

# **“Moving on from Transacting to Transforming”**

## **South Lanarkshire’s Five Year Local Autism Action Plan**

### **(2018-2023)**

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#### **A brief background – Autism in the UK, Scotland and South Lanarkshire**

South Lanarkshire has produced the present document along with the full involvement of all stakeholders within the South Lanarkshire Autism community in realising our shared vision to improve Autism supports and services across the entire Partnership.

Following the launch of the Scottish Strategy for Autism in 2011, in 2013 the Scottish Government commissioned a National Autism Mapping Project - a short-term fact finding and analysis exercise to build up a picture of Autism service provision nationally and provide information on Autism coordination at a local level. It was this process which gave rise to the funding of One Stop Shops across Scotland for a fixed term including North and South Lanarkshire between 2013-2016.

The prevalence of Autism in children is rising yearly. In 2003, it was reported to be one child in 163, ten years later in 2013 it was reported to be one child in 67. This is equivalent to almost 1.5% of Scottish children having a diagnosis of Autism Spectrum Disorder (ASD). A recent North American prevalence rate was published in April 2018 by the Centre for Disease Control (CDC) and estimated the prevalence figure to be one in 59. (This document will make use of the term Autism Spectrum Condition (ASC) as a preferred alternative; and autistic people rather than people with Autism.)

These rates and trends are comparable to that of the rest of the UK. This means that in South Lanarkshire with a population of 316,230 and applying the one in 67 prevalence statistic there are approximately 4,711 (1.49%) autistic people. The prevalence is expressed as a percentage of the total school population.

Data Source: [www.scotland.gov.uk/Topics/Statistics/Browse/SchoolEducation/dspupcensus](http://www.scotland.gov.uk/Topics/Statistics/Browse/SchoolEducation/dspupcensus).

In terms of the costs of Autism to the UK economy a study conducted by Knapp and collaborators from Kings’ College London estimated the cost of ASD across the lifespan to range from £0.80 to £1.23 million per person depending on the co occurrence of an additional intellectual disability diagnosis.

One of the recommendations made by the Scottish Government in relation to the Scottish Strategy for Autism was to commission an analysis of the Knapp report and place it within the context of Scottish localities. This segmentation exercise was undertaken by Professor Tommy McKay at Strathclyde University and Professor Martin Knapp at The London School of Economics between 2014-2018 and some of the most important findings are outlined in summary later in this document.

The segmentation report provided important information on what interventions lead to better outcomes for autistic individuals and the economy as a whole, as well as examining UK prevalence figures in considerable detail.

It is essential to have a firm appreciation of the current level of Autism funding in order to strategically invest in interventions that lead to better outcomes. High care costs are often associated with crisis situations, which have arisen as a consequence of unmet need. By segmenting the Autism population, the 2018 report will hopefully contribute to more targeted cost effective interventions, backed by research led approaches.

For the purpose of clarity the research initially conducted in 2014 by The London School of Economics and The Journal of the American Medical Association relating to the financial impact of Autism will be noted, and contrasted with the comparative low investment in Autism supports and services.

The subsequent segmentation of this research into the Scottish context is then outlined following the publication of the Micro Segmentation Report in March 2018;

The 2014 Report -

Autism costs more per year than other chronic conditions including; Dementia, Cancer, Heart Disease and Strokes. (Outlined below)

Costs to UK economy (2014):

- £23billion – Dementia
- £12billion – Cancer
- £8billion – Heart Disease, and
- £5billion – Stroke; compared to:
- £32.1billion – Autism

By comparison – annual research spend:

- £50million – Dementia
- £590million – Cancer
- £169million – Heart Disease
- £32million – Stroke;
- £4million – Autism

When it came to the average spend per person per year throughout the UK, this equated to the following (2014);

- £61.00 - Dementia
- £295.00 - Cancer
- £75.00 - Heart Disease
- £22.00 - Stroke
- £6.60 – Autism (generally) and
- £0.60 - Adults with Autism

**Source:**

<http://www.lse.ac.uk/website- archive/newsAndMedia/news/archives/2014/06/Autism.aspx>

### **The 2018 report –**

As from 26 March 2018, a major study commissioned by the Scottish Government from Professor Tommy McKay at Strathclyde University, and Professor Martin Knapp at The London School of Economics has reported back on the 'Micro Segmentation' of the above findings translated into the Scottish economy context.

