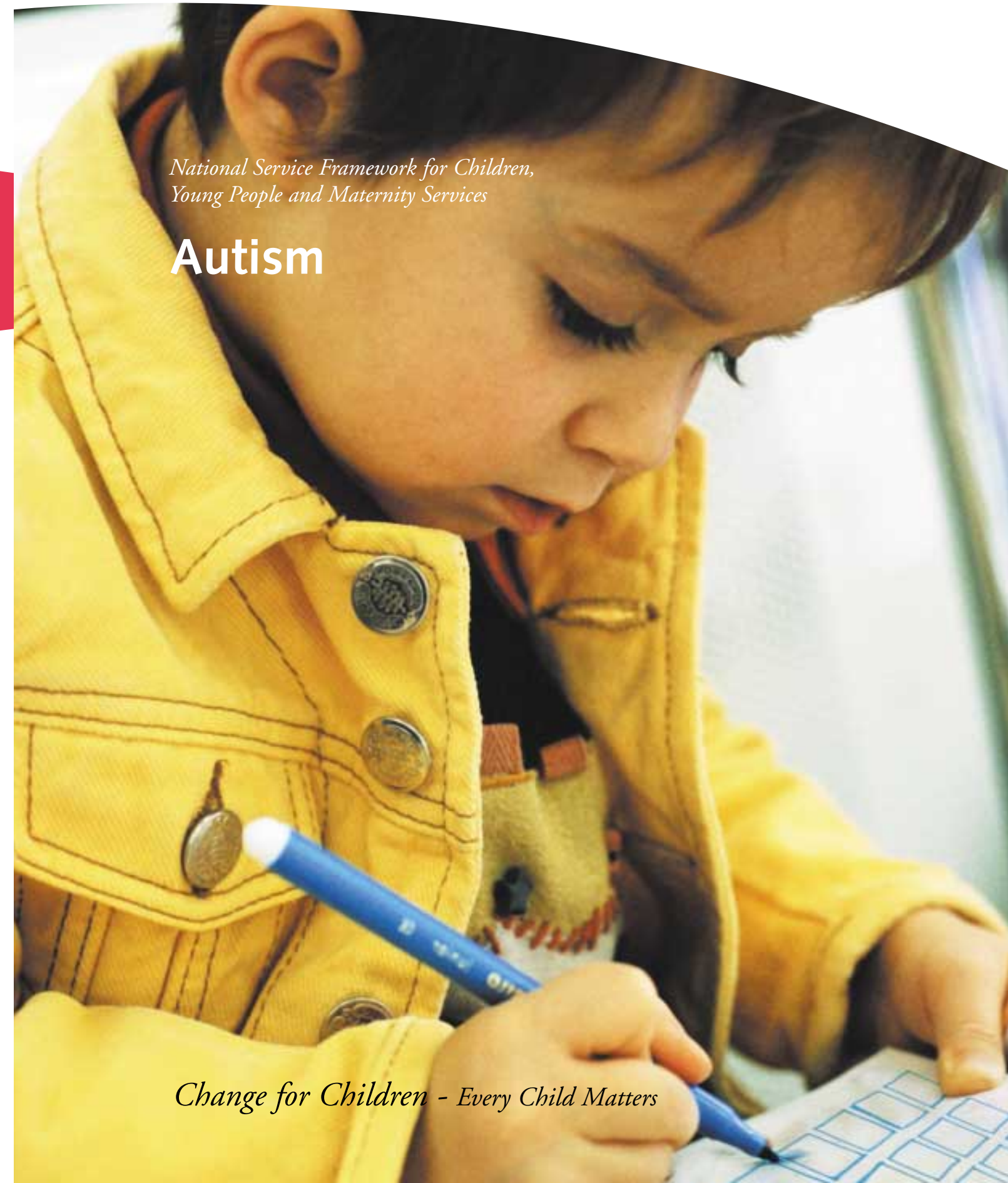


*National Service Framework for Children,
Young People and Maternity Services*

Autism



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| Policy | Estates |
| HR/Workforce | Performance |
| Management | IM & T |
| Planning | Finance |
| Clinical | Partnership Working |

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Introduction

The National Service Framework (NSF) for Children and Maternity Services will be published alongside supporting material, which includes a series of exemplar patient journeys. Whilst it is not the role of the NSF or the exemplars to provide detailed clinical discussion on individual childhood conditions or aspects of pregnancy or childbirth, exemplars illustrate some of the key themes in the NSF.

