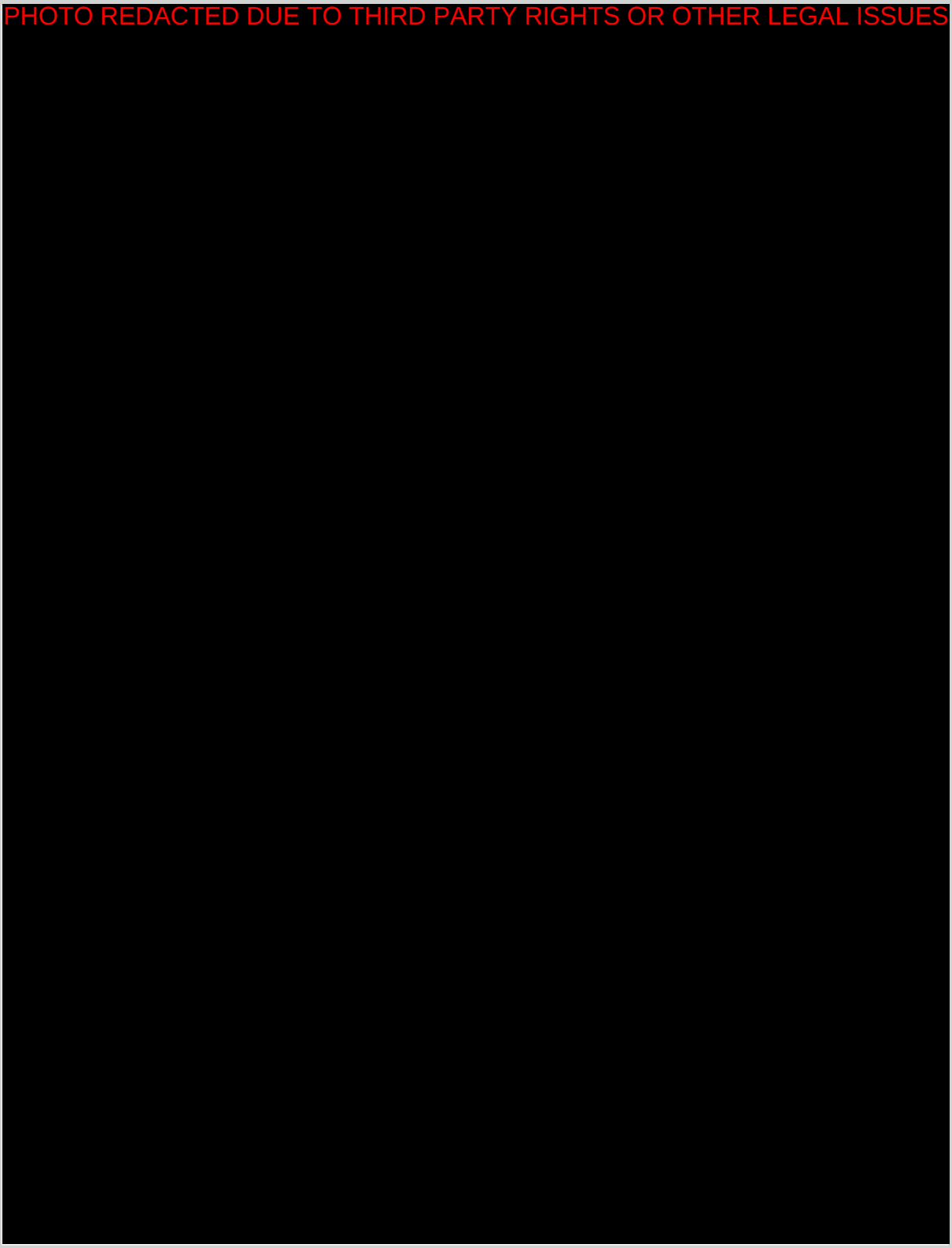
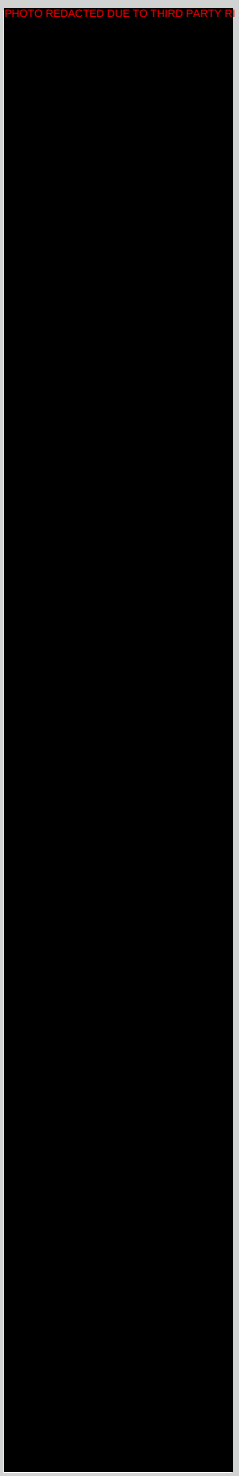




