



Mapping the Journey for Children and Young People with Possible Autism Spectrum Disorder



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The need for a review of the provision of services for children and young people with possible *autism spectrum disorder (ASD)* was identified following the submission of the following question at the

Lanarkshire NHS Board Annual Review Public Questions and Answers (2009):

“Why is there not a clear pathway for possible Autistic Spectrum Disorder (ASD) children with standard waiting times and an equity throughout NHS Lanarkshire and Scotland which dovetails in with educational authorities to ensure that earlier diagnosis occurs and children have developmental opportunities which will enhance their overall quality of life?”

The answer given at that time included details of the services available and how they should join up, and following this a group was brought together, made up of all interested parties, to review and clarify the journey. The aim of the group was to ensure that the journey consisted of:

- ◆ The right people
- ◆ In the right order
- ◆ In the right place
- ◆ Doing the right thing
- ◆ At the right time
- ◆ With the right outcomes
- ◆ Always taking into account the service user’s experience

The group’s focus was on ensuring that the service was centred on needs of service users and reflected current evidence and best practice including:

- ◆ Scottish Intercollegiate Guidelines Network (*SIGM*) Number 98 – Assessment, diagnosis and clinical intervention for children and young people with autism spectrum disorders
- ◆ Getting it right for every child (*GIRFEC*)

The revised journey would incorporate:

- ◆ Early identification
- ◆ Prompt assessment and investigation
- ◆ Appropriately tailored information about ASD, the services available and how to access them
- ◆ Access to support
- ◆ Access to intervention
- ◆ Appropriate educational support
- ◆ Good communication liaison and continuity of care.

First Meeting

An initial event took place in November 2009 bringing together all stakeholders (health and local authority staff, parents and carers, voluntary organisations) to map out the current journey (**see Appendix 1**). This journey was mapped separately from both the North and South Lanarkshire local authority area perspectives, to reflect the different service configurations in each area, producing two current journey maps.

The group then used a service redesign method (*LEAM*) to identify the gaps, duplication/variation, waits and issues with the current journeys in each area. The final step in the process was to determine what actions would be needed to produce an optimal journey for all children and young people with possible autism spectrum disorder across Lanarkshire.

Second Meeting

The mapping of the optimal journey was taken forward at a second event which took place in February 2010. The meeting began with a recap of the two current journey maps and then a review of the issues we identified (**see Appendix 2**), where there was the chance to add in anything missed.

An overview of [GIRFEC](#) (Getting It Right For Every Child) was given (the national approach to supporting and working with children and young people in Scotland), emphasising an integrated approach to working with children and young people to develop their well being. Discussion then took place on how to ensure the Lanarkshire journey reflected the GIRFEC approach. The event concluded with agreement on a draft single optimal journey, together with a list of actions required to address the identified issues and the person who would take forward each action.

Third Meeting

At the third and final meeting the journey map was reviewed and amendments agreed (**see Appendix 3**). The actions agreed at the previous meeting were reported upon.

How does the journey work?

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| <p>Child/ Young Person</p> | <p>Step ▶▶ The journey can begin at any time for a child or young person when concerns about development are raised.</p> |
| <p>Difficulties recognised by:</p> <ul style="list-style-type: none"> • Parent or carer • Information from Red Book • Surveillance Public health • Education | <p>Step ▶▶ Recognition of issues can be identified by parents and carers using the information on normal development found in the Red Book (personal child health record issued to all children in Scotland), via early years surveillance by the health service, <i>public health nursing</i> or by school staff at any time during nursery or school education.</p> |
| <p>Point of contact/Named Person:</p> <p>Public Health Nurse (named person for birth to school age)</p> <p>Education (named person for young person of school age)</p> | <p>Step ▶▶ Contact is made with the Named Person responsible for the child's age group – the public health nurse is the Named Person from birth up to school age and a member of school staff (education) is the Named Person for a young person of school age.</p> |
| <ul style="list-style-type: none"> • Single agency assessment • Potential issues identified • Appropriate planning • Interventions • Review | <p>Step ▶▶ Single agency assessment identifies potential issues and is followed by planning, ongoing appropriate interventions and review. At this point only a single agency is involved and interventions can take place from the point of initial assessment.</p> |
| <p>Named Person requests assistance</p> | <p>Step ▶▶ If following an initial assessment or review issues are identified which require input from other professionals within the single agency or from another agency or several agencies, then the Named Person requests assistance from those professionals/agencies. If requests for assistance are going to another agency then informed consent should be sought following the guidance in the <i>Lanarkshire Information Sharing Protocol</i>.</p> |

How does the journey work? (continued)