Several factors influenced the selection of exemplar conditions, for example: large numbers of children and families affected, significant cause of illness and distress, wide variability in standards of practice or service provision and suitability for demonstrating the NSF themes. Such themes include the importance of responding to the views of children and their parents, involving them in key decisions, providing early identification, diagnosis and intervention, delivering flexible, child-centred, holistic care, which is integrated between agencies and over time and is sensitive to the individual's changing needs.

The primary audience for the exemplars is professionals from a broad range of backgrounds including education, NHS, social services and the voluntary sector, (although they could also be of interest to parents and older children). The exemplars may be useful in a number of ways, for example, to:

- > Highlight further references, which relate to evidence in the NSF and elsewhere, including key clinical guidelines;
- > Stimulate local debate and assist multi-agency partners to re-evaluate the way they collaborate on, commission and deliver children's services, for this and other conditions, to the optimum benefit of children;
- > Provide an aid to examining and improving local clinical & non-clinical governance;
- > Provide a multi-disciplinary training tool for staff working with children and young people to raise awareness of specific issues and stimulate discussion;
- > Canvas the views of children and families on specific children's issues (eg via focus groups), provide a non-threatening mechanism to open discussion, such as good and 'not so good' aspects of the current service, and
- > Provide a starting point or template for debate, prior to development of new local strategies for managing complex childhood conditions.

Autism is a spectrum disorder and every child will present differently and have needs specific to them. This example is just one example of the possible patient journey.

George's Autistic Spectrum Disorder

| | Journey | Children's NSF Theme |
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| Identification of Problem v | <ul style="list-style-type: none"> > George, aged 3 years, has been growing well physically and has reached his developmental milestones within an appropriate timeframe. However, he has been causing his parents some concern about his delay in learning to talk. He also appears more withdrawn than his older sister was at the same age. He becomes absorbed for long periods in a solitary game or activity and then becomes very angry and frustrated, if disturbed. The "early years" worker at his local play group, which he attends twice a week, has also expressed similar concerns. | |
| Seeking Advice v | <ul style="list-style-type: none"> > There are different ways that George's parents could obtain advice, but they decide they would like to have a chat with the health visitor first to see whether they should take any further action or wait and see for a little longer. They find the health visitor's contact telephone number in George's parent held child record. They phone and leave a message for her to call them at home. | Standard 1 and 8 – easy access to health care team, when required. |
| Health Visitor Visit. (7 days) v | <ul style="list-style-type: none"> > The health visitor calls back and arranges an appointment to see George and his family at home. When the health visitor comes a week later, the parents describe their concerns about George's behaviour and communication difficulties. > George's mother says that she was unable to return to work after George was born. | Standard 1 – access to advice, Standard 2 – supporting parents. |

| | Journey | Children's NSF Theme |
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| | <p>The grandparents were happy to help but it was not fair to ask them to look after George, as they were becoming frail. Apart from George's two mornings at play group, he is cared for by his mother the whole time. She finds this very stressful.</p> <ul style="list-style-type: none"> > The Health Visitor observes George for herself and, when she tries to engage his attention, she experiences problems similar to those reported by his parents. She uses the training she has received on identifying autistic spectrum disorder (ASD) in toddlers, to help identify concerns. > The health visitor says that she is not in a position to diagnose if George has a medical condition, but advises them to discuss their concerns with George's GP. The GP could then refer George for further advice, if required. The health visitor writes a referral note for the parents to take to the appointment with their GP. | Standard 3 and 8 – consider the context of child and family needs. Standard 1 – timely access to advice and services. |
| GP Visit (9 days) v | <ul style="list-style-type: none"> > George and his parents visit the GP 2 days later (as required by Issues for Primary Care, the Existing Commitment in the Planning Framework 2005-2008 – access to GP within 48 hours). After reading the health visitor's note, the GP asks the parents to describe in more detail the background to their concerns. He listens to their anxieties and, despite the more limited context of the surgery, he is able to observe George's reactions and behaviour towards others. | Standard 3 and 8 – integrated, co-ordinated care. |