The Scottish Strategy for Autism

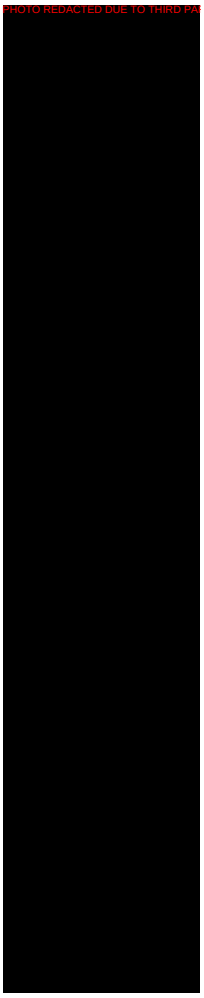
Menu of Interventions

The Scottish Government
Riaghaltas na h-Alba

The Scottish Strategy for Autism

Menu of Interventions

The Scottish Government, Edinburgh 2013



John Cornock
(Self Portrait, pen, 2011)

Fiona Birrell
(Portrait of Shona, pen, 2011)

John Ellsworth
(Self Portrait, coloured pencil, 2011)

Rachel Hook
(cover image – abstract painting, 2010)

Rachel Hook
(Portrait of Mandi, coloured pencil, 2011)

Scott Cation
(Portrait of Alister, felt tip pen, 2011)

Kubus Joss
(Portrait of Stuart, coloured pencil, 2011)

The artists featured on the cover all attend Scottish Autism's Art Opportunities service. Art Opportunities is a day service for adults with autism specialising in arts and crafts based activities, from painting and drawing to textiles and glass work. They include the abstract painting by Rachel Hook which was painted for Young Talent 2010, an exhibition of artwork created by young people with disabilities.

This document is also available from our website at **www.scotland.gov.uk**.

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Guide to Interventions and Supports for People on the Autism Spectrum

Foreword

I am delighted to introduce this guide to interventions and supports for people on the autism spectrum, as envisaged by Recommendations 10 and 11 of the Scottish Strategy for Autism as follows:

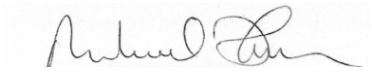
Recommendation 10: recommends that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with an ASD, that are appropriate and flexible to individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions.

Recommendation 11: recommends that consideration is given to the specific supports needed for the more able individuals with ASD.

I know this guide – which has been developed by a multi-agency group including people with ASD and their parents and carers– has been widely anticipated by autism professionals as well as those on the spectrum and their parents and carers.

The guide will help identify available advice and support and set out the referral and assessment processes for all other services and interventions.

I am confident that you find this guide an excellent tool for supporting people on the spectrum and their parents and carers and it will go a long way towards improving peoples' lives – a fundamental aim of the Scottish Strategy for Autism.



Michael Matheson
Minister for Public Health

Guide to Interventions and Supports for People on the Autism Spectrum

“Children and adults on the autism spectrum each have a unique set of conditions which will not necessarily fall within the categories of learning disabilities or mental health, although these conditions may be present. Autism impacts on the whole life experience of people and their families.” (Public Health Minister 2011)

The Scottish Autism Strategy highlights indicators of good practice for developing local autism provision and these include the development of local ASD strategies. It is for localities to decide how these are drawn up in their area but it is recommended that there is involvement with people representing all statutory and appropriate voluntary bodies, individuals on the spectrum and families.

This guide is intended to provide a framework for the development of these strategic plans around Scotland. It provides information, drawn from a wide range of professionals, individuals and families of people on the spectrum, regarding the challenges faced by people with ASD across the lifespan and ability range and how these might be best addressed. This is a flexible approach which allows for the guidelines to be used both generally, across services and locations, but also, more specifically, as required by individuals. (See worked examples Appendices 1-3 to illustrate how it might be used) It is not however, a comprehensive list of all possible interventions and supports nor can it provide information regarding the efficacy of specific interventions.

Guide to Interventions and Supports for People on the Autism Spectrum

Introduction

This paper was drawn up by a multi agency group including parents and carers and aims to provide a guide to interventions and supports required by people on the autism spectrum across the lifespan and ability range. These are to meet the Scottish Autism Strategy recommendations 10 and 11:

RECOMMENDATION 10
It is recommended that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with an ASD, that are appropriate and flexible to individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions.

RECOMMENDATION 11
It is recommended that consideration is given to the specific supports needed for the more able individuals with ASD.

In this document we will outline the background and rationale for the development of the menu of interventions drawn up to meet recommendations 10 and 11 of the Scottish Autism Strategy, list broad outcomes, restate requirements of good ASD care provision, discuss potential measurement of outcomes and provide an overview of interventions and supports.

The language used in this document is as used in the Scottish ASD strategy:

“It is important to explain the choice of language and terminology used in the document because the complex nature of the autism spectrum gives rise to a range of personal and professional perspectives. Although this means that it is not easy to find a common language that reflects the views of the various groups, what we have tried to do is reflect the diversity of the community in a positive way. More generally, we recognise that there is

a need to be sensitive about the use of words like “disorder” or “impairment”. These are clinical terms that are understood in those settings and included in sections of that nature. However, we know that many individuals on the autism spectrum do not accept those terms, preferring to stress that they have a different way of being in, perceiving and engaging with the world and those with whom they share it. At the same time, some individuals on the spectrum face significant challenges in their daily living and are in need of high levels of support specifically tailored to their needs.”