The **Micro Segmentation Report** is the conclusion of four years of research, and as Scotland has approximately 8.4% of the total UK population, Professors' Knapp and McKay's comprehensive study found that Autism costs amount to **£429.00** for every person in Scotland. With a South Lanarkshire population of approximately 316,000 this totals some **£135,564,000 per annum** for the entire Health and Social Care Partnership community.

Of particular significance was one of the segmentation report's findings that "parent training and support programmes could benefit families of autistic children and adults both with and without an Intellectual Disability" (Micro Segmentation Report; p 216) which when combined with other evidence based interventions constitute early and effective strategies.

The report also highlights both the 'inescapable' costs of Autism i.e. prevalence of Autism, Autism and Intellectual Disabilities and Co Morbid conditions such as ADHD, as well as the 'escapable' costs i.e. lost productivity for the 85% of autistic people with no full time gainful employment. This issue in particular can be hugely influenced by research-informed policies such as Employment Support Programmes and other similar initiatives.

The 357 page micro segmentation study concluded that for every **1% of reduced 'escapable' costs** affected by evidence based interventions for children and adults with Autism, savings of **£22million** would be made, and for **10% of reduced escapable costs** by evidence based interventions for children and adults with Autism there would be some **£223million** savings to the Scottish economy (page 218).

In addition to the obvious economic benefits, the study also concluded that **quality of life measures** would increase accordingly for the estimated **44,133** Scottish autistic people, their families and communities. **"The strong links between economic impacts and quality of life have been demonstrated over a long period in a wide variety of studies"** (page 208).

The Micro Segmentation Report's 'invest to save' philosophy would therefore seem indisputable and compelling on both ethical and economic grounds.

Source: <http://www.gov.scot/Resource/0053/00533382.pdf>

### **How South Lanarkshire Arrived Here: A timeline for our transaction with the autism community –**

#### **2011 –**

When the ten year long Scottish Strategy for Autism was implemented in 2011, it initially centred on the ten indicators of good practice (below);

#### **Ten Indicators for best practice in the provision of effective Autism Spectrum Disorder (ASD) services:**

1. a local Autism Strategy developed in cooperation with people across the Autism spectrum, carers and professionals ensuring that needs of people with ASD and carers are reflected and incorporated within local policies and plans;
2. access to training and development to inform staff and improve the understanding amongst professionals about ASD;
3. a process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication;
4. an ASD Training Plan to improve the knowledge and skills of those who work with people who have ASD, to ensure that people with ASD are properly supported by trained staff;

5. a process for data collection which improves the reporting of how many people with ASD are receiving services and informs the planning of these services;
6. a multiagency care pathway for assessment diagnosis and intervention to improve the support for people with ASD and remove barriers;
7. a framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement;
8. services that can demonstrate that service delivery is multiagency in focus and co-ordinated effectively to target meeting the needs of people with ASD;
9. clear multiagency procedures and plans which are in place to support individuals through major transitions at each important life stage; and
10. a self evaluation framework to ensure best practice implementation and monitoring.

#### **2015 –**

The Scottish Strategy for Autism was revised and reformed into 'The Outcomes Approach'. The South Lanarkshire Local Autism Action Plan set out to address the four strategic outcomes identified (below) in this revised strategic model:

- a healthy life
- choice and control
- independence
- active citizenship

#### **2016 –**

South Lanarkshire established the **ARCH** (Autism Resources Coordination Hub) following the closure of the previous Pan Lanarkshire resource based in Motherwell.

#### **2017 –**

In 2017 the Scottish Government undertook a further 'Engagement Exercise' which concluded with the '**Engagement Analysis**' and revised '**Outcomes and Priorities 2018-2021**' documents (both Links provided below).

The documents resonated with the feedback from the 'Engagement and Involvement' process undertaken at the same time across South Lanarkshire and with all relevant stakeholders between September–December 2017.

The development of the **South Lanarkshire Local Autism Action Plan**, referred hereafter in the present document as 'The Plan'; has been an iterative process spanning a four year period from 2014 onwards culminating in the present document. The Plan will mirror both the revised '**Outcomes Approach (2015)**' adopted in the revised Scottish Strategy for Autism as well as the '**Outcomes and Priorities 2018-2021**' issued by the Scottish Government in March 2018.

The Plan also sets out South Lanarkshire's strategic vision for the next five years for Autism services and supports between 2018-2023.