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| <p>Single agency</p> | <p>Step ▶▶ Following a request(s) for assistance the child/ young person’s needs will be clarified, appropriate interventions planned and reviewed as required. The Named Person will collate single agency assessment information. Where multi-agency assessment is requested and provided, a Lead Professional will then be identified to co-ordinate the planning.</p> |
| <ul style="list-style-type: none"> Identify needs Planning Interventions Review | |
| <p>Multi-agency</p> | |
| <p>Lead Professional identified</p> | |
| <ul style="list-style-type: none"> Update assessment(s) and/or Working diagnosis | <p>Step ▶▶ Following update/collation of assessment(s) a working diagnosis may be given at this point. A confirmed diagnosis can also take place at this point or at any other point along the journey following assessment. Timescales from request for assistance from an Education Authority to provision of assessment information are covered by The Education (Additional Support for Learning) (Scotland) Act 2004 as amended which gives at timescale of 10 weeks for action.</p> |
| <p>Appropriate planning</p> | <p>Step ▶▶ Appropriate planning takes place following assessment or review.</p> |
| <p>Interventions and Support</p> | <p>Step ▶▶ If the decision is to go down the ‘meeting needs route’ then appropriate interventions and support takes place, together with reviews of these plans and updated plans are implemented. Parents, carers or the young person can choose to move to the diagnostic route at any time during this cycle.</p> |
| <p>Review of Plans</p> | |
| <p>Appropriate planning</p> | |
| <p>OR</p> | |
| <p>Interventions and Support</p> | <p>Step ▶▶ If the decision is to go down the ‘diagnostic route’ via the Lanarkshire Autism Diagnostic Service (<i>LADS</i>) or Child and Adolescent Mental Health Services (<i>CAMHS</i>), then interventions and support take place along with reviews of these plans following diagnosis. All plans are reviewed, updated and implemented.</p> |
| <p>LADS/ CAMHS Service</p> | |
| <p>Diagnosis</p> | |
| <p>Review of Plans</p> | |
| <p>Appropriate planning</p> | |

What progress have we made with the actions?

During the mapping process a number of actions were identified as part of the development of the journey and progress was reported on at (or after) the final meeting:

| Action | Progress |
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| Mapping the actual journeys and stakeholder analysis | <p>Parent and carer focus groups were held and came up with the following list of comments/requirements of the service:</p> <ul style="list-style-type: none"> ◆ Pathway to be developed ◆ Named person/key communication contact ◆ Clearer/more information at all stages in the process ◆ Reduced waiting times for LADS/Speech and Language Therapy ◆ Insufficient resources for the service ◆ More training required for GPs, Public Health Nurses. ◆ Positive comments regarding therapies offered, being listened to and appreciation of support. |
| Consultation with Public Health Nurses and GPs | <p>Points raised by Public Health Nurses and GPs:</p> <ul style="list-style-type: none"> ◆ Public Health Nurses (PHNs) and GPs liked the Red Flags poster (see Appendix 4) to alert professionals regarding ASD. There is also a section on warning signs in SIGN Guideline No.98, pages 6 – 8). Further work is required to develop a Lanarkshire version using the information from these sources. ◆ Posters and leaflets would be helpful – further work is required to source Lanarkshire and/or national information leaflets |
| Diagnosis | <p>Agreement has been reached on the following sentence to be used for a 'standard working diagnosis':</p> <p>"The child (name) presents with features (these can be identified or not here) which are often seen in children/young people on the autistic spectrum."</p> |

Progress with the actions (continued)

| Action | Progress |
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| <p>Information and Resources</p> | <p>Useful Website Links*:</p> <ul style="list-style-type: none"> ◆ http://www.idiomsite.com – a list of many idioms. ◆ http://www.autism.org.uk – The National Autistic Society which has information, checklists and many advice sheets for parents and professionals. ◆ www.scotland.gov.uk/publications/2009/07/06111319/0# - the Autism Toolbox, a Scottish Government resource designed to support education authorities, schools and pre-schools in the delivery of service and planning for children and young people with Autism Spectrum Disorders (ASD). It gives advice to schools, including what is expected of education staff. ◆ http://www.autismuk.com – to increase the awareness of autism. Gives an overview of many topics and issues. ◆ http://www.firstsigns.org – dedicated to educating parents and professionals about autism related disorders. ◆ http://www.partnersinplay.org.uk – an independent parent/carer led charity, established in 1996 which offers direct support and information to families of young children/ young people with disabilities. PIP is based in Motherwell and operates throughout North Lanarkshire. ◆ http://www.scottishautism.org – enabling people with autism in Scotland through the whole life journey. ◆ http://www.autismspeaks.org – Autism Speaks has grown into the nation’s largest autism science advocacy organisation, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. <p><i>*Please note that we take no responsibility for the content of the websites described.</i></p> |