Background

There is a proliferation of “interventions” for people on the autism spectrum. An initial trawl by the group identified several hundred. However, the evidence base in support of most of these interventions is scant. The SIGN guideline 98 published in 2007 relates only to those under 18. The NICE guidelines for adults with ASD published in 2012 provides useful information but emphasises that the evidence base identified to underpin their recommendations is limited and frequent recourse was made to the literature relating to children or to those with Learning Disabilities.

The group drawing up this guideline is not, therefore, in a position to make evidence based recommendations. However, it is clear that many people are working effectively with people on the spectrum and their families. Much work of practical use is going on throughout the country that is not necessarily formally evidenced by research studies.

There is a need to evaluate this work with an emphasis on practice into theory rather than the other way about. The Scottish Autism Strategy requires that a menu of interventions be drawn up so the group, comprising specialist clinicians, educationalists, researchers, autism practitioners and carers took a pragmatic view and decided that, rather than look at existing interventions, they would look at the nature of the autism itself and the challenges it poses for many. This would then enable them to identify interventions to address these challenges.

Guide to Interventions and Supports for People on the Autism Spectrum

The difficulties and challenges common to people on the spectrum were discerned following lengthy consultation and are as follows:

- Understanding the implications of an autism spectrum diagnosis
- Development of effective means of communication
- Development of social communication
- Developing and maintaining relationships
- Social isolation for individual with autism
- Social isolation for family
- Learning to learn skills
- Predicting and managing change
- Behaviour and emotional regulation protecting wellbeing
- Restricted and repetitive interests and behaviours
- Motivation issues
- Sensory issues
- Daily living skills
- Co-existing conditions (e.g. epilepsy, anxiety etc).

It is hoped that identifying ways of addressing these issues provides a practical framework for interventions and supports where required.

Interventions

Intervention, whether it be through Education, Social Work, Health or Voluntary Services, needs to follow on from appropriate assessment by a team with specialist knowledge and experience of ASD. Ideally, adults with ASD would have been diagnosed in childhood but, in reality, many have been missed and present in adulthood. They should have access to accurate diagnostic assessment carried out by qualified and experienced clinicians as a precursor to intervention.

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Following diagnosis for children, current Scottish Early Years Policy outlined four principles of early intervention. These principles underpin the group's thinking around interventions for both children and adults.

- We want all to have the same outcomes and the same opportunities
- We identify those at risk of not achieving those outcomes and take steps to prevent that risk materialising
- Where the risk has materialised, we take effective action
- We work to help parents, families and communities to develop their own solutions, using accessible, high quality public services as required.

There are many forms of intervention and, as an initial guide when collecting examples of ASD interventions, the group took the definition as being "things people do that help". This was further refined to clinical, educational and social interventions. A distinction was made between interventions which are to lead to some form of change and supports which are to maintain skills when developed. However, the group was keen not to be too prescriptive and specific as much depends on the individual with ASD and their context. Some interventions are supports and vice versa so it was decided not to make artificial distinctions between the two terms.

Clinical intervention, usually provided by health services, requires that the client be assessed by a specialist ASD clinician who has the knowledge about their particular condition in the context of the ASD spectrum and all its co-existing conditions. This clinician has detailed knowledge of development across the lifespan and/or adult personality as well as family dynamics and lifestyle. They need to have the level of knowledge and therapeutic skill to be able to intervene at an appropriate level to effect behaviour change where required. Individuals and their families need to be able to quickly have access to the clinician when necessary.

An educational intervention is usually carried out by qualified education specialists such as teachers or educational psychologists but may be supported by other staff depending,

as previously stated, on the individual and the context of the intervention. Social interventions, in their broadest sense, may be introduced and maintained by a range of potential providers and all may be supported by families and carers working together with the team involved. It is important to remember that people on the spectrum may be carers themselves. This has implications across the lifespan from maternity care to care of the elderly and all points in between.

Capacity and consent issues should be considered regarding the individual thought likely to benefit from the potential implementation of any intervention. There may be considerable overlap between types of intervention and multi agency collaboration may be required with a clear lead identified for each individual.

MENU OF INTERVENTIONS

Level of intellectual ability and stage of life mean that interventions and support should be customised to meet the needs of each individual with an autism spectrum disorder and the needs of their families.

ASD CHALLENGE	INTERVENTIONS (to include advice, therapeutic interventions and counselling)
1. Understanding the implications of an autism diagnosis	Post diagnostic discussion (s) and individualised counselling The provision of good quality education and information packs for individuals, families/carers along with appropriate verbal discussion at time of need. Use of visual props if needed. Signposting to useful websites and forums.
2. Development of effective means of communication	Individualised language therapy assessment. Updated as required. Alternative and augmentative communication systems introduced where required. Work to ensure language system (regardless of form) is used functionally and is therefore effective on an individual basis. Teaching/learning on internet etiquette and supervision.
3. Social communication	Targeted social communication programmes delivered either individually or in a group setting as required and appropriate to the individual to include internet etiquette and promotion of online safety.

