



ARGYLL & BUTE STRATEGY for AUTISM

May 2014



PREFACE.

This document was prepared on behalf of the Argyll & Bute Council and NHS Highland (hereafter the Partnership) by the charity Scottish Autism, the largest provider of autism-specific services in Scotland and a leading authority and advocate for good autism practice. Scottish Autism exists to help those diagnosed with autism to lead full and enriched lives and become valuable members of the community they live in. The organisation also seeks to share its knowledge and expertise with parents, carers and other professionals in order to support the development of skills and strategies needed to provide the best care and support for people with autism.

The charity was closely involved in the generation of the Scottish Strategy for Autism and is managing a number of projects on behalf of the Scottish Government in the implementation of the Strategy.

Scottish Autism was therefore well-placed to take the provisions of the national strategy and adapt them for local application. Consultation with the Argyll & Bute Strategy Group has helped to shape the document into one which reflects local priorities.

FOREWORD.

As Council Autism Champions we were delighted to be involved in the work of the Autism Strategy Group; having the opportunity to inform the Argyll and Bute Autism Strategy; and to be associated with this important document.

We congratulate everyone who has been involved in producing the strategy which has been developed in conjunction with a number of different agencies both statutory and voluntary, and most importantly had input from carers and users through the strategy group. We believe that this has resulted in the production of a strategy which will assist in developing service's that will be fit for purpose.

It is important that the roles and responsibilities of all involved in supporting and caring for those with Autism are clearly defined and that agreed pathways are adopted. By implementing this strategy we would expect to see the right services being delivered at the right time in the right place promoting independence and resilience for people with autism and their carers.

We look forward to engaging with our communities during a period of consultation on actions required to deliver the aims and objectives of this strategy, and to the feedback from those sessions to finalise the implementation plan.

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Policy Lead for Adult Care & Autism Champion

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Autism Champion

CONTENTS.

	Page
1. Introduction	5
2. The Evolving Understanding of Autism	9
3. The Strategy	15
4. Outcomes for People with Autism	18
5. Autism Services and Models of Support	20
6. Education	24
7. Employment	28
8. Autism Awareness and Training	29
Appendices	30
References	49

1. Introduction.

1.1 Language and Terminology.

The complex nature of the autism spectrum gives rise to a range of personal and professional perspectives. It can therefore be a challenge to find a common language that reflects the understanding, values and principles of the various groups who are invested in advancing our understanding and support of people of all ages across a very diverse spectrum.

Throughout this document the language and terminology used will reflect the diversity of the autism community and those invested in it whilst aiming to reflect the positive and inclusive ethos that underpins the vision values and philosophy of the Strategy.

The Partnership is sensitive to the potential for perceived negative connotations in connection to terms such as “Disorder” or “Impairment”. These are clinical terms that are understood in such contexts.

The Partnership understands that many individuals on the autism spectrum wish to assert themselves as neurologically diverse, as having a different way of being in, perceiving and engaging with the world and those they share it with. Such individuals would consider that being on the spectrum does not necessarily equate with impairment but can give rise to a unique world view, assets and skills. The Partnership is respectful of this view and would support it whilst also acknowledging that some individuals on the spectrum face significant challenges in their daily living and are in need of high levels of support that is specifically tailored to their needs.

1.2 What is the strategy and why has it been developed?

In November 2011 the Minister for Public Health Michael Matheson and Councillor Douglas Yates on behalf of COSLA launched the Scottish Strategy for Autism. The Scottish Government has called on the Scottish Local Authorities to produce Strategic Plans in support of the National Strategy for Autism using the results from a national project which mapped the services available in all Scottish local authorities, and the principles set out in the Strategy itself. This document is the response from Argyll & Bute and NHS Highland (henceforth the Partnership) to that call.

The Argyll & Bute Strategy for Autism is a policy planning document which sets the scene for the allocation of resources to need, resources which are inevitably constrained at the present time.

1.3 How has it been developed?

Autism has seen a number of initiatives in Scotland since the millennium which contributed in no small measure to its present status as a priority for policy development. The requirement for local authority autism strategies came immediately from the implementation of the Scottish Strategy for Autism. That latter document was produced over the course of about a year through the deliberations of an External Reference Group made up of *inter alia* medical clinicians, psychologists,

educationalists, representatives of COSLA and other local authority based organisations, representatives of the major autism charities and parents and carers of people on the autism spectrum.