Progress with the actions (continued)

| Action | Progress |
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| GIRFEC | <p>The 'Getting it right for every child' agenda recognises the excellent work of single agencies such as health, education and social work, but further promotes the need for integrated working. There is an interdependence between single agencies that necessitates integrated working to enable achievement of positive outcomes for children and families.</p> <p>GIRFEC promotes integrated working where agencies move from working alongside each other with separate assessments and plans for children and families to a stage where they work as one: sharing information and actions to meet a wider range of support needs to promote well being. North and South Lanarkshire have been working together as learning partners to develop the getting it right agenda.</p> <p>Work being carried out in North Lanarkshire:</p> <ul style="list-style-type: none"> ◆ In North Lanarkshire multiagency support teams (MAST) are being developed to support integrated working at all stages, these are being rolled out across all six localities. <p>Work being carried out in South Lanarkshire:</p> <ul style="list-style-type: none"> ◆ Early Years Multi-Agency Teams (EYMAT) – each locality in South Lanarkshire Council has an identified core EYMAT, consisting at the moment of representatives from Psychological Service, Community Paediatrics and Social Work. EYMAT provides a service for early years children with any significant additional support needs/disability (including autism) and their families. It aims to ensure early multi-agency notification and co-ordination through core groups planning and multi-agency meetings. ◆ GIRFEC Early Years Multi-Agency Forum – a group of practitioners has been identified from each of the four localities. Their role is to support the implementation of key elements of GIRFEC, identify local trends, needs, issues and responses and generally to assist with the local delivery of the Early Years Framework. While these groups do not have a direct function in relation to autism or individual children and families, they can provide a forum for locality issues to be examined and directed to area managers groups or to the Children Services Planning Early Years Subgroup at a strategic level. |

Progress with the actions (continued)

| Action | Progress |
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| <p>Training (North Lanarkshire)</p> | <p>Available in North Lanarkshire:</p> <ul style="list-style-type: none"> ◆ North Lanarkshire Learning and Leisure Service's training, support and development programme for Autism Spectrum Disorders is available twice a year for teachers, senior management, classroom assistants and additional support needs assistants. This full day training is followed up by two sets of half day workshops designed for different age groups of children and young people (early years and early primary/upper primary and secondary). ◆ A half day training programme (an Introduction to ASD) is run three times a year for all professionals in North Lanarkshire who come into contact with a child or young person with ASD or who support parents who have a child or young person with ASD. This is open to everyone in health, GPs, dentists, social work services, community learning teams, police, housing, youth justice and voluntary organisations. ◆ Professional Development – opportunities for education staff to access professional development courses (including modular, certificate and diploma courses) related to additional support needs and ASD through tertiary education opportunities. A nine week twilight training programme is offered in term 1 and 3 to all teaching staff embarking on study leading to a postgraduate certificate and diploma in autism (mainly in preparation for access to courses at Strathclyde and Glasgow Universities). Classroom assistants and additional support needs assistants can access a range of ASD related development courses at Coatbridge College. ◆ Whole School opportunities – all schools have a linked educational psychologist and additional support manager who can deliver whole school training on ASD as and when required outwith the training calendar. Teaching staff in Language and Communication bases also provide advice and support to mainstream establishments if required. ◆ Transport contractors – all contractors who provide transport for children and young people are required to attend a full day training event at the start of every school year which includes ASD awareness raising and guidance on how to support the children and young people they transport. |

Progress with the actions (continued)

| Action | Progress |
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| Training (South Lanarkshire) | <p>Available in South Lanarkshire:</p> <ul style="list-style-type: none"> ◆ All primary schools have been asked to nominate an ASD co-ordinator for the school. These co-ordinators receive enhanced training involving 1 full day and 5 twilight sessions, building on the Autism Toolbox. Their role is then to cascade and co-ordinate ASD information in the school and to identify further needs in order to meet the needs of pupils in the school effectively. ◆ Individual nurseries/schools can approach the Early Years Specialist Support Teachers, the ASD Outreach Team or Psychological Service regarding specific training at the level of the establishment. ◆ Education and Social Work resources routinely offer courses in autism to workers in these services via their service training directories. ◆ Schools have been provided with supportive information relating to the identification and management of sensory issues in autism, with additional input if required. |
| Interventions and Support for Families | <p>Community Paediatricians:</p> <p>Community Paediatric services are located in various locations within North and South Lanarkshire. Referrals would be accepted by community paediatricians from any agency for further medical and developmental assessment. At this stage, up-to-date reports are reviewed and following assessment of the child, further management decided. This may be a period of observation, collection of further information, or consideration of investigations or referral to other specialist teams or services such as in education, social services, speech and language therapy, audiology, neurology, Child and Adolescent Mental Health Service (CAMHS) or Lanarkshire Autism Diagnostic Service (LADS).</p> <p>There are variations in waiting times for an appointment in different locations and children would be offered an appointment routinely as soon as is possible.</p> |