The Plan will act as the template for the proposed five thematic work streams to be organised around the key themes set out within the Plan. The five work streams will be tasked to progress each of the key priorities set out later in this document, and agree on any additional local performance measures to allow South Lanarkshire's Autism services to be benchmarked and reported back upon alongside existing national measures.

Each of the five work streams will be chaired by identified leads within the Partnership best suited to steering each group toward progressing each of the priorities and locally agreed performance measures outlined. This will include representation from South Lanarkshire's autistic people and parent carers themselves. Each work stream chair will be accountable to the main South Lanarkshire Autism Management Steering group.

Overall, the Plan outlined in the final sections of this document is the culmination of the four year long engagement process which involved the entire Autism community in identifying and addressing the support needs of autistic people and their parent carers within South Lanarkshire. These

engagement exercises and events took place in three distinct phases, prompted in response to strategic developments taking place at a national level. As much of the content of the Plan can be directly traced back to these earlier events, it would therefore seem helpful to firstly place the Plan within this historical context;

Sources: <http://www.gov.scot/Resource/0053/00533386.pdf>  
<http://www.gov.scot/Resource/0053/00533392.pdf>

#### **The First Phase: 10 November 2014 'An initial consultation event' -**

This initial event took place in the Murray Owen Centre, East Kilbride. A wide range of Autism community stakeholders participated in the consultation and engagement process which was intended to hear what the Autism community as a whole felt should be progressed in developing the Local Autism Action Plan. The themes this event identified were 'clustered' around the following areas;

- diagnosis (adults and children)
- post diagnostic support
- training
- information ,and
- parent carer/service user involvement

#### **The Second Phase: 21 January 2016 'A second Autism Strategy multi agency development day' –**

This event was organised in response to the revised 'Scottish Strategy for Autism's –Outcome Approach' published in December 2015.

The Autism Strategy Development Day organised its feedback and discussions around the four strategic outcomes already identified;

#### **The Four national Strategic Outcomes in the Scottish Strategy for Autism –**

- a healthy life
- choice and control
- independence
- active citizenship

#### **The Outcome-Based Priorities identified at the event were:**

##### **A Healthy Life –**

- increased awareness and understanding of Autism and how it fits in with the Child and Adolescent Mental Health Service (CAMHS) model of service;
- shared beliefs and being solution focussed;
- looking for a more joined up approach between CAMHS and PACT (Paediatric Autism Consultancy Team);
- establishing multi disciplinary teams to support people - post diagnosis;
- establishing a clear diagnostic pathway for adults;
- Advocacy Services for people with Autism and who have no learning disability or mental health problems; and
- greater skills sharing throughout services and supporting children and young people with Autism in their transition stages.

##### **Independence –**

- support for future planning processes – life long transitions;
- support for people with Autism at night time;
- change language from 'independence' to 'reducing dependency';
- increase Autism awareness in the wider community;
- Identify areas of good practice and share these; and
- change attitudes to those with Autism.

##### **Choice and Control –**

- develop better research and data gathering processes around autism and use practice informed research to develop supports;
- develop the effective use of Self Directed Support (SDS) to support choice and independence for individuals with Autism;
- ensure professionals treat individuals with dignity; and
- wider availability of clear and accessible sources of Autism-specific information.

#### **Active Citizenship –**

- all agencies to collaborate in seeking to provide equal access to education /employment/ training and purposeful activity – only 14% of adults with Autism are in full time employment;
- raise awareness of stay at home children, young people and adults with Autism; and
- early intervention by all agencies will prevent further escalation in the future.

#### **The Third Phase: 2017 ‘Developing Local Key Priorities’ - ‘transforming our transactions’**

A comprehensive ‘Engagement and Involvement’ exercise took place over the last four months of 2017 by firstly developing a Snap Autism Survey which was distributed to all partners within the South Lanarkshire Autism community. The survey asked all Autism partners and stakeholders including; people with Autism, their parent carers, siblings, extended family members, friends and all agencies and autism partners within South Lanarkshire to outline their views on the status of current Autism supports and services, and what they thought needed to be done to improve and develop these services over the next five years.

The survey was completed in November 2017, and from the feedback provided, common themes were drawn from the data collected relating to Autism supports and services. Many of these themes ‘echoed’ and built upon the issues identified in the two other events which took place in 2014, and 2016.