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4. Developing and maintaining relationships	Work to assess the understanding of relationships and promotion of skills to develop relationships including sexuality issues and intimate relationships. Access to social groups, friendship circles etc
5. Social isolation for individual with autism	Accessible social groups and opportunities, support in the community. Befrienders. Respect the need to be alone at times. Acceptance by families that friendships can take many forms
6. Social isolation for family	Family/ Partner/ Carer support, opportunity for respite. Access to autism friendly environments
7. Learning to learn skills	A functional assessment of the person's cognitive abilities and learning style leading to a planned programme both directly with the individual and indirectly with the family, carers etc. Formal psychometric testing may be conducted if appropriate to inform intervention.
8. Predicting and managing change	Timely individual direct work with individuals to teach methods where required. Family/carer /employer guidance/education in these methods Visual supports; timetables, timers, text alerts, choice boards etc to be used as appropriate
9. Behaviour and emotional regulation protecting wellbeing	Knowledge development in understanding behaviour in the context of ASD. Individual work with the individual on assessing behaviour, recognising triggers and developing and managing the implementation of strategies to help. Behaviour support plans, cognitive interventions, psychotherapy or counselling as required and indicated by life circumstances eg around transitions of all types including bereavement. Work with the individual's family/carers, criminal justice, social work, Police as appropriate. Autism Alert card possession
10. Restricted and repetitive interests and behaviours	Assessment and positive day to day management on an individualised basis. Treatment by mental health clinician if required
11. Motivation issues	Structured programmes as appropriate to the individual linking to the other core challenges as required. Career guidance, employer/HE/FE support.
12. Sensory issues	Assessment of sensory difficulties. Identification and implementation of strategies. Environmental adaptation on an individual basis with individual control working towards reducing the impact of sensory sensitivities
13. Daily living skills	Assessment of core life skills as required across the lifespan and to take account of changing needs at various transitions. Specific individual programmes to teach and maintain these skills where needed. Involvement of families/carers in assessment and implementation of new learning Education for families/employers/ care providers/housing dept re practical needs

14. Co existing conditions- examples	epilepsy, dyspraxia, dyslexia, disorders of attention, sensory impairment, anxiety, sleep disorder, addiction, anger management, depression, self harm, psychosis, personality disorder, OCD, disordered eating patterns etc These require assessment and treatment/management by appropriate specialist clinician. Joint working is crucial across specialities with a clear case co-ordinating lead identified.

These interventions and supports fit within the Scottish Autism Strategy recommendations for good Autism provision which state that there should be:

1. A local autism strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the 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 multi-agency 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 multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD.
9. Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.
10. A self-evaluation framework to ensure best practice implementation and monitoring.

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Referral

This should by existing means of referral to the respective services ie to NHS services via GP, to social work services via local referral systems, education via schools etc. Those services should have a heightened awareness of the need for attention being paid to potential ASD referrals. There are implications for ASD awareness training here.

Evaluation

Measuring the extent and appropriateness of the implementation of the relevant interventions and supports should be locally decided. As part of local ASD strategy development the menu should be used to measure and record the availability of the interventions from the table. This will enable the identification of any gaps in provision. (See worked example Appendix 1). There is clear scope for localised variation within the framework provided. It may also contribute to development of clear pathways to referral for intervention as appropriate.

It is important to measure outcomes in order for their effectiveness to be measured. A number of outcome measures were identified. Some appeared to be mainly for people with a learning disability, others were very highly specific to people on the autism spectrum who had very discrete needs. There are some outcome measures that require commercial registration and specific training on implementation. People on the autism spectrum are a disparate group and outcome measures relevant to all yet specific enough to be useful are required. Selection of outcome measures is perhaps a task for the local multi agency strategic groups. They are best placed to consider the outcome measures most applicable in their areas and reflecting local needs.

It may be that quality of life outcomes are more appropriate than, for example, educational or health based ones. Schalock's (2000) framework, and its predecessor's, Schalock (1994) have been widely adopted by many studies that have investigated the quality of life of disability populations. Schalock (2000) outlines quality of life domains in a manner that

fuses a social model of disability with an individual commitment to self-determination and self-advocacy. The group acknowledges that people on the spectrum are not necessarily disabled by their condition but feel that Schalock`s outcomes are relevant for them too. It is important that individual outcomes must link to individual interventions. (See worked example Appendix 2)

Broad outcomes

Core Domains of Quality of Life	Indicators
1. Self-Determination	Autonomy, Choices, Decisions, Personal Control, Self-Direction, Personal Goals/Values
2. Social Inclusion	Acceptance, Status, Supports, Work Environment, Community Activities, Roles, Volunteer Activities, Residential Environment
3. Material Well-Being	Ownership, Financial, Security, Food, Employment, Possessions, Socio-economic Status, Shelter
4. Personal Development	Education, Skills, Fulfillment, Personal Competence, Purposeful Activity, Advancement
5. Emotional Well-Being	Spirituality, Happiness, Safety, Freedom from Stress, Self-concept, Contentment
6. Interpersonal Relations	Intimacy, Affection, Family, Interactions, Friendships, Support
7. Rights	Privacy, Voting, Access, Due Process, Ownership, Civic Responsibilities
8. Physical Well-Being	Health, Nutrition, Recreation, Mobility, Health Care, Health Insurance, Leisure, Activities of Daily Living