Progress with the actions (continued)

| Action | Progress |
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| <p>Interventions and Support for Families (continued)</p> | <p>Child and Adolescent Mental Health Services (CAMHS):</p> <ul style="list-style-type: none"> ◆ CAMHS provides a specialist assessment and diagnostic service for children where a question of ASD is being raised where there is also concern of concurrent mental health disorders such as ADHD, Anxiety Disorder, Psychosis, Mood Disorder (depression) or other complex neuro-developmental issues. ◆ CAMHS uses an holistic assessment process including biological, psychological and social factors. ◆ CAMHS provides evidence based clinical interventions for young people meeting a dual diagnostic criteria and their families, interventions available include:- <ul style="list-style-type: none"> • Psychopharmacology (medication for a variety of clinical presentations). • Behaviour Management Approaches • Family Work and Family Therapy • Parenting Interventions • Psycho-education • Cognitive Behaviour Therapy • Psychotherapy <p>Learning and Leisure Services (North Lanarkshire):</p> <p>The Pre-5 Support for Learning team are teachers and early years workers with experience and training in Additional Support Needs in the Early Years. They support children (from birth to transition into Primary 1) at home or nursery.</p> <p>Following observation and identification of need, they intervene by assessing and targeting next steps in development to encourage positive outcomes for the children, their families and staff in early years establishments. They offer effective support to children with language and communication disorders and particularly those with a diagnosis of autism spectrum disorder. Staff are trained in the techniques of TEACCH, PECS, Boardmaker, Visual Timetabling, EarlyBird and EarlyBird Plus, Emerge T4T and Sleep Scotland Counselling.</p> |

Progress with the actions (continued)

| Action | Progress |
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| <p>Interventions and Support for Families (continued)</p> | <p>Learning and Leisure Services (North Lan) cont.:</p> <ul style="list-style-type: none"> ◆ Early Bird Programme® (National Autistic Society) – a three month programme for parents/carers of children up to 5 years, combining group training for parents with occasional home visits. Video feedback is used to help parents apply what they learn, whilst working with their child. Parents/carers have a weekly commitment to a 3 hour training session of home visit and ongoing work with their child at home during the programme. Parents/carers of pre-school children with a diagnosis of ASD or on the waiting list for a diagnosis can attend. Parents/carers are helped to understand their child’s ASD, develop their child’s communication, apply practical strategies to manage behaviour and increase their skills, knowledge and confidence. ◆ Early Bird Plus – is a three month programme for parents/carers of young children (4-8 years) with an ASD and for the professionals supporting them. It involves 8 group sessions and 2 home visits. Three places are allocated to each family including one for a professional currently working with their child. Parents and professionals are trained together to encourage a consistent approach between home and school. Parents and professionals are helped to understand the child’s autism, improve communication with the child, and develop strategies to pre-empt problem behaviour and/or manage those which do occur. ◆ Sleep Scotland Counsellors – trained counsellors work with families of pre-school children with additional support needs using specially adapted techniques to effectively treat sleep disturbances. Parents/carers have a commitment to attend regular clinic sessions where they discuss and monitor their child’s sleep problems. A home visit will be offered as part of the programme so that the counsellors can meet the child. This partnership helps the parent/carer to understand their child’s specific sleep problems; develop a programme of techniques to improve their child’s sleep patterns and build confidence and skills to deal with their child’s sleep problems. |

Progress with the actions (continued)

| Action | Progress |
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| <p>Interventions and Support for Families (continued)</p> | <p>Education (South Lanarkshire):</p> <ul style="list-style-type: none"> ◆ Early Years Specialist Support Teachers – this is a team of teachers trained and experienced in early years and additional support needs. They work with families and children from birth into Primary 1 as required, in the home and in nurseries. They work directly with children but also in an advisory capacity with parents and nursery staff. They collaborate closely with colleagues in other services and are experienced and trained in a range of ASD specific interventions. ◆ Psychological Service – all schools and nurseries have a named link educational psychologist. In addition there are psychologists in the service with particular specialism in language/ communication/ASD issues. Depending on the age/stage of the child and the impact of the condition, the psychologist may be involved directly with the child (e.g. individual assessment, support and intervention/therapy) or in a support/advisory role with families and staff, including contributing to programme planning. Part of the educational psychologist’s role is to contribute to, and in the early years to co-ordinate assessment information to inform decisions regarding school placements. ◆ Autism Outreach Team – this consists of ASD specifically trained and experienced teachers who support mostly school age children and staff in mainstream provision. They are often particularly involved at important transition points, i.e. Nursery to Primary 1, Primary 7 to Secondary 1. ◆ Additional Support Needs Educational Placements – the authority offers a range of both general additional support needs placements and ASD specific ones. These provisions offer more targeted supports and interventions, and a greater ASD specific approach than in mainstream. |

Progress with the actions (continued)

| Action | Progress |
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| <p>Interventions and Support for Families (continued)</p> | <p>Education (South Lanarkshire), continued: Authority wide, across the range of provisions and services, the approaches and interventions are eclectic and reflect the needs of the individual children. Staff draw on a variety of such approaches and interventions including TEACCH, concrete communication, visual supports and schedules, PECS, social stories, intensive interaction, sensory management and curricular adaptation. This is often in collaboration with other services, both within education (e.g. Outreach, Psychological Service) and outwith education (e.g. Speech and Language Therapy).</p> <p>Specific Interventions/Programmes:</p> <ul style="list-style-type: none"> ◆ Early Bird Programme (National Autistic Society) – see North Lanarkshire Council entry for full description. The programme in South Lanarkshire runs twice a year, typically March to June and September to December. Parents can self-refer to the programme. ◆ Parent Support Group – run in partnership with Integrating Children’s Services, Health and the Princess Royal Trust. The aim of the group is to provide support to parents of children with additional needs from others in the same situation, access to professionals, advice and a forum to relax and access therapies/courses. The group also provides fun days for the children and their families. ◆ Social Interaction Group – for children with autism. This is aimed at ages 7-10 years and is run 4 times per school year. The children receive 2 x 8 week blocks in an after school setting (3:30 – 5:30pm). Funded by ICS. ◆ Sleep Scotland Counsellors – see North Lanarkshire Council entry for full description. |