| | Journey | Children's NSF Theme |
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| <p>GP Visit (9 days) cont.</p> <p>∇</p> | <p>The GP does not attempt to examine George, as he becomes agitated when approached.</p> <ul style="list-style-type: none"> > The GP says that from his own observations and those of the parents and health visitor, he would advise a referral to the local Child Development Centre (CDC), for a full assessment. At the CDC, George will see a consultant developmental paediatrician for a general developmental assessment. > Also, based on the parents' concerns about George's communication difficulties, the doctor advises referral to a speech and language therapist immediately, without waiting for further assessment. > The parents agree and the GP writes referral letters, as agreed. Meanwhile, he suggests that the parents keep in touch with the general practice or health visitor, if they need additional support before the assessment appointment. | <p>Standard 2 and 8 – proactively seek to support parents, listen to parents' concerns.</p> <p>Standard 1 – early intervention</p> <p>Standard 8 – access to therapy services.</p> |
| <p>CDC Developmental Assessment (7 weeks)</p> <p>∇</p> | <ul style="list-style-type: none"> > George's parents receive an appointment to take him for the assessment by a consultant developmental paediatrician at the CDC in 6 weeks' time. > At the assessment, details of George's developmental history (including any problems during pregnancy) and family history (especially similar problems in the family) are taken from the parents by the paediatrician. George has a full examination, which he finds rather distressing. | <p>Standard 1 – early diagnosis, early intervention</p> <p>Standard 3 & 8 - child seen in the context of the family.</p> |

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| | <ul style="list-style-type: none"> > After George's assessment has been completed, the paediatrician provides feedback, in line with the "Right from the Start Template¹¹ (SCOPE & DH 2003) that George's likely diagnosis is ASD. The doctor provides an opportunity to discuss this and says that when the assessment report is written, a copy will be sent to them for comment. An appointment to review the report is made for the parents in 3 weeks time. | <p>Standard 2 - support for parents.</p> <p>Standard 3 & - information on child's condition.</p> |
| <p>CDC Developmental Assessment Report (10 weeks)</p> <p>∇</p> | <ul style="list-style-type: none"> > At the assessment review meeting, the paediatrician again discusses with the parents his view that there are sufficient grounds to suspect ASD. The doctor gives the parents the opportunity to express their anxieties and ask questions and discusses the best way to receive more certainty about the diagnosis. > He recommends a multi-agency assessment and explains that if this is done at an early stage it will help maximise their access to the support for George, both at home and for his education. The parents agree to the doctor making a referral so that the ongoing process of multi-agency assessment can begin. | <p>Standard 8 – easily accessible and timely information about condition and services.</p> <p>Standard 8 – parents involved in decisions affecting their children.</p> <p>Standard 2 – provide information to support parents in their caring role.</p> |

| | Journey | Children's NSF Theme |
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| CDC Developmental Assessment Report (10 weeks) cont. | <p>> The doctor also discusses with the parents the probability that George may have special educational needs (SEN) and informs the local education authority and designated SEN lead at the Primary Care Trust of this.</p> <p>> The parents are provided with information about benefits, services, possible interventions and local support groups to help George. Also, they are given contact details of national support organisations, such as:-</p> <p>> Contact-a-Family - tel 0808.808.3555 National Autistic Society (NAS) - tel 0845.070.4004 Parents for the Early intervention of Autism (PEACH) - tel 01344.882248 family fund - tel 0845 130 4572</p> <p>> The parents are also told that a member of the multi-agency assessment team will personally contact them within 6 weeks, after receiving George's CDC assessment referral report.</p> | Standard 2 and 8 – information for parents about available services. |
| Multi-agency Assessment Team Contact (14 weeks) | <p>> The CDC implements the joint agency protocol to set up a multi-agency assessment meeting.</p> | Standard 8 multi-agency Assessment of Disabled Children |