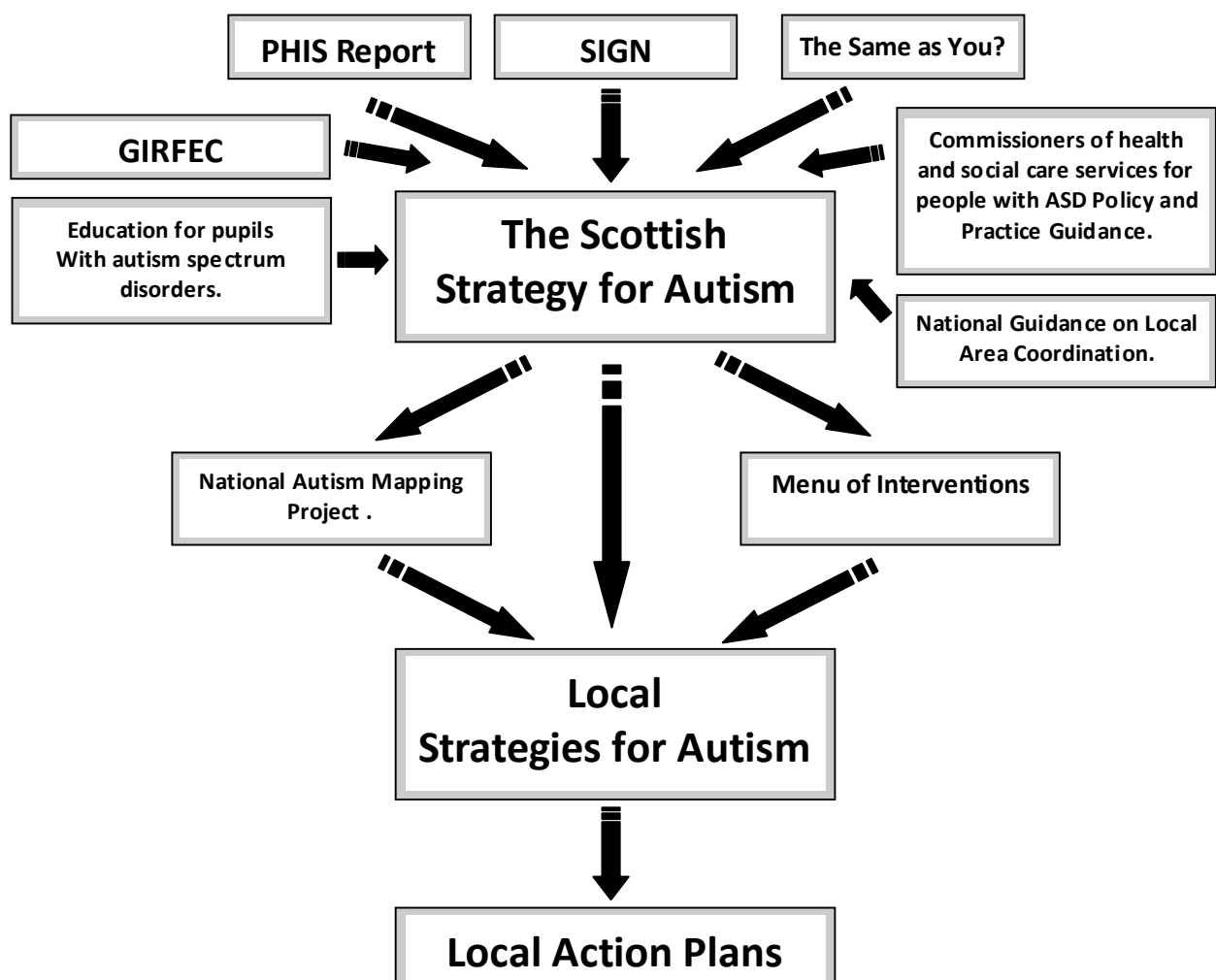
The Strategy was produced very quickly following the decision of the Scottish Government to produce a strategy rather than follow the earlier model adopted by Westminster to go straight to legislation.