Progress with the actions (continued)

| Action | Progress |
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| Interventions and Support for Families (continued) | <p>Hope for Autism:</p> <ul style="list-style-type: none"> ◆ Family Support - 2 monthly support groups; 1:1 emotional and practical support for families (strategies, advocacy, representation, counselling, signposting) at centre and home visiting; library of books, DVDs and Weighted Blankets; website with forums (in progress); fundraising, party get-togethers. ◆ Children's Groups and Support - (waiting list applies), youth group activities within their centre (play centred therapeutic activities); weekly Friday evening social group for higher functioning teenagers; trampoline with Rebound Therapist (out with the centre); Activ8; siblings group (for brothers and sisters of the children with an ASD); family swimming; holiday projects; annual outings or parties; 1:1 strategies and cognitive/behavioural/emotional support for higher functioning teenagers. ◆ Training and Other Resources - Free in-house training in ASD Awareness and Sensory Perceptual Differences for parents/carers, subsidised external training. ◆ For more information on what they do and services available see: http://www.hopeforautism.org.uk. <p>The National Autistic Society – South Lanarkshire:</p> <ul style="list-style-type: none"> ◆ Membership area includes Cambuslang, East Kilbride, Hamilton, Rutherglen and Strathaven. ◆ NAS provides services, support and advice to those affected by autism and their carers. ◆ The NAS Autism Helpline is available from 10am to 4pm Monday to Friday on 0845 070 4004. ◆ NAS aims to offer support to parents and carers of individuals with autism or Asperger Syndrome. They do this through monthly meetings, by telephone/email and regularly publish a newsletter. They also hold events that provide opportunities for social contact for the children and allow them to share experiences with the whole family. They also seek to raise awareness of Autism Spectrum Disorder (ASD) in South Lanarkshire, both in the general public and throughout the professional agencies that work with those affected by ASD. ◆ For more information on what they do and services available see: http://www.trialogue.org.uk/. |

Progress with the actions (continued)

| Action | Progress |
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| <p>Interventions and Support for Families (continued)</p> | <p>Lanarkshire Autism Diagnostic Service (LADS): LADS was established in June 2005 at a Lanarkshire wide tertiary level. Its remit is to assess and offer a diagnostic opinion for children and young people who present with features often seen on the autistic spectrum. The team currently consists of SLTs and Community Paediatricians with training currently being given to other colleagues in health and in education. It is the intention that more locally based diagnostic clinics are established over time as a result of this training.</p> <p>The assessment and diagnostic process is recognised as being a potentially lengthy and difficult one for families. LADS aims to offer as much information on the process on the way along, reassuring families of the robust nature of their diagnostic process and efforts to gain as complete a picture of their child as possible. Children are observed in nursery or school at primary level with a detailed phone call to the guidance teacher for high school pupils. The child's Child Health Record will have been requested and relevant information and reports noted. Local involved professionals will also have been contacted for their input/information.</p> <p>LADS has a range of clinic bases across Lanarkshire to which families are invited for a morning or afternoon appointment on their assessment day. 2 LADS team members are involved in the assessment – one will take a full, detailed and specific case history whilst the other assesses the child/young person using autism specific formal/informal approaches as appropriate. In most cases, the diagnosis can be given to the family on that day. Occasionally, in complex cases, more time is needed and further review or investigative appointments will be offered.</p> <p>A full report will be written and circulated to parents and agreed professionals. A young person may receive his or her own diagnostic report if appropriate too. Families are supplied written information on the Autism Spectrum and are signposted to national and local services. No follow up work is offered, the LADS team's remit being purely diagnostic.</p> |

Progress with the actions (continued)