| | Journey | Children's NSF Theme |
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| | <p>> Four weeks later George's parents receive an introductory phone call from a member of the multi-agency assessment team and they agree to start the assessment process for George at a time which is convenient for the parents.</p> | Standard 3 & 8 – child centred care, involving parents in decisions about assessment and care. |
| Multi-agency Assessment (16 weeks) | <p>> George and his parents attend for the multi-agency assessment meeting, which includes representatives from health, social services and education and involves several different elements, including:-</p> <p>> Review of previously gathered information,</p> <p>> ASD development and family history, including diagnostic semi-structured interviews,</p> <p>> Observations of George's behaviour in varied settings,</p> <p>> Cognitive assessment which includes:- psychological input by ASD trained clinical or educational psychologist and educational input by specialist teachers or "early years" professional and/or educational psychologist,</p> <p>> Mental health and behaviour assessment,</p> <p>> Assessment using the "Framework for the Assessment of Children in Need and their Families, DH/DfES 2000" considers the family's needs and strengths which affect care for George and his difficulties (e.g. sleep and behaviour problems) and maximise his inclusion in family life.</p> | <p>Standard 8 – prompt multi-agency assessment of Disabled Children</p> <p>Standard 2 and 8 – supporting parents, keeping them informed</p> |

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| Multi-agency Assessment (16 weeks) cont. ✓ | <p>It also includes assessment of the needs of the other child in the family and the parents as carers. This includes an assessment of the parents' needs under Carers & Disabled Children's Act 2000</p> <ul style="list-style-type: none"> > Assessment of wider economic and housing needs, > Medical history and physical examination, > Medical tests, as appropriate following doctor's consultation and examination, > Other assessments included co-ordination and sensory assessment, but further interventions were found to be unnecessary in these areas, > At the end of the assessment, the doctor informs George and his parents that all multi-agency assessment team members involved in George's assessment would be contributing to the final written report. A follow-up meeting is offered to discuss the draft report when completed. A copy will be sent for the parents to see before the feedback meeting. > On the basis of the feedback, the local education authority (LEA) receives from the assessment team, it decides to carry out a statutory assessment with a view to drawing up a special educational needs (SEN) statement. | <p>Standard 3 and 8 – seeking the views of parents.</p> <p>Standard 3 & 8 – parents actively involved in partnerships.</p> |

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| | <ul style="list-style-type: none"> > There are statutory timescales for this that they need to meet. They also work to have the assessment completed well in advance of George starting school. > The assessment team and George's parents agree that the family need the support of a Key Worker and the family's Health Visitor is appointed to this role. It is agreed that the Key Worker should be the main contact with the family and take responsibility for co-ordinating review meetings and liaising with professionals to ensure all agreed support is acted upon. The Key Worker should also take responsibility for communication and making sure everyone has up-to-date information about George. | <p>Standard 8 - key worker for children and young people with complex needs to provide single point of contact and help obtain services required.</p> |
| Multi-agency Assessment Team Feedback (17 weeks) ✓ | <ul style="list-style-type: none"> > George, his parents and the Key Worker attend a feedback meeting with 2 team members of the multi-agency assessment team, to go through the draft report. > Using the "Right from the Start Template", (Scope and DH 2003) George's parents are told that the assessment indicated that George has ASD and the reasons for this conclusion are explained to them. George showed reduced ability or impairment in the 3 areas which define a diagnosis of ASD: | <p>Standard 8 – information about child's condition.</p> |