Conclusion

As stated by the Public Health Minister and COSLA in the introduction to the Scottish Autism Strategy “Strategic action is needed both nationally and locally. Children and adults on the autism spectrum each have a unique set of conditions which will not necessarily fall within the categories of learning disabilities or mental health, although these conditions may be present. Autism impacts on the whole life experience of people

and their families. They need to be supported by a wide range of services such as social care, education, housing, employment and other community based services. A holistic, joined-up approach is necessary".

The establishment of local autism strategies and their ongoing development and the implementation of the recommended interventions and supports has the potential to lead to major positive improvements in the lives of people with autism and their families. It is in keeping with the spirit as well as the good practice it highlighted in the Scottish Autism Strategy. It is hoped that the ultimate creation of experienced, dynamic teams working with individuals and their families will evolve to the significant, measurable benefit of those on the spectrum.

A note about the worked examples

Appendix 1: Example 1 was drawn up to demonstrate how the menu of interventions could be used across a whole area to identify services potentially able to meet the identified challenges.

Appendix 2: Example 2 is based on a case drawn up by a group of people affected by autism. The menu was then used to identify what his needs were and how and by whom they might be addressed. Both show how gaps in services can be identified.

Appendix 3: Example 3 is based on a child and adolescent case within a local authority area in Scotland. The menu was used to identify what their needs were and how and by whom they might be addressed and shows how gaps in services can be identified.

These are examples only and may vary from how other areas and individuals might use the menu of interventions.

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Appendix 1

Worked example for children with autism in a local authority area

This example is designed to show how the framework could be used to map services within a local authority, for a particular age group. As an example, descriptions of the type of service providers have been used rather than specific names of services.

ASD CHALLENGE	Strategy Guidance	Service/provider (bold if available immediately)	Referral path	Desired outcomes
1. Understanding the implications of an autism diagnosis	Post diagnostic discussion (s) and individualised counselling The provision of good quality education and information packs for individuals, families/carers along with appropriate verbal discussion at time of need. Use of visual props if needed. Signposting to useful websites and forums.	Specialist diagnosis clinic, CAMHS Specialist voluntary sector services	Follow on from diagnosis Self-refer	Individual and family develop an understanding of their autism Individual and family know where to receive further help and support i.e. where to go next
2. Development of effective means of communication	Individualised language therapy assessment. Updated as required. Symbolised communication systems, sign systems, verbal behaviour methods as required on an individual basis. Internet etiquette and supervision.	Pre-school specialist service Speech and Language Therapy Specialist voluntary sector service	Diagnosing service Information not currently known Self-refer	Individual can express their needs, wants...

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3. Social Communication	Targeted social communication programmes delivered either individually or in group setting as required and appropriate to the individual to include internet etiquette and promotion of online safety.	Speech and Language Therapy (in school) Speech and Language Therapy (social groups) Educational placement Specialist voluntary sector service (youth clubs)	Information not currently known Information not currently known Information not currently known Self-refer	The individual develops social skills which improve their relationships.
4. Developing and maintaining relationships	Work to assess understanding of relationships and promote skills to develop relationships including sexuality issues and intimate relationships. Access to social groups, friendship circles etc.	Speech and Language Therapy (in school) Educational placement Speech and Language Therapy (social groups) Specialist voluntary sector service (social clubs)	Information not currently known Information not currently known Information not currently known Self-refer	The individual develops social skills which improve their relationships.

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5. Social isolation for individual with autism	Accessible social groups and opportunities, support in the community. Befrienders. Respect the need to be alone at times. Acceptance by families that friendships can take many forms.	Specialist voluntary sector service (youth clubs) Specialist voluntary sector service (play centre) Some clubs at community leisure centres Some scout groups Some brownie groups	Self-refer Self- refer No referral necessary No referral necessary No referral necessary	The individual can access social opportunities.
6. Social isolation for family	Family/ Partner/ Carer support, opportunity for respite. Access to Autism friendly environments.	**Respite** Voucher system via specialist voluntary sector organisation Local authority day time respite Local authority overnight respite **Parent support** Various specialist voluntary sector services **Sibling groups** Specialist voluntary sector	Social work assessment Social work assessment Social work assessment Self-refer Self-refer	The family of the individual with autism can access social opportunities.