A number of recommendations were put out for consultation, but at that time no mechanism was established by which these recommendations could be reviewed or altered in the light of their effectiveness in delivering the goals of the Strategy.

The intention behind creating a strategy rather than going straight for legislation was that experience would illuminate successful policies as well as failures. It was always intended that flexibility was required in response to the affordability of service provision and the findings of key research projects designed to illuminate the key decisions relating to need and value for money.

The origins and policy context of these documents is shown in the diagram below.

1.4 Context of the Strategy.



A full referenced list of these strategy and policy documents underpinning this strategy together with the non statutory documents taken into account in the development of the strategy can be found in Appendix 1.

1.5 Structure and Rationale of the Strategy.

Strategic management is a name given to top management to distinguish it from operational management. Schendel and Hatten (1972) define strategic management “as the process of determining (and maintaining) the relationship of the organization to its environment expressed through the use of selected objectives, and of attempting to achieve the desired states of relationship through resource allocations which allow efficient and effective management programs by the organization and its subparts”.

This is a good definition which reflects a number of the issues facing us in Argyll & Bute. The “selected objectives” are simple – they are the Goals set out in the Scottish Strategy. These goals are deliberately wide ranging and general in nature. They are also aspirational and anticipate that foundation work in the early years will be required before tackling the more difficult goals. Most importantly they are not time-limited but represent objectives which might well be delayed if resources are not immediately available. The objective remains, but must remain dependant on scarce resources which might only become available after public finances recover. The goals are the very heart of the strategy and its most important elements. It would be perfectly possible to address all of the recommendations in the Strategy and still fail to achieve its goals. This could be as a result of for example patchy geographical implementation – the so-called postcode lottery, or through failure to address workstreams which had not been identified at the start of the Strategy and which later emerge as key to success.

Autism is often referred to as being multidimensional in nature and these dimensions will be addressed in greater detail in Section 3. It is clear that any one individual on the autism spectrum will encounter different “organs” of the state at different times of life – principally education, health and social services – and that these must work together efficiently and cost-effectively if we are to live up to the lofty values espoused in the Strategy. As it says in the definition we must achieve the desired states of relationship through resource allocation which allow efficient and effective management by the organisation and its subparts. How this might be achieved is also addressed further in Section 3. We might add the word “seamless” to the list of desired qualities because eliminating barriers to transition and access to services feature heavily in the strategic goals.

Strategic planning is only one part of strategic management. The other two components are resource allocation and evaluation and control.

It is assumed that the initial resource allocation is set out in the Action Plan. The function of this document apart from buying in to the vision, values and strategic goals of the national strategy is to set out the philosophy behind the systems of allocation and control. It is a well recognised phenomenon in large complex organisations that as people practice their own disciplines and focus on the use of the tools associated with those disciplines gradually the tools take the place of the

strategy. This strategy for Argyll and Bute recognises this and aims to reserve as much flexibility to the Partnership as possible so that it may react appropriately to changes in the environment principally in the following areas:

- Financial resources;
- Outputs from national research projects (in the socio-economic field as opposed to the medical arena);
- Changing political priorities;
- Developments in the understanding of ASD and best practice in enabling individuals on the spectrum;
- Changes in service commissioning practice, such as Self-Directed Support or the integration of Health and Social Care.

It also sets out gaps in service provision which would be desirable to fill if and when resources become available.

The Partnership recognises that the development of a local autism strategy is a declaration of our intention to improve the quality of life of people on the autism spectrum across Argyll and Bute.

The Argyll & Bute Strategy for Autism begins with a review of our evolving understanding of autism. Autism is a complex phenomenon, and the issues it generates for people on the autism spectrum are often dictated by other co-existing or co-morbid conditions. Much remains to be learned about the demographics of these co-morbid conditions. The Scottish Government has commissioned important research which it is hoped will provide a clear rationale for the allocation of scarce resources. It is important that this Strategy is read in the context of this evolving understanding.

The Strategy then goes on to outline vision, values and strategic goals, as well as ten indicators for current best practice in the provision of effective autism services which are all set out in the Scottish Strategy for Autism.

The remainder of the document comprises thematic chapters – these are included this way for ease of access as they represent aspects of autism representing professional disciplines and/or which affect people’s quality of life and define the way they access services. One individual might in the course of their life require support in all of the areas.