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| Multi-agency Assessment Team Feedback (17 weeks) cont. | <ul style="list-style-type: none"> > 1. social understanding and social behaviour, > 2. social communication (verbal & non-verbal), > 3. rigidity of thinking & difficulties with social imagination. <ul style="list-style-type: none"> > George's parents are relieved to have a diagnosis, at last, but need time to grasp the reality and to ask questions. The team members take some time to explain the findings of each assessment component. > They are able to reassure George's parents that he has many strengths. > The recommendations in the assessment report (e.g. on education) are discussed with the parents and they are assured that with proper support, George will be able to develop to his optimum potential. > The parents are concerned because George has developed bowel pain and his behaviour is becoming more challenging. This is having an impact on the whole family. In view of these changes, the parents are asked to consider whether they wish George to be referred for a tertiary ASD assessment for further opinions. A member of the multi-agency assessment team offers to visit them at home in the next few days to discuss this. | <p>Standard 6 – parents require explanation of the diagnosis.</p> <p>Standard 1 – timely access to appropriate services.</p> <p>Standard 8 – information about services.</p> <p>Standard 8 – listening and responding to children, young people and their families.</p> <p>Standard 7 – access to hospital specialist as part of co-ordinated care.</p> |

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| ASD Pre-school Educational Support | <ul style="list-style-type: none"> > The parents are advised that in discussion with them and their key worker, over the next few weeks, a family support plan, and a co-ordinated programme of intervention will be considered and developed. This will link with any additional interventions being developed for George by the Special Educational Needs Co-ordinator (SENCO) at his early years setting, supported by an Area SENCO, and any forthcoming assessment process under the SEN statementing procedure. | <p>Standard 3 & 8 – child centred, co-ordinated care.</p> |
| Family Support Plan (ongoing) | <ul style="list-style-type: none"> > A follow-up meeting between George, his parents, the Key-Worker and assessment team representative is arranged 2 weeks later to progress the family support plan. This sets out:- <ul style="list-style-type: none"> > the findings from George's multi-agency assessment, the impact on the family, the progress on existing interventions and the need for additional input, > the level and type of support George needs including therapy, other interventions, information and practical advice, > how, where, when and by whom professional support will be provided, > how often the family will be visited in the home and by whom, > how often and when George's care/support will be reviewed, | <p>Standard 1 and 8 – early identification.</p> <p>Standard 8 – partnership and involvement of parents.</p> <p>Standard 2 and 8 – supporting parents' individual needs.</p> |

| | Journey | Children's NSF Theme |
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| <p>Family Support Plan (ongoing) cont.</p> <p>√</p> | <ul style="list-style-type: none"> > how, when and by whom George's development will be monitored, > the package of support to be received by George, which includes the timely provision of speech and language therapy services for his communication difficulties and physiotherapy services for advice and guidance on his co-ordination problems. > It is acknowledged that due to the additional stress of caring for George, regular short breaks are required for the family. The family's key worker introduces the idea of short term breaks for the family. These provide George with some space and support from ASD experienced carers and the family with some space for themselves and their other child. The social worker gives them the <i>Parents Guide to Direct Payments</i> (CDC 2004) and informs them that direct payments could be used to provide such support (Carers and Disabled Children's Act 2000) but the parents decide not to pursue this at this point. > George's developments are recorded in the Parent Held Child Record, following visits to health and other professionals, including copies of all correspondence. > George's parents are reminded by their Key Worker about how to claim for Disability Living Allowance and for support from the Family Fund. | <p>Standard 8 – access to therapy services.</p> <p>Standard 8 – short breaks for children, young people, parents and carers provides positive experience and reduces stress.</p> <p>Standard 1 – Parent Held Child Record for all children.</p> |

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| | <ul style="list-style-type: none"> > A member of the multi-agency assessment team visits to discuss whether Georges parents would like an ASD tertiary assessment to be arranged. George's parents say they would like the referral made. > They also agree that the Key Worker should liaise with the LEA about provision to meet George's special educational needs, to be determined under the statutory process for drawing up a statement of SEN. > The family are reminded of contact details for local support groups for parents of children with ASD, which can provide additional information and support (eg NAS, PEACH and Contact-a-family.) > The assessment team representative agrees to make contact to arrange:- <ul style="list-style-type: none"> - ASD tertiary assessment, - visits to potential 'short breaks' carers. - to feed into the educational support from George's early settings. > The next appointment to progress the family support plan is arranged in one month, recognising the need for regular update, given the ongoing changes in George's interventions. | <p>Standard 3 & 8 – co-ordination of care.</p> <p>Standard 8 – information about services, access to full range of services</p> <p>Standard 3 and 8– child centred, co-ordinated assessment and care.</p> <p>Standard 1 and 8 – early identification,</p> |