		service **Autism friendly environments** Specialist voluntary sector play facility Local play centre offering autism friendly sessions Some cinema screenings	 No referral necessary No referral necessary No referral necessary	
7. Learning to learn skills	A functional assessment of the person's cognitive abilities and learning style leading to a planned programme both directly with the individual and indirectly with the family, carer etc. Formal psychometric testing may be conducted if appropriate to inform intervention.	Pre-school specialist service Educational placement including input from Educational Psychology	Diagnosing service Information not currently known	Individual had skills to access and benefit from an educational setting
8. Predicting and managing change	Timely individual direct work with individuals to teach methods where required. Family/carer /employer guidance/education in these methods. Visual supports; timetables, timers, text alerts, choice boards to be used as appropriate.	Pre-school specialist service Educational placement Specialist education support service (in school) Community LD Nursing (at home) Specialist voluntary sector service	Diagnosing service Information not currently known Parent or school Information not currently known Self-refer	The individual can cope with transitions with minimal distress

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9. Behaviour and emotional regulation	Knowledge development in understanding behaviour in the context of ASD. Individual work with the individual on assessing behaviour, recognising triggers and developing and managing the implementation of strategies to help. Behaviour support plans, cognitive interventions, psychotherapy or counselling as required. Work with the individual's family/carers, criminal justice, social work, Police as appropriate. Autism Alert card possession.	CAMHS Specialist education support service (in school) Specialist voluntary sector service	GP Parent or school Information not currently known	Everyone relevant to an individual knows how to support that person to behave appropriately and manage their emotions.
10. Restricted and repetitive interests and behaviours	Assessment and positive day to day management on an individualised basis. Treatment by Mental Health clinician for OCD if required.	CAMHS Educational placement	GP Information not currently known	Any negative impact of restricted and repetitive interests/behaviours is minimised.
11. Motivation issues	Structured programmes as appropriate to the individual linking to the other core challenges as required. Career guidance, employer/HE/FE support.	CAMHS Educational placement Specialist voluntary sector service	GP Information not currently known Self-refer	Unconventional motivations contributing to an ASD challenge are addressed.

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12. Sensory issues	Assessment of sensory difficulties. Identify strategies and implement. Environmental adaptation on an individual basis with individual control working towards reducing the impact.	Occupational Therapy Educational placement	Information not currently known Information not currently known	The individual can experience social and learning opportunities without distress or discomfort due to sensory difficulties.
13. Daily living skills	Assessment of core life skills. Specific individual programmes to teach and maintain these skills where needed. Involvement of families/carers in assessment and implementation of new learning. Education for families/employers/ care providers/housing dept re practical needs.	Occupational Therapy Educational placement Community LD nursing Specialist voluntary sector services	Information not currently known Information not currently known Information not currently known Self-refer	The individual learns and demonstrates the skills they need to function as independently as possible within day to day life.
14. Co existing conditions	Eg: epilepsy, dyspraxia, dyslexia, ADHD, ADD, sensory impairment, anxiety, sleep disorder, addiction, anger management, depression, self harm, psychosis, personality disorder, OCD, disordered eating patterns etc. These require assessment and treatment/management by appropriate specialist clinician. Joint working is crucial across specialities with a clear case co-ordinating lead identified.	Appropriate specialist clinician Case co-ordinating lead identified	Will depend on the specialism Via GIRFEC	An individual's needs that don't directly relate to ASD are addressed appropriately.

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Services appear to be available to address each of the challenges, provided by a mix of health, education, social work and voluntary sector services. Closer analysis of referral criteria would however be required to be sure that services exist across the age range and intellectual ability and that these services are available across environments e.g. both home and school.

It would seem that referral paths aren't always clear with many instances where is has been hard to find the information required.

Few services appear to be immediately available which may indicate that whilst the services exist they currently don't have sufficient capacity to meet demand.

Finally, further work would be required to ensure that the services available are indeed generating the desired outcomes for individuals and their families.

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Appendix 2

Worked example re an individual adult on the autism spectrum

John Brown is 45 and lives in a small town in Scotland. He lives alone in the family house which he inherited on his mother's death last year. He has never worked since he left school but is under pressure from the benefits agency to find a job. An elderly neighbour contacted his GP with concerns about John. He has become dirty and unkempt. There has been a recent dramatic weight loss and she was worried to see him being brought home by police officers.

On discussion with the GP, it transpired that the recent negative changes in his appearance had drawn unwelcome attention to him from gangs of youths and his angry response to them had led to the Police being called. When the GP contacted the social work department, and a social worker called to the house, she found that it was in a very poor state. John had been hoarding newspapers and plastic bags and containers. He didn't appear to have any fresh food in the house. He told her that his mother had always done the cleaning, washing, shopping and food preparation. In addition to this he was being harried on money matters by other family members who appeared to resent his inheritance. He found it difficult to ask for help and didn't know who to contact. He has no friends.

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John had not previously been known to services. He did not have a learning disability or a mental illness. He was referred for diagnostic assessment and found to have Asperger Syndrome. The menu of interventions was used to clarify his requirements and identify what services were currently available and which need to be developed in the area.