Appendix 4 to this strategy is a series of tables which map the Strategic Goals in the national strategy against the Good Practice Indicators and the relevant sections of the Argyll & Bute Action Plan.

2. The Evolving Understanding of Autism.

This strategy for autism in Argyll & Bute reflects the evolving understanding of autism. Why is a specific strategy for autism needed?

The justification for making a special case for autism is that it is in fact a special case. The autism spectrum represents the major part of the group of conditions classified as 'pervasive developmental disorders' (American Psychiatric Association, 1994; World Health Organization, 1992). It is the very nature of its pervasiveness that makes the autism spectrum different from other conditions, no matter how high their prevalence or how potentially debilitating their effects. (Jones and MacKay 2013 P4).

2.1 The Characteristics of Autism.

People often associate autism with what they can see and observe, in other words a person's behaviour. It is however important to recognise that autism is not a behavioural problem and that observable behaviours arise as a result of a range of complex and interacting factors.

Autism occurs as the result of significant differences in the way people develop. The most noticeable differences are in the areas of social communication, social interaction, and social imagination, and sensory and cognitive processing.

The differences in each area and how they affect a person will vary across the spectrum and from person to person. Some examples of differences in social communication may include:

- Limited or absent verbal language;
- Difficulties using and understanding body language;
- Limited motivation to initiate and sustain conversation;
- Limited language and/or use of learned or echoed words and phrases with varying degrees of relevance to the context;
- Literal understanding of language;
- Some people may have a strong desire to verbally interact but with a focus on restricted interests. Individuals who have such tendencies may attempt to dominate conversations and may be very able to divert any conversation back to their preferred topic.

In terms of social interaction the following may be observed:

- An apparent lack of desire or motivation for social engagement;
- An apparent lack of understanding of the feelings, intentions and motivations of others;
- Initiation of social interaction can be rare but if approached, a person may respond to this and be compliant;
- May have a strong desire for social engagement but be unaware of social rules and how to apply them depending on the context.

The idea of social imagination is complex; we can be sidetracked by thinking that imagination is limited to creative, aesthetic or play activities. Social imagination instead refers to the ability to imagine and predict what other people will do, understand abstract ideas and imagine situations outside of a person's routine.

Some examples are that individuals with autism:

- May find it difficult to adjust their behaviour and respond to different situations;
- May find new and unfamiliar experiences stressful, threatening and confusing;
- May resist change or exposure to new experiences due to having limited ability to generate a concept or form an idea without prior experience;
- May find it difficult to recognise emotional expressions and body language in relation to the social context.

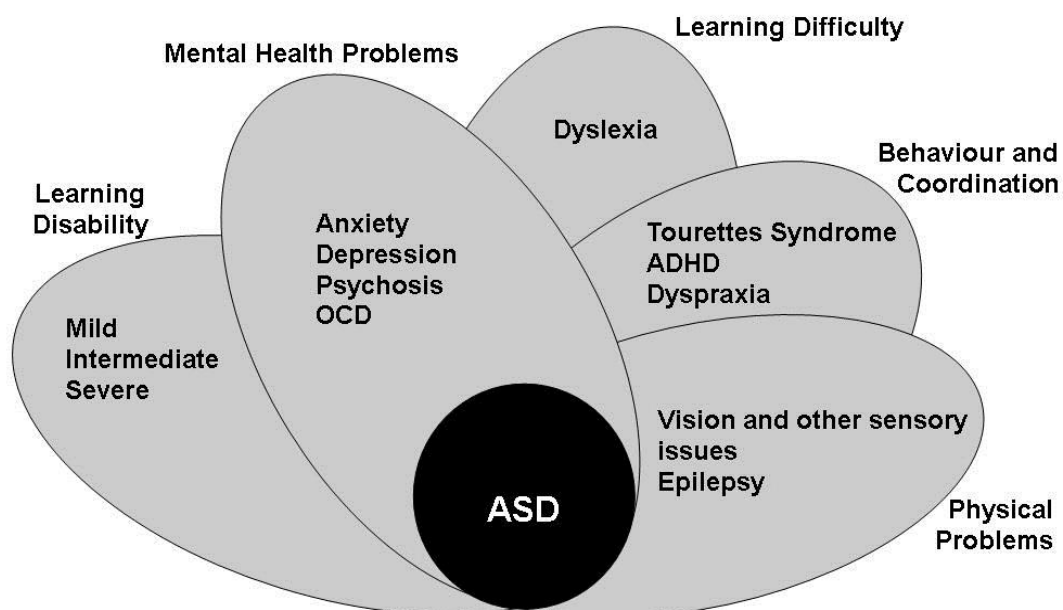
2.2 Co-Morbidities.