Thereafter, a number of **Locality-based Focus groups** were organised, comprising representative groups drawn from;

- autistic people;
- parent carers and siblings affected by autism, and
- multiagency professionals and other stakeholders with a role relating to Autism in South Lanarkshire

#### **The Key Priorities Identified by the Focus Groups:**

In order to achieve locally defined goals, stakeholders identified five overarching ‘themes with 15 Key Objectives set out for the next five years of the Local Action Plan:

#### **The South Lanarkshire Local Autism Action Plan (the Plan)**

Has now been developed to sit within, and be consistent with the revised outcomes and priorities within The Scottish Strategy for Autism updated and refreshed in 2018. This approach will help to ensure that each person on the Autism Spectrum finds a route that is appropriate to them, a route that is not necessarily reliant on services but one where the right knowledge and right support, at the right time, can assist the person to achieve their potential and life outcomes. To support this it is also important that some people will be able to use family networks and friends to help themselves. Other people may require information, signposting, support, services or funding.

Not everyone has family or friends and some people on the Autism Spectrum remain invisible, marginalised or excluded from wider community life in spite of efforts to reach them by services. Specialist service provision alone will not address this. It has been noted that “culture eats strategy for breakfast...” and if people with Autism are to be truly integrated significant changes are needed not only in strategic priorities, but equally within the neuro typical community in order to embrace neuro diverse conditions such as Autism. This will require an understanding of the social and communication challenges autistic people face in simply living their daily lives.

The South Lanarkshire Local Autism Action Plan seeks to ensure that people on the Autism Spectrum are connected to the wider community in a way that best fits each person's needs,

aspirations and outcomes. Where necessary; training, knowledge, mentoring, support and multiagency approaches will be developed in order to make this happen. Information, signposting, pro active or preventative work and individual resourcing when necessary, are all in keeping with the Scottish Strategy for Autism, which highlights that when support is required to help achieve outcomes, people with autism may **'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 2011)

Prior to the development of the South Lanarkshire Local Autism Plan, there was no integrated, locally devised all age Autism strategy for children, young people and adults on the autistic spectrum.

The Autism survey findings, and responses provided by the South Lanarkshire Autism community was presented at a **Feedback Event** hosted on **21 March 2018** by ARCH (The Autism Resources Coordination Hub), attended by autistic people themselves and representatives from all stakeholders in the statutory, voluntary, private and parent led sectors in South Lanarkshire.

The proposed Local Autism Action Plan was set out at the feedback event, and endorsed by the autism community.

Following the consultation process with stakeholders the following 'Vision' was outlined to guide the Local Autism Action Plan;

**"The Plan will have at its centre the views and ambitions of all autistic people, their parent carers and families to create a relevant and responsive network of provision across the lifespan and improve their overall quality of life. We will actively promote the full participation and involvement of autistic people in the life of the South Lanarkshire community."**

### **The five overarching themes and 15 key objectives Identified by the South Lanarkshire Autism Community for incorporation into the South Lanarkshire Local Autism Action Plan:**

The five **overarching 'themes'** which emerged from feedback in the survey, and subsequent locality-based Focus Group discussions were:

1. better and more consistent diagnostic processes and pathways with the provision of post diagnostic supports for people with autism and their families throughout their lifespan in South Lanarkshire;
2. improved life opportunities through supported employment, training and education placements in South Lanarkshire;
3. better and more accessible Information and awareness for all in the wider community and general workforces within South Lanarkshire;
4. better support during key life transitions such as; moving from preschool to primary, primary to secondary; secondary on to adult services, employment, education or training, independent living and rehabilitation into the community, and
5. improved professional awareness and training throughout South Lanarkshire as well as joined up working approaches.

These five overarching themes provided the basis of the subsequent four month long focus group events and discussions. The groups collectively identified **three key objectives** which they wanted embedded within each of the five themes, as well as other points for consideration within the Local Autism Action Plan.

The 15 key objectives are outlined below and include relevant 'National Outcome Measures' upon which South Lanarkshire Health and Social Care Partnership already report back to the Scottish Government. Also outlined are additional locally determined measures which, when taken together, will constitute the aspirations of South Lanarkshire's Local Autism Action Plan and allow us to benchmark our progress from where services and supports are now; to where we want them to be in five years time.

### **The three key objectives identified under each of the five overarching Themes:**

Theme 1 – Better and more consistent diagnostic processes and pathways with the provision of post diagnostic supports for people with Autism and their families throughout their lifespan in South Lanarkshire.

- **priority 1** – access to diagnostic services should be timely and consistent through the person with autisms lifespan within South Lanarkshire;
- **priority 2** – services should be proactive and not rely on local provision or place the onus on people with autism and their parent carers to access services and supports. A named professional could offer a single point of contact; and
- **priority 3** – Maintain timely diagnostic pathway, with communication being maintained throughout by services.