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| Testiary ASD Assessment | <p>> George and his parents attend for a tertiary ASD assessment to access co-ordinated specialist advice, which is provided in a child and family-centred context by a multi-agency team.</p> <p>> The paediatric neurologist concludes that George's motor difficulties are associated with ASD and agrees to write to the LEA informing the Authority of George's difficulties in this area, adding to any advice being given by health professionals to the LEA under the SEN assessment and statementing process.</p> <p>> The gastroenterologist discusses management strategies with the parents and agrees to write to the GP about his symptoms and its management.</p> <p>> Both the neurologist and gastroenterologist copy the letters and reports to the parents.</p> <p>> Following assessment, the psychologist discusses with the parents ways of helping George and addressing his challenging behaviour. The psychologist offers to write to the LEA about George's and also to contact the Child and Adolescent Mental Health Service (CAMHS) to request their input.</p> | <p>Standard 3 and 8 – child centred, co-ordinated assessment and care.</p> <p>Standard 7 – integration and co-ordination of services.</p> <p>Standard 8 – access to full range of specialist services and advice for children with complex needs.</p> <p>Standard 3 and 6 - letters should be copied to parents</p> |

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| Family Support Plan Review (Ongoing) | <p>> George, his parents, and Key Worker return for a multi-agency assessment appointment one month later to continue development of the Family Support Plan.</p> <p>> The multi-agency assessment team have received copies of the report on the tertiary ASD assessment,</p> <p>> Progress on the ASD pre-school support is fed back and they consider any additional or alternative provision which may be needed,</p> <p>> Once the family support plan is set up, George and his parents continue regular 6 monthly reviews with the local ASD specialist team and family social worker. The Key Worker also attends and remains a pivotal contact both for the family and for other professionals. The team welcome George's sister also attending reviews from time to time because it is helpful in providing insight into family strengths and needs. Sometimes the meetings take place in the home.</p> | <p>Standard 8 – Multi-agency partnership, Access to full range of services.</p> <p>Standard 3 - information sharing.</p> <p>Standard 8 – full range of support services, routinely supported and involved in care,</p> |
| Statement of SEN Primary School (5 years old) | <p>> George has learning difficulties, and the LEA have decided to make special provision through an SEN statement. His progress is reviewed regularly through an Individual Education Plan (IEP).</p> | <p>Standard 3 and 8 – Child centred care, working with partners.</p> <p>Standard 8 - support for Disabled Children with SEN.</p> |

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| Statement of SEN Primary School (5 years old) cont. | <p>> Once George reaches 5 years, support is provided in an ASD unit with ASD trained staff within a mainstream primary school. The school is an extended school. The NHS continues provision for George's health needs, including speech and language therapy.</p> <p>> The school has a strong inclusion policy and in discussion with George's parents they arrange for him to be included with his peers in the main school for some activities, with appropriate support.</p> | Standard 8 – Promoting social inclusion. Supporting Disabled children with SEN |
| Regular Reviews | <p>> As well as the 6 monthly regular reviews during his primary school years ongoing input includes after-school care, short breaks and school holiday care, as required.</p> <p>> George's special educational provision is reviewed through annual reviews of his SEN statement and termly reviews of his progress through IEPs with input from the LEA's ASD support team. George's IEP information is included by the school within the whole school records they keep for all pupils.</p> <p>> George's parents agree that now George has started school, it is more appropriate for his key worker to be a social worker than a health visitor.</p> | Standard 8 – routinely supported and involved in care. Co-ordination of health, education and social services. |