ASD CHALLENGE	WHAT NEEDS TO HAPPEN?	WHO SHOULD DO IT?	AVAILABILITY	OUTCOMES (*Schalock's)
1. Understanding the implications of an autism diagnosis	John needs to have as many individual sessions as he requires from the diagnosing clinician to explain Autism and the implications of his condition to him and to respond to his questions. He may also benefit from a small group	NHS Voluntary sector	Yes Yes	1,4, 5, 6
2. Development of effective means of communication	Assessment of language comprehension to ascertain whether he needs further specific input	NHS Speech and Language Therapist	No	2, 4, 5, 6
3. Social communication	Specific work on practical aspects of social communication eg with neighbours. Informal social communication practice in small group setting	NHS Speech and Language Therapist Specialist ASD provider	No To be commissioned	2, 4, 5, 6

4. Developing and maintaining relationships	Individual sessions to develop understanding of the skills required to develop relationships. Review of extent to which sexuality is an issue. Informal peer mentoring group	NHS Psychologist/ counsellor Specialist provider	Yes but limited time available To be commissioned	4, 5, 6
5. Social isolation for individual with autism	Informal social communication practice in small group setting	Specialist ASD provider	To be commissioned	2, 4, 5, 6
6. Social isolation for family	NA	NA	NA	
7. Learning to learn skills	Assessment of cognitive abilities to ascertain whether he needs further specific input	NHS Clinical Psychologist	Yes but limited time available.	1, 3, 4, 7, 8
8. Predicting and managing change	Specific work on planning and managing what needs to be done on a practical basis in day to day life including preparation for appointments and meetings	Voluntary sector specialist provider	To be commissioned	4, 5

9. Behaviour and emotional regulation protecting wellbeing	Individual counselling focussed initially on bereavement and the transition to his new stage of life. Help with understanding how his behaviours may be seen by others and the implications. Ongoing support. Registration for Autism Alert card	NHS Clinical Psychologist Voluntary sector specialist provider	Yes but limited time available To be commissioned Yes	4, 5, 6
10. Restricted and repetitive interests and behaviours	Observation by care provider of the extent to which this is a problem. Referral on if it is found to be required	Specialist Care provider NHS Psychologist	To be commissioned Yes but limited time available	8
11. Motivation issues	Observation by care provider of the extent to which this is a problem. Referral on if it is found to be required	Specialist Care provider	To be commissioned	1, 4
12. Sensory issues	Sensory Assessment to find out the extent to which this is a problem for John	NHS OT	No	8

13. Daily living skills	Detailed assessment of John`s self care skills. Specific teaching regarding all aspects found to be problematic. Housing dept to carry out maintenance assessment as required. Training to be provided to Housing dept staff re AS and how it impacts on John	SW OT Housing dept Specialist care provider	Yes Yes To be implemented	1, 3, 4, 7, 8
14. Co existing conditions-examples	GP to monitor John`s mental and physical health on a regular basis.  Referral as required to relevant specialists.  John`s AS to be flagged on NHS system so that his requirements are understood in the event of emergency admissions	GP CPN Psychiatrist	Yes Yes Yes System to be implemented	5, 8,

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What are the gaps?

- SLT
- Specialist care provider
- NHS OT
- Training for housing dept
- Clinical Psychology time
- System to flag up AS on medical notes

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Appendix 3:

Worked example of a young person on the Autism Spectrum

Joe Beattie is an 11 year old boy who lives in village just outside a small city in Scotland. He lives with his family and attends a small village school. Joe's behaviour has always been a bit different from the other children. He has always struggled to make and maintain friendships; does not pay attention in class; dislikes noise and, often needs to leave the class. Differences in his behaviour have become more apparent since entering the older P4-7 class in the village school and there has been a dramatic increase in more 'challenging' behaviours. There is now a lot of concern regarding his current school placement and transition to high school.

Joe was not previously known to health services but did have Additional Support Needs Meetings annually at school. Recently, due to the escalation in challenging behaviour, he has been discussed at the Senior Integrated Team (SIT) Meeting by the Complex Needs Co-ordination. The complex needs co-ordinator and ASD Outreach Teacher, who both work within the Local Authority Department of Education were able to talk to colleagues from Child and Adolescent Mental Health and Social Work at the SIT meeting as both also attend this group every 6-8 weeks to discuss kids who appear to be struggling at school because of mental health and/ or developmental difficulties. The SIT meeting agreed that he would benefit from a developmental assessment. His family agreed and his GP referred for an urgent diagnostic assessment at which he was found to have a dual diagnosis of ASD and ADHD. Meaning that in addition to a developmental social communication impairment, which fulfilled criteria for a diagnosis of ASD, he also had a generalised attention difficult in keeping with a diagnosis of ADHD - ADD subtype. The menu of interventions was used to clarify his requirements and identify what services were currently available and which need to be developed in the area.