### **Other Points for consideration:**

- there is a need for better recognition of the emotional toll on parent carers at the point of diagnosis;
- access to support and information should be offered in a structured manner, applied consistently across the Unitary Authority. Working parent carers require a flexible approach to support provision;
- early recognition of Autism could be via preschool screening for all children; and
- people with Autism need more information which is presented in plain, unambiguous language and free from jargon.

**Theme 2** – Improved life opportunities through supported employment, training and education placements in South Lanarkshire

- **priority 1** – on the job employment coaches/mentors to support people with Autism locate appropriate positions of employment, education or training and sustain these;
- **priority 2** - access to Autism Advocacy Services across the lifespan; incorporating children, young people and adults with ASC. Autism 'champions' appointed to represent the community; and
- **priority 3** – greater emphasis on equipping children, young people and adults with Autism with relevant and effective life skills in school, training, further education, higher education and employment.

**Theme 3** – Clear, relevant and accessible information and autism awareness for the wider community and general workforces throughout South Lanarkshire.

- **priority 1** – more asset based public information promoting the positive aspects of Autism, not just the challenges;
- **priority 2** – a 'whole community' Autism consultation process where any interested person can access Autism specific information and training opportunities; and
- **priority 3** - more 'joined up' collaborations between stakeholders in the Autism community and the wider 'neurotypical' community.



#### **Other points for consideration –**

- allow workers with Autism knowledge, experience and qualifications to be used to promote Autism awareness programmes;
- use audio visual and social media formats as well as written information in line with the principles outlined in the national document 'A Right To Speak' for those who require Augmentative and Additional Communication (AAC) support; and
- people with Autism need more information which is presented in plain, unambiguous language and free from jargon.

**Theme 4 -** Better support during key life transitions including; moving from preschool to primary, primary to secondary; secondary on to adult services, employment, education or training; independent living and rehabilitation into the community from residential settings.

- **priority 1** – provision of truly independent advice for people with autism and their parent carers during key transition stages;
- **priority 2** – embed the 'Principles of Good Transition 3' strategy documents within all transition stages for people with Autism; and
- **priority 3** – clear unambiguous pathways bridging one service to another via effective tools like communication passports, and lead professionals working side by side with people with Autism and their parent carers.

#### **Other points for consideration –**

- more transparency with users and carers by services when transition planning is taking place;
- transition plans should remain clear and achievable; and
- the Autism community need more positive role models to act as successful and included examples.

**Theme 5 -** Improved professional awareness and training throughout South Lanarkshire as well as joined up working approaches.

- **priority 1** – all undergraduate teachers, and relevant staff supporting people with Autism should have mandatory autism awareness training
- **priority 2** – specialist Autism informed staff available to act as points of contact/ consultants for other staff members; and
- **priority 3** – more joint professional forums to collaborate and exchange best Autism practice between agencies.

#### **Moving on to the Fourth Phase – 'Transforming Autism Services'**

##### **The South Lanarkshire Health and Social Care Partnership Local Autism Action Plan 2018-2023**

The information provided in the survey and focus groups will now be incorporated into the South Lanarkshire Health and Social Care Partnership Local Autism Action Plan.

The Plan will form the strategic direction of Autism service development within South Lanarkshire Health for the next five years; **between 2018 until 2023**. In order to ensure that the priorities identified are progressed, the **five thematic work streams** will be formed around themes outlined in the present report. These work streams will be comprised of representatives from all stakeholders including parent carers and autistic themselves.

The five work streams will be tasked with progressing the outcomes measures which will benchmark current provision, and lead on developments in realising the key objectives highlighted by the consultation exercise, and incorporated into the Plan to ensure a significant and measurable improvement in all Autism services and supports within South Lanarkshire over the next five years.

This Plan will be presented to both the Social Work and Executive Committees of the Council to ensure 'buy in' from all resources throughout South Lanarkshire. This will ensure a 'joined up' approach and endorsement of the Plan as a genuinely coproduced document with South Lanarkshire and the Autism community's full and ongoing involvement and commitment.

**Appendices:**

<b>Appendix 1a</b>	All South Lanarkshire Stakeholders Organisations involved in the Consultation
<b>Appendix 1b</b>	A Glossary of Acronyms
<b>Appendix 1c</b>	The Governance of the Local Autism Action Plan