| Action | Progress |
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| <p>Interventions and Support for Families (continued)</p> | <p>Regional Childcare Commissioning Initiative: Work is underway through the Regional Children's Commissioning Initiative, which was established following the Clyde Valley Report chaired by Sir John Arbuthnott to critically examine the supports required by children and families affected by Autism Spectrum Disorders.</p> <p>The main issues being addressed by this group are a reduction on the reliance of residential placements, the provision of care closer to home, the development of a comprehensive range of community alternatives, the development of pre and post diagnosis supports and the training requirements of professionals and families. The intention is that this range of social and health supports will be accessible and responsive to need for all families in the Clyde Valley area.</p> <p>The Group taking this work forward is multi agency and includes representatives from the Health Boards and Local Authorities in the Clyde Valley area as well as representatives from the leading National charities and local support charities. It is anticipated that the report from this group will be available later in 2011.</p> <p>Speech and Language Therapy Interventions: Speech and Language Therapy interventions are based on the impact of a child or young person's difficulties and not on a diagnosis of autism spectrum disorder. In assessing this impact, the Speech and Language Therapist will consider the following:</p> <ul style="list-style-type: none"> ◆ What is the impact of this person's difficulty? ◆ How does it actually affect him/her in everyday life right now? ◆ Is this an issue that can be addressed or the impact of it reduced by a Speech and Language Therapist/Speech and Language Therapy? <p>The chosen intervention will have a focus that reflects where the greatest reduction in impact can be achieved. The impact of the child/young person's difficulties may be affecting the child/young person, the family, carer or the education environment and could change over time.</p> |

Progress with the actions (continued)

| Action | Progress |
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| <p>Interventions and Support for Families (continued)</p> | <p>Speech and Language Therapy (continued): In deciding on an intervention the Speech and Language Therapist will be considering the outcome and the predicted change in the person as a result of the SLT intervention. If the intervention does not reduce the impact of the child/young person's difficulties, the Speech and Language Therapist would decide whether to continue seeing them. He/She will also consider support and identify whether the necessary support for the intervention is available from the family, carer, education or support agency. Following assessment, the interventions provided by Speech and Language Therapy will be based on best practice and may include the following:</p> <ul style="list-style-type: none"> ◆ More Than Words - designed specifically for parents of children on the autism spectrum to show them how they can use their child's unique strengths and preferences to build communication skills during everyday routines and activities. As a result, children receive effective autism treatment throughout each day, and not just while attending speech therapy sessions. It is designed for parents of children ages 5 and under on the autism spectrum. ◆ Talkability – specifically designed for parents of verbal children ages 3-7 with social communication difficulties, the <i>TalkAbility</i> Program teaches practical ways to help your child learn people skills. ◆ PECS – a communication system that encourages children to express their needs through the use of pictures. ◆ Social Skills Groups support children and young people who have difficulties with social communication. These groups are often aged based and cover a range of subjects depending on where the child or young person's area of impact lies. Groups can include: <ul style="list-style-type: none"> ● Getting ready for school ● Moving onto high school ● Developing friendship skills ● Working with others |

Progress with the actions (continued)

| Action | Progress |
|--|--|
| <p>Interventions and Support for Families (continued)</p> | <p>Speech and Language Therapy (continued)</p> <ul style="list-style-type: none"> ◆ Social Skills Group (continued): The groups target key social communication skills that children and young people may find difficult. These groups also link closely with carers and schools to ensure that skills are transferred into a range of situations. These key people in the child and young person's life are crucial to supporting their language and communication by using the strategies taught and aiming for appropriate goals. With older children and young people there is an emphasis on developing skills and strategies that the young people identify as being most important to them. ◆ Social Stories – describe a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal of a Social Story™ is to share accurate social information in a patient and reassuring manner that is easily understood by its audience. Half of all Social Stories™ developed should affirm something that an individual does well. Although the goal of a Story™ should never be to change the individual's behaviour, that individual's improved understanding of events and expectations may lead to more effective responses. ◆ TEACCH (Treatment and Education of Autistic and Communication related handicapped Children) – an intervention program for individuals of all ages and skill levels with autism spectrum disorders. <p>Generally, the intervention programme provided by Speech and Language Therapy will be a combination of these approaches to meet the needs of the individual. Interventions may be delivered on an individual or group therapy basis and provided in the home, clinic, nursery, school or special units.</p> |

What will we do next?

1. We will send this document out to key stakeholders in Health, Education and Social Work in North and South Lanarkshire Councils, Voluntary Organisations in North and South Lanarkshire. This report will be available on websites for [NHS Lanarkshire](#), [North Lanarkshire Council Learning and Leisure](#), [South Lanarkshire Council](#), [Hope for Autism](#), and the [National Autistic Society South Lanarkshire](#).
2. We will review this journey in two years time or sooner if the need arises.