The following depiction of the autism spectrum is helpful in illustrating the wide range of individuals on that spectrum.

Severe Autism	Autism with LD (IQ < 70)	High Functioning Autism (IQ > 70)	Asperger's Syndrome (IQ normal/ above normal intelligence)	Broader Autism Phenotype	Neurotypical
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Clearly autism is not a generic learning disability but needs tailored, specific support. People with Asperger's Syndrome who may be highly intelligent, capable individuals may still require support in areas of social interaction which are fundamental to integration and participation in society.

Autism is a multidimensional phenomenon, with great complexity generated by the possible permutations of co-morbid conditions (sharing of symptoms across disorders), *inter alia* those shown in the greatly simplified (and purely conceptual) Venn diagram below.



In fact autism rarely occurs alone and it is more common for autism to be accompanied by co-morbid conditions such as those in the conceptual diagram above. Indeed in many cases it will be addressing the co-morbid conditions that provides the key to an improved quality of life for the individual concerned.

The concept of a single spectrum is outdated. Just as it takes a minimum of three dimensions to define a regular three dimensional object, multiple spectra would be required to reflect all the dimensions of such a complex phenomenon as autism.

It seems likely that some form of conceptual “map” of autism and its co-morbid conditions would be required, but at present it does not exist. Many people in the social care community find the idea of “classifying” people undesirable, but this is also a barrier to understanding in terms of resourcing an autism strategy.

The various spectra are unlikely to be continuous, with certain combinations of conditions existing in “clumps” irregularly along the length of any particular spectrum. In other words “autism-space” is neither homogeneous nor isotropic. Such a map would attempt to identify these concentrations/associations and also to assess the size of the population within each grouping.

Existing statistics on the autistic population are of limited value in isolation. They are often the result of studies commissioned by education, social care or health bodies and tend to record only the aspects of people’s autism which interfaces with that particular dimension. It seems quite possible that the majority of the adult autistic population does not present as a “problem” to any of the major organs of the state and therefore it is conceivable that a significant proportion of the total autism population does not appear anywhere in statistics gathered by any public agency.

It is equally likely that a significant number of people have been misdiagnosed and are receiving the wrong sort of support e.g. schizophrenia is often cited as a diagnosis which can wrongly be given to people on the autism spectrum. In other cases individuals might be diagnosed with the dominant co-morbid condition and their autism not mentioned.

Fairly sophisticated statistical analysis of available data would be required to identify these gaps and the inevitable double counting, but this is routine in economic studies and would not present serious difficulties to good quality economic practitioners.

This problem is being addressed in the “Microsegmentation Project” funded by the Scottish Government and being carried out by Professor Tommy MacKay of the University of Strathclyde and Professor Martin Knapp of the London School of Economics. Findings to date suggest that the quality of existing information is even worse than was originally thought:

The scoping of the literature has highlighted two key issues which must be further addressed as a basis for any ASD economic analysis:

1. Prevalence data are inadequate and conflicting;
2. Data on ability levels – crucially, the proportion with learning disability, is inadequate and conflicting.

A meta-analysis of high quality prevalence studies is being prepared, with an analysis of the sources of variance in published figures and this will provide a basis for better economic analysis and planning in relation to autism in Scotland. The project should report in October 2014 and it will have implications for the affordability of all autism strategies, national and local. It will also provide a first sketch of the map of “autism space” as defined earlier.

Professor Chris Gillberg of the University of Göteborg also attests that the co-existence of disorders – including attention-deficit/hyperactivity disorder, oppositional defiant disorder, tic disorder, developmental coordination disorder, and autism spectrum disorder (co-morbidities) *“is the rule rather than the exception in child psychiatry and developmental medicine”*.

