support to maintain and progress in employment.

For more information, the Framework for Supported Employment in Scotland (2010) is available online at:

www.scotland.gov.uk/Resource/Doc/303584/0095164.pdf

10.1.7 The Same As You? (**SAY**)

A Scottish Government review of services made recommendations for improving the quality of life for individuals with learning disabilities extends to include people with autism spectrum disorders, whether or not they also have a learning disability.

www.scotland.gov.uk/Resource/Doc/1095/0001661.pdf

10.1.8 Reshaping Care for Older People

The Scottish Government, working with partners in Health, Local Government, the third and independent sectors is looking at ways of reshaping the provision of care for older people, with the aim of ensuring “the highest quality care for every older person, every time”.

10.1.9 Self-Directed Support

Support should be designed around the citizen and not the service. Self-directed support is a term that describes the ways in which individuals can exercise greater choice and control, and autonomy over their own decision-making. More information is available online at:

www.selfdirectedsupportscotland.org.uk

10.1.10 The Protecting Vulnerable Groups Scheme

The Protecting Vulnerable Groups Scheme (PVG Scheme) is designed to help to ensure people who have regular contact with vulnerable groups in Scotland through regulated work do not have a known history of harmful or abusive behaviour.

10.1.11 Social Housing Allocations

Scottish Housing laws require social housing landlords to encourage equality of opportunity and outcomes and provide services in a way that promotes equality in policies and practices, including the Allocations process.

11 References and Resources

11.1.1 Autism sources

- National Autistic Society Scotland www.autism.org.uk/scotlandservices
- Scottish Autism www.scottishautism.org
- Autism Initiatives www.autisminitiatives.org
- I Exist – The Message from Adults in Scotland (2008) National Autistic Society Scotland survey report, accessed online August 2013 at:
www.autism.org.uk/get-involved/campaign-for-change/learn-more/our-campaigns/past-campaigns/i-exist/i-exist-campaign-in-scotland.aspx
- “Autism and Ageing” National Autistic Society PowerPoint presentation accessed online August 2013 at:
www.autism.org.uk/~media/nas/documents/news-and-events/nas-conferences/international-conference-2008/short-seminar-presentations/richard%20mills%20and%20carol%20povey%20-%20ageing%20and%20autism.ashx

11.1.2 Falkirk Council Corporate Plans

- One Council, One Plan; Falkirk Council Corporate Plan 2012-17
www.falkirk.gov.uk/about_council/performance_zone/PDFs/corporate_plan/corporate_plan.pdf
- Falkirk Council Education Services Service Performance Plan, 2013-16
www.falkirk.gov.uk/about_council/performance_zone/service_performance/education_services/performance_plan.pdf
- Falkirk Council Social Work Services Service Performance Plan, 2013-16
www.falkirk.gov.uk/about_council/performance_zone/service_performance/social_work/service_plan.pdf
- Forth Valley Inter Agency Adult Support and Protection Practice Guidance and Procedures
www.falkirk.gov.uk/services/social_work/community_care/fv_inter-agency_guidelines.pdf

11.1.3 Scotland

- The Scottish Strategy for Autism (2011) Scottish Government, Edinburgh
- National Records of Scotland: Falkirk Council Area - Demographic Factsheet (last updated 08/08/2013) accessed online September 2013 at:
<http://www.gro-scotland.gov.uk/files2/stats/council-area-data-sheets/falkirk-factsheet.pdf>
- Education (Additional Support for Learning) (Scotland) Act 2009
<http://www.scotland.gov.uk/Topics/Education/Schools/welfare/ASL>
- The Keys to Life; Improving Quality of Life for People with Learning Disabilities (2013) The Scottish Government, Edinburgh.
<http://www.scotland.gov.uk/Resource/0042/00424389.pdf>
- Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders: A national clinical guideline (1998) Scottish Intercollegiate Guidelines Network (SIGN). <http://www.sign.ac.uk/pdf/sign98.pdf>

11.1.4 NICE clinical guidance, “Autistic spectrum conditions in adults” (draft, March 2012). There is a review underway of NICE guidelines, specifically looking at how the guidelines can be adapted to include adults with autism. The latest draft version, dated March 2012, is available online at: <http://www.nice.org.uk/nicemedia/live/12339/58812/58812.pdf>

11.1.5 Resources

- Support for **children and their families** affected by disabilities, a series of ‘handy hints’ leaflets available online (Sept 2013) at:
www.falkirk.gov.uk/services/social_work/children_and_family_services/support_for_children_affected_by_disabil/support_for_children_affected_by_disabil.aspx
- Supporting **Adults with Autism**; A good practice guide for NHS and local authorities (2009) National Autistic Society
www.autism.org.uk/~media/NAS/Documents/Extranet/Autism-library/Magazines-articles-and-reports/Reports/Our-reports/Supporting%20adults%20with%20autism%20-%20a%20good%20practice%20guide%20for%20NHS%20and%20local%20authorities.ashx
- The **Self-Directed Support in Scotland** website, a ‘one-stop stop’ with information about Self-Directed Support, for people who use social care services and health and social care professionals.
www.selfdirectedsupportscotland.org.uk
- **Information for parents** who receive a diagnosis of ASD for their child
http://scottishautismnetwork.org.uk/information/info_for_parents_booklet.pdf