Appendix 1: People who took part

Lila Agrawal, Consultant Paediatrician, NHS Lanarkshire
Colin Angus, Carer
Trevor Baxter, Inclusive Education Manager, South Lanarkshire Council
Paul Begley, Family Support Services Manager, South Lanarkshire Council
Richard Burgon, General Manager, North East Unit, North Community Health Partnership, NHS Lanarkshire
Dr Anne Chowaniec, Consultant Paediatrician, NHS Lanarkshire
Charles Clark, Consultant in Public Health Medicine, NHS Lanarkshire
Duncan Clark, Head of Child and Family Mental Health Services, NHS Lanarkshire
Magnus Cormack, Psychologist, NHS Lanarkshire
Dawn Cunningham, Additional Support Manager, North Lanarkshire Council
Helen Delaney, Additional Support Manager, North Lanarkshire Council
Anne Donaldson, Education Officer, Support for Learning, North Lanarkshire Council
Alison Downie, Speech and Language Therapy Team Leader, NHS Lanarkshire
Martin Egan, Service Manager, Children and Families, North Lanarkshire Council
Irene Houston, Inclusion Development Teacher, South Lanarkshire Council
Carol-Ann Jamieson, Senior Nurse/LEAN Leader, NHS Lanarkshire
Alison Kay, Consultant Paediatrician, NHS Lanarkshire
Patricia Kent, Practice Development Practitioner, NHS Lanarkshire (Working Group Facilitator)
Jean Kirkpatrick, PA to Pauline McCartan, NHS Lanarkshire
Liz Leggat, Support Manager, Pre-5 Support for Learning Team, North Lanarkshire
Janice Longford, Associate Director of Nursing for Primary Care, NHS Lanarkshire
Mairi MacIntosh, Inclusive Education Co-ordinator, South Lanarkshire Council
Hazel McCallum, Depute Head, Robert Owen Primary School, South Lanarkshire
Pauline McCartan, Professional Lead/Head of Service, Speech and Language Therapy, NHS Lanarkshire (Working Group Lead)
Anne McDade, Lead Speech and Language Therapist, Hanen Research and Audit
Ross McFadyen, Branch Officer, National Autistic Society, South Lanarkshire
Shirley Muir, Early Years Specialist Support Teacher.(East Kilbride), South Lanarkshire Council
Shirley Paterson, Psychological Service, South Lanarkshire Council
Geraldine Queen, Associate Director of Nursing for Primary Care, NHS Lanarkshire
Giselle Rothenberger, Educational Psychologist, North Lanarkshire Council
Carol Russell, Chairperson, Hope for Autism
Nici Sandison, Lead Speech and Language Therapist, LADS
Adrienne Shaw, Lead Speech and Language Therapist, LADS
Colin Sloey, Director of North Lanarkshire Community Health Partnership
Colin Smith, Autism Services Manager, Hope for Autism
Gregor Smith, Divisional Medical Director, NHS Lanarkshire
Linda Smith, Depute Head, High Blantyre School, South Lanarkshire
Karen Telfer, Educational Psychologist, North Lanarkshire Council
Elaine Walker, Additional Support Manager, North Lanarkshire Council
Owen Watters, General Manager, Coatbridge, NHS Lanarkshire

Appendix 2: Issues we identified

| Issues Identified: North Lanarkshire | | | |
|--|---------------------------|------------------------------------|------------------------------------|
| GAPS | DUPLICATION/ VARIATION | WAITS | ISSUE |
| Awareness of ASD and supporting organisations, e.g. HOPE | Early Bird | Waiting for assessment | Discussion with parents |
| No follow up from LADS | Therapeutic interventions | Wait for therapeutic interventions | Not all parents access HOPE |
| People who do not get a diagnosis | | | Transition, especially post school |
| Sensory assessment (<i>OT</i> involvement) | | | |
| Ongoing training and development for Public Health | | | |

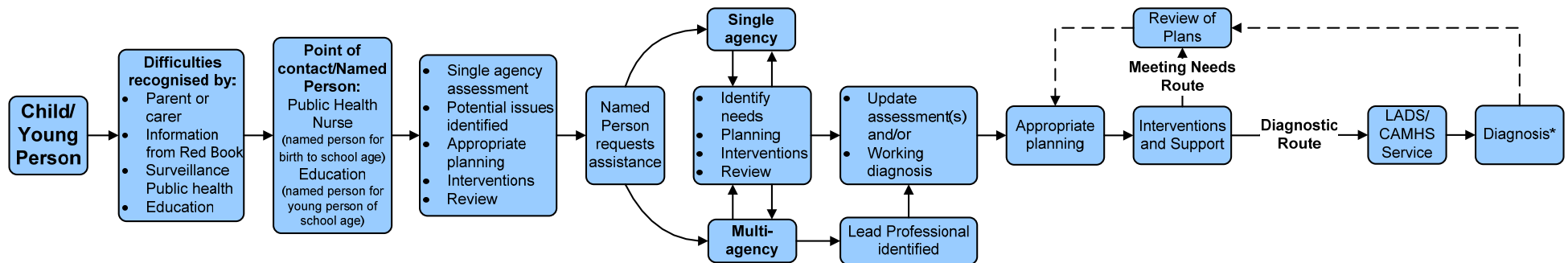
| Issues Identified: South Lanarkshire | | | |
|--------------------------------------|---------------------------------|--|----------------------|
| GAPS | DUPLICATION/ VARIATION | WAITS | ISSUE |
| Awareness of ASD | Variation in services available | Waiting for assessment | LADS resources |
| Training | | How early children are identified | Reduced surveillance |
| Support for parents | | Cover | Reduced surveillance |
| | | Parental consent key | |
| | | No educational placement without a diagnosis | |

Appendix 3: Child and Young Person Journey

Lanarkshire Autistic Spectrum Disorder Service
Child and Young Person's Journey
 April 2011



Timescale for assessment information following request for assistance, 10 weeks (as per ASL Legislation)**



Key to Abbreviations:
 ASL Additional Support for Learning Act
 CAMHS Child and Adolescent Mental Health Services
 GIRFEC Getting It Right For Every Child
 LADS Lanarkshire Autism Diagnostic Service

* Diagnosis can take place at any point along the pathway following assessment.