This leads him to conclude that children may need to see specialists in multiple disciplines to understand the complexity of their presentation.

“There is no time to wait; something needs to be done, and that something is unlikely to be just in the area of speech and language, just in the area of autism or just in special education.” (Gillberg 2010 P1543)

2.3 “Mainstream” models and specialist support.

The Scottish Strategy for Autism sets out ten indicators for current best practice in the provision of effective Autism Spectrum Disorder (ASD) services. ASD provision should include:

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.

These are intended to provide a guide for local authorities and should be regarded as the “mainstream” elements for the provision of services for people on the autism spectrum. All of these indicators of best practice will be addressed in the course of this strategy document. The *degree* to which they are implemented by the local authority is of course defined by the parameters set out at the end of the Introduction.

Section 5.6 of this document outlines the current perception of progress against these indicators within Argyll & Bute as presented in the National Autism Mapping Project (Scottish Government 2013).

While much progress can be made in setting out services for people on the spectrum in this way, it cannot be “one size fits all.” The spectrum is wide, ranging from people who require care all their lives, to people who are of very high intelligence but might require support in social situations – e.g. for such activities as employment interviews. The saying “if you’ve met one person with autism, you’ve met one person with autism” is as true today as it ever was. In this complex environment it is more productive to address the specific requirements of the various spectra when planning services rather than treating the condition as a homogeneous whole.

The implication of this is that we must segment the autism spectrum in order to make sense of the services people require. The following is one possible high-level segmentation of the autism spectrum commonly used by one prominent service provider as a guide when designing packages for service users.

1. Group requiring 24 hour care and support for all of their lives.
2. Individuals with autism, autism and a learning disability or Asperger’s Syndrome who require substantial care and support on a daily basis.
3. Individuals with autism/autism and a learning disability who require moderate support. These individuals would not present with serious behavioural challenges.
4. Individuals with Asperger’s Syndrome who can achieve a measure of independence with structured, regular support on a weekly basis.
5. Individuals with Asperger’s Syndrome who have minimal support requirements.
6. Individuals with Asperger’s Syndrome who have challenging behaviour, are sometimes violent or who engage in offending behaviour.

Service specification should always be uniquely personalised. However as an aid to understanding the following table is illustrative of how service providers might offer their services to people falling within the six groupings. It should be noted that this represents a typical mapping of service provision against our indicative segmentation and not a prescription for services for any individual.

Service User "Segment"	1	2	3	4	5	6
Typical Service Package						
24 hr care & support	XXX					
Care & support at home		XXX	X	XXX		
Day opportunities	XXX	XXX	XXX	X		
Respite short break		XXX	XX			
Children's day opportunities			X			
Community outreach			XX	XXX	X	X
Social groups				XXX	XXX	X
Higher education				X	XXX	X

This is a “menu of services” set out from the perspective of social care provision and should not be confused with the Menu of Interventions (Scottish Government 2013). Depending on the exact nature of a person’s autism there could be a whole series of other appropriate interventions from say the mental health paradigm.

Malcolm K. Sparrow is Professor of the Practice of Public Management at Harvard’s John F. Kennedy School of Government. It is his thinking set out in his book *The Character of Harms: Operational Challenges in Control* which led to the Scottish Government and the charity Scottish Autism jointly funding a workshop in Edinburgh in December 2012 – “The Scottish Strategy for Autism: Structuring Services and Harm Reduction Work for the ASD Community.”

The arguments underpinning this part of the Argyll & Bute strategy are complex. For brevity here the detailed account of his reasoning is presented as Appendix 2 to this document. A brief summary of the conclusions is presented here:

- Addressing the various elements of a complex issue which straddles different departments of an organisation naturally produces a series of tailor-made interventions which are outside the normal policies and procedures of the organisations which make up the Partnership.
- Conventional quality improvement policies in local government tend to focus on *process* improvement i.e. they are managerial tools for improving the Partnership’s processes. By contrast a *problem-solving* approach is an operational way of working on external issues.
- This suggests additional resources specifically to manage all the various requirements of complex individuals - clearly not practicable in the current economic climate. The Partnership therefore recognises that for such a complex multidimensional phenomenon as autism, staff in all disciplines must recognise that they may only be seeing one facet of the individual’s condition

and adopt an individual-focused approach (i.e. a problem solving approach) if all the individual's needs are to be met and quality of life maximised.

3. The Strategy.

3.1 Vision and Values.

In the context of this strategy it is clearly most logical to adopt those set out in the national strategy, which are compatible with the local vision and values presented in various policies and strategies.

Our vision

Our vision is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.

Our values

Underpinning values will be:

- **Dignity:** people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity;
- **Privacy:** people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens;
- **Choice:** care and support should be personalised and based on the identified needs and wishes of the individual;
- **Safety:** people should be supported to feel safe and secure without being over-protected;
- **Realising potential:** people should have the opportunity to achieve all they can;
- **Equality and diversity:** people should have equal access to information assessment and services; health and social care agencies should work to redress inequalities and challenge discrimination. People with ASD should expect to have the support of professionals working in their best interests to make these values a reality.

3.2 Strategic Goals.

The goals are set out in three parts: Foundations (by 2 years), Whole-life journey (by 5 years) and Holistic-personalised approaches (by 10 years). These broadly reflect the degree of difficulty associated with each set of goals and the complexity of organisational change required in delivering them.

Some goals will principally be for one discipline to deliver whilst others will require a multi-disciplinary response.

Foundations: by 2 years.

1. Access to mainstream services where these are appropriate to meet individual needs.
2. Access to services which understand and are able to meet the needs of people specifically related to their autism.
3. Removal of short-term barriers such as unaddressed diagnoses and delayed intervention.
4. Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis).
5. Implementation of existing commissioning guidelines by local authorities, the NHS, and other relevant service providers.

Whole life journey: by 5 years.

1. Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism.
2. Access to appropriate transition planning across the lifespan.
3. Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas.
4. Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism.

Holistic personalised approaches: by 10 years.

1. Meaningful partnership between central and local government and the independent sector.
2. Creative and collaborative use of service budgets to meet individual need (irrespective of what the entry route to the system is).
3. Access to appropriate assessment of needs throughout life.
4. Access to consistent levels of appropriate support across the lifespan including into older age.

At the time of writing, we are two years into the implementation of the national strategy. This is an appropriate time to review progress to date, identify elements of the two year goals which are incomplete, review the membership of the External Reference Group and the working groups set up to deliver the recommendations set out in the national strategy. This review has just begun but will have an impact on the future evolution of the national strategy. This is another reason to seek to reserve flexibility for local authorities in their own strategic plans.

The national strategy contains recommendations relating to research that will examine and compare outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision. Argyll & Bute will take account of the relevant findings of these projects in relation to local service planning, commissioning and delivery.

One development overshadows all the others with respect to the provision of services for people with autism and that is the integration of health and social care.

Much depends on this project for the success of the Scottish Strategy for Autism, indeed the ten year goals are almost entirely dependent upon it. It seems logical that any local authority autism strategy should adapt itself to the systems thus evolved rather than the other way round. This is another reason not to attempt to be too prescriptive in these early stages of the strategy.

4. Outcomes for People with Autism.

The stated overarching aim of the national strategy for autism is to improve quality of life for people on the autism spectrum. Quality of life has been variously defined, however frameworks such as those defined by Schalock (1996) are well quoted. Schalock takes a domain based approach to identifying areas that are key to quality of life. These are:

1. Physical wellbeing
2. Material wellbeing
3. Interpersonal relationships
4. Social inclusion
5. Personal development
6. Self determination
7. Emotional wellbeing
8. Rights

Identifying and measuring outcomes for people with autism has to take account of the unique world view of the person on the spectrum. Whilst many people with autism aspire to accessing similar life experiences to those of the typically developing population, there are those who seek a good life by their own measure and on their own terms. To this end it is important to understand the potential impact of autism on any given domain but be able to personalise learning and experiences so that individuals reach their full potential. Plimley (2007, P6) outlines, in broad terms, how autism might be considered in relation to quality of life.