| | Journey | Children's NSF Theme |
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| | <p>> As a result of these reviews, George receives services from CAMHS, which provides specialist assessment and advice to the LEA for George's special educational needs in relation to his behavioural difficulties.</p> <p>> George also receives health support on a continuous basis in ways which maximise his attendance at school.</p> <p>> The family also apply for and receive a direct payment. They decide to use this to employ someone to look after George and another boy with ASD, who they have met through the local NAS group, for a couple of hours each weekend and during school holidays. It has been previously explained to the family that direct payments can be used to obtain a variety of support services. (Carers and Disabled Children's Act 2000).</p> | <p>Standard 9 - comprehensive psychological and mental health services, which meet the needs of disabled children, including those with learning difficulties and ASD.</p> <p>Standard 8 - use direct payments to maximise flexibility of services.</p> |
| Transition to Secondary School (11 years old) | <p>> George, aged 11 years, needs longer than other children, to become familiar with the idea of his forthcoming move to a special unit within a mainstream secondary school. This is a known feature of ASD and special arrangements are made to help George adjust to the idea before the final move. The regular support George has been receiving is to re-focussed to meet his current needs.</p> | Standard 8 – Services for disabled children centred around needs. |

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| Transition to Secondary School (11 years old) cont. | <p>∨</p> <ul style="list-style-type: none"> > The annual review of George's SEN statement in Year 5 considers his forthcoming transfer from primary to secondary school and the type of provision that may be required. This enables the parents to visit possible schools and to consider their preference for the school they wish George to attend. > George's statement is amended by 15th February in his year of transfer (Year 6), to include the name of the secondary school he will be attending, taking account of his parents' preference. The LEA talk to George's parents about the arrangements for transport to school. > Information, including the latest IEP information, is transferred to the new school and the primary school staff who know George visit the receiving school so that the secondary school staff have a clear understanding of his needs. > In year 6, George makes regular visits to his new school, so that he can start to become familiar with the staff, the children and the surroundings. > During one school visit, an introductory meeting is arranged between George, his parents, the SENCO and the school nurse. | Standard 8 - supporting disabled children with SEN |

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| Secondary School | <p>∨</p> <ul style="list-style-type: none"> > George's new school has resourced provision for children and young people with SEN and a strong policy on inclusion. They are aware of the additional risks of bullying to children with SEN and tackle these issues in their policy on bullying. However, the school agrees with George and his parents that he should join in mainstream school activities as much as possible, for a trial period, and arrangements are made to support this. > The arrangements made to support George's inclusion work well and after a difficult first term adjusting to a new school, he settles down well and he is able to increase his involvement in activities over time. | Standard 8 – Promoting social inclusion. |
| Transition to Adulthood (16 years old) | <p>∨</p> <ul style="list-style-type: none"> > During his 5 years at secondary school, George progresses well and develops new skills, which enable him to gain 3 Award Scheme Development and Accreditation network (ASDAN) qualifications > Regular reviews of his family support plan and SEN statement continue on an annual basis (or more frequently, as required), | Standard 4 and 8 – Growing up – transition processes are planned and focussed around the young person. |

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| <p>Transition to Adulthood (16 years old) cont.</p> <p style="text-align: right;">v v</p> | <ul style="list-style-type: none"> > At the Year 9 annual review of George's SEN statement his transition needs are discussed in a multi-agency meeting, which includes representatives from health, education, social services and a Connexions Personal Adviser. A Transition Plan is drawn up and the delivery is overseen by the Connexions Personal Adviser. It includes support George may need in a range of areas:- > for independent living, including housing needs > social services support including direct payments > health care support > social skills training > social life and relationships, > George goes on to further education (FE) at his local FE. The college receives financial support from the local Learning and Skills Council to help meet students' additional needs. Following discussion with George and his parents, the Connexions Service personal advisor takes on the role of his key worker. > The transition planning also begins to consider important issues relating to George's longer-term progression beyond school, including opportunities for work experience, employment and leisure activity. | |