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ASD CHALLENGE	WHAT NEEDS TO HAPPEN?	WHO SHOULD DO IT?	AVAILABILITY	OUTCOMES (*Schalock's)
1. Understanding the implications of an autism diagnosis	Joe, his parents and extended family would be invited to attend New Pathways Post Diagnosis Group – 5 sessions covering ASD. Joe may also benefit from post-diagnostic support delivered by the diagnostic team and/or core worker co-ordinating his care.	NHS and/ or Voluntary Sector NHS CAMHS Core Worker	Yes Yes	1,4, 5, 6
2. Development of effective means of communication	Assessment of language comprehension to ascertain whether he needs further specific input.	NHS Community (school-based) Speech and Language Therapist	Yes	2, 4, 5, 6
3. Social communication	Specific work on practical aspects of social communication informed by socialSMARTS profile - to improve consistency of social skills, develop further social skills/ or social strategies and inform 'good fit' environments. Opportunities for informal social communication practice in small group setting	NHS Speech and Language Therapist Specialist ASD provider: Perth Autism Support Group/ Spectrum Club	Yes – needs ongoing funding Yes	2, 4, 5, 6

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4. Developing and maintaining relationships	Individual sessions to develop understanding of relationships. Informal peer mentoring group Buddy Systems	NHS CAMHS/ Specific ASD Resource/ Specialist ASD provider Specialist ASD provider Education	Yes - but limited Yes – but ongoing funding required To be commissioned	4, 5, 6
5. Social isolation for individual with autism	Informal social communication practice in small group setting.	Specialist ASD provider: Perth Autism Support Group/Spectrum Club	Yes – both require ongoing funding	2, 4, 5, 6
6. Social isolation for family	Family support and social activities.	Perth Autism One-Stop-Shop/Perth Autism Support Group.	Yes – both require ongoing funding	
7. Learning to learn skills	Assessment of cognitive abilities to ascertain whether he needs further specific input	NHS CAMHS Specific Worker: Clinical Psychologist	Yes	1, 3, 4, 7, 8
8. Predicting and managing change	Specific work on planning and managing what needs to be done on a practical basis in day to day life including preparation for appointments and meetings	Voluntary sector specialist provider: Perth Autism Support and/ or Parent to Parent	Yes	4, 5

9. Behaviour and emotional regulation protecting wellbeing	socialSMARTS (Profile, Skills/ Strategies and Accommodations) Model Trainings – delivering workshops to professionals in health, education and social work -to improve/ develop emotion regulation skills/ strategies and help with understanding how his behaviours may be seen by others and the implications. Ongoing support. Registration for Autism Alert card.	NHS Clinical Psychologist and/ or ASD outreach teachers/ schools and/ or SW and or Voluntary Sector: Perth Autism Support Group/ Parent to Parent. Voluntary sector specialist provider: Perth Autism Support/ Parent to Parent	Yes – being rolled out Yes – rolled out over the past year Health and Education Funded - ongoing funding required Yes	4, 5, 6
10. Restricted and repetitive interests and behaviours	SMART Observation by care provider/NHS CAMHS MH Service/Specialist ASD Resource for assessment if required.	Specialist Care provider/ CAMHS MH Service with Specialist ASD Resource	Yes – rolling out	8
11. Motivation issues	SMART Observation by care provider/NHS CAMHS MH Service/Specialist ASD Resource for assessment if required.	Specialist Care provider/ CAMHS MH Service with Specialist ASD Resource.	Yes – rolling out	1, 4
12. Sensory issues	Sensory Assessment to determine the purpose for Joe and intervention e.g. sensory diet	NHS OT – limited resource	Yes – but increased capacity required	8

13. Daily living skills	Detailed assessment of Joe`s self care skills. Detailed assessment of suitability of Educational Placement Specific work on daily living skills	CAMHS MH Service with Specialist ASD Resource and/ or OT Local Authority Complex Needs Group –Senior Integrated Team involvement, ASD Outreach teachers and school. Placement Panel and Specialist Educational Bases SW Locality Team and/ or SW Transitions Group	Yes Yes – but underfunded Yes – needs to be more accessible	1, 3, 4, 7, 8
14. Co existing conditions- examples	CAMHS/ GP to assess Joe`s mental, developmental and physical health when and if necessary with the help of the Specialist ASD Resource when needed. Joe`s diagnosis to be flagged on NHS data systems so that his requirements are understood in the event of emergency admissions	CAMHS MH Service/GP MIDIS clinical data system	Yes Yes – rolling out	5, 8,

There are fewer gaps but many funding issues are highlighted when mapping ASD services in this locality with need.

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References

National Institute Clinical Excellence (2012) guideline 142
Autism: recognition, referral, diagnosis and management of adults on the autism spectrum
www.nice.org.uk/cg142

Schalock R (2000) Three Decades of Quality of Life
Focus on Autism and Other Developmental Disabilities Vol 15: 116

Scottish ASD Strategy (2011) www.scotland.gov.uk.

Scottish Early Years Strategy (2012) www.scotland.gov.uk

Scottish Intercollegiate Guideline Network (2007)
Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders

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Resources

Getting it Right for Every Child
http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright

Guidance on procurement of care and support services
http://www.scotland.gov.uk/Topics/Government/Procurement/policy/SocialCareProcurement

Joint Strategic Commissioning Learning Development Framework
www.jitscotland.org.uk

Scottish Adult Mental Health Strategy
http://www.scotland.gov.uk/Publications/2012/08/9714/9

Scottish Learning Disabilities Strategy “The Keys to Life”
http://www.scotland.gov.uk/Publications/2013/06/1123/0

Self directed support
http://www.selfdirectedsupportscotland.org.uk/sds-act/

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This document is also available on the Scottish Government website:
www.scotland.gov.uk

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