QoL domain	Monitoring variables	Outcome indicators	ASD focus
Emotional wellbeing	Increased safety, stable and predictable environments, positive feedback	Contentment, self concept, lack of stress	Ability to identify personal stress and de-fuse it. Role of sensory hypo/hyper sensitivity. Objective self evaluation, satisfaction levels
Interpersonal relations	Foster friendships, encourage intimacy, support families	Interactions, relationships, supports received	Articulation of social needs, seeking out others and choice of time alone
Material wellbeing	Ownership, possessions employment	Financial status, employment status, residential status	Role and status within employment and accommodation. Financial decision making
Personal development	Functional education/training, augmentative technology	Education status, personal competence, performance	Choice of FE/HE options. Access to IT and pursuit of special interests to enhance potential
Physical wellbeing	Health care, mobility, wellness, nutrition	Health status, activities of daily living, leisure and recreation	Awareness of principles of healthy living; monitoring of physical condition; role of sensory hypo/hyper sensitivity in personal choices. Facilitated access to leisure and recreation opportunities
Self determination	Choices, personal control, decisions, personal goals	Autonomy, goals, personal values, choices	Universally recognized means of making choices; opportunities to regularly exercise choice; respect for personal wishes/values/lifestyle
Social inclusion	Community role, community activities, volunteerism	Community integration, community roles, social supports	Social valorization in micro/macro-community roles; recognition of strengths; choice of level of community involvement
Rights	Privacy, voting, due process, civic responsibilities	Human (e.g. respect), legal rights (e.g. access)	Respect for life choices and need for privacy and being alone; facilitated information on rights, processes and responsibilities

It is a real challenge for local authorities and service providers to evidence outcomes in this area however it is important to demonstrate that the impact of autism on an individual's quality of life as well as their general health, well being and happiness has been taken into account.

The challenge remains how best to assess progress in relation to outcomes. This is, quite rightly, usually done on an individual basis however the indicators of good practice require that local authorities have in place, "a self-evaluation framework to ensure best practice implementation and monitoring." There is therefore a need to measure, monitor and evaluate outcomes at a strategic level.

Self evaluation is a useful process but is one that requires identification and evaluation of robust evidence as well as transparency in terms of findings and action planning in order to improve.

Argyll and Bute Partnership already demonstrates a commitment to continuous improvement by its involvement in The Public Service Improvement Framework (PSIF). Applying the self assessment methodology that is central to PSIF to the local strategy and to autism services would enable effective evaluation within a recognised, validated framework. A small number of voluntary organisations, including Scottish Autism have signed up to PSIF. Scottish Autism has developed a specific self evaluation tool based on the PSIF methodology, The Autism Practice Improvement Framework. This demonstrates that there is scope for customisation of the core approach. This is worthy of consideration as a means of evidencing progress in relation to this specific indicator of good practice. NHS Highland developed its own system of quality improvement known as Highland Quality Approach (HQA).

5. Autism Services and Models of Support.

Over recent years there has been a significant change in Autism commissioning practice, where in line with the national focus, local authorities seek to make placements into supported living rather than traditional registered care homes, which had previously been the default position.

The emphasis should be focused on the individual at the centre of the planning and commissioning process, with services being flexible and adjusting to changes in need over the whole life journey.

A one size fits all approach is therefore not advocated but one that is underpinned by person-centred values and tailored to individual needs and complexity.

Overall it is fair to say that the autism services commissioning landscape going forward is difficult to predict. What models of support will be available, where and for whom they are required, is likely to be determined locally rather than nationally, with different Councils having very different requirements. This is another area where flexibility in the Council's strategy is essential.

What is not in doubt is that the demand for high quality support for people with autism will not decrease.

5.1 Transition Planning for Individuals – The Key to Success.

Argyll & Bute Partnership recognises that establishing new provision for individuals will mean a period of transition. It is essential whilst planning transition and throughout implementation that all parties are aware of their role and responsibilities and are accountable for participating fully in the process to ensure success.

It is recognised that transitions are a source of anxiety and unpredictability which can have a major impact on individuals living with autism. The Partnership must further develop its skills in managing such transitions and ensure that plans are in place to support the sensitive nature of such a life changing experience. Recognition of the specialist needs of individuals and in particular the complexities associated with transition is essential. Individuals with autism may experience difficulties with communication, socialisation, adaptation to environments and flexibility of thought, therefore any transition whether it be micro or macro can result in an increase in anxiety for individuals and challenging