**In addition, parents and carers will be informed of the timescales (including national waiting times) and service information for the particular service(s) they have been referred to.

Appendix 4: Red Flag Warning Signs

Red Flags of Autism Spectrum Disorders and Developmental Delays in the Second Year of Life

ASD Red Flags

- Lack of showing
- Lack of coordination of nonverbal communication
- Lack of sharing interest or enjoyment
- Repetitive movements with objects
- Lack of appropriate gaze
- Lack of response to name
- Lack of warm, joyful expressions
- Unusual prosody
- Repetitive movements or posturing of body

ASD & DD Red Flags

- Lack of pointing
- Lack of playing with a variety of toys
- Lack of response to contextual cues
- Lack of communicative vocalizations with consonants

<http://firstwords.fsu.edu/flags.html>

| | |
|-------------------|---|
| <p>ASD</p> | <p>Autism Spectrum Disorder – complex developmental disorders, behaviourally defined, that include a range of possible developmental impairments in reciprocal social interaction and communication, and also a stereotyped, repetitive or limited behavioural repertoire. ASD may occur in association with any level of general intellectual/learning ability, and manifestations range from subtle problems of understanding and impaired social function to severe disabilities. Impairments in each of the areas relevant to ASD diagnoses occur along a continuum from minimal to severe and categorical diagnoses inevitably involve defining a cut off. Diagnostic classification in itself should not be the basis for decisions about provision within education or needs for social care and support. (SIGN 98)</p> |
| <p>ASL</p> | <p>The Education (Additional Support for Learning) (Scotland) Act 2004 as amended by The Education (Additional Support For Learning) (Scotland) Act 2009 provides a framework for local authorities and other agencies to support all children.</p> <p>For children and young people aged three – eighteen years <u>in</u> education a parent or young person (sixteen years and over) has the right to make a request of the education authority:</p> <ul style="list-style-type: none"> • to determine if the child or young person has additional support needs • to specify/describe the additional support needs • for a specific type of assessment. <p>The request for assessment may include an educational, psychological or medical assessment. Where a request has been made for an examination/assessment, the education authority may make a request to another agency to help them discharge their duties under the act. The education authority is not required to arrange for examinations or assessments to be carried out by a named individual or organisation requested by the parent or young person, it is the decision of the education authority to identify who is best placed to carry out the examination/assessment. The education authority may refuse the request for assessment if they feel the request is unreasonable. Once the decision to proceed with any assessment has been made, the process should be completed within a reasonable time frame, of approximately ten weeks.</p> <p>In terms of the journey the named person may make a request to their own agency or another agency to ask for assistance in terms of additional information/assessments to clarify the needs of the child or young person so that appropriate planning can be put in place and interventions begun. This may lead to a working diagnosis. It would be reasonable to follow legislative guidance when compiling assessment information. This should be done within 10 weeks.</p> |

Glossary and abbreviations (continued)

| | |
|-------------------------------------|---|
| CAMHS | Child and Adolescent Mental Health Services |
| LADS | Lanarkshire Autism Diagnostic Service |
| LEAN | Lean is a process that focuses on improving quality and flow to the way we work. Supporting a culture of continuous improvement across NHS Lanarkshire empowers healthcare workers in supplying an effective and efficient experience to our clients. Developed by Toyota, Lean is about getting the right things done, in the right place, at the right time, with the right quantities whilst being flexible and open to change. |
| GIRFEC | Getting It Right For Every Child is a national approach to supporting and working with all children and young people in Scotland. It affects all services for children and adult services where children are involved. It is based on research, evidence and best practice and designed to ensure all parents, carers and professionals work effectively together to give children and young people the best start we can and improve their life opportunities. |
| Information Sharing Protocol | Lanarkshire Information Sharing Protocol provides good practice guidance on obtaining and sharing information about young people amongst agencies. Parents of children under 12 years agree for information to be shared about their young person. Young people over the age of 12 years should be asked for their consent to share their information. |
| OT | Occupational Therapy |
| PHNs | Public Health Nurses – previously they were known as health visitors. |
| RED BOOK | This is the new Personal Child Health Record for use across Scotland. It should be used for all children born on or after 1 st January 2010 and includes World Health Organisation (WHO) growth charts. The Red Book should be given to the parent or carer on or as close to the 10 th day after the baby is born, normally by the Health Visitor or Public Health Nurse. |
| SIGN | Scottish Intercollegiate Guidelines Network - SIGN was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland. Its objective is to improve the quality of healthcare for patients in Scotland by reducing variation in practice and outcome, through the dissemination of national clinical guidelines containing recommendations for effective practice based on current evidence. For further information contact: www.sign.ac.uk |
| SLT | Speech and Language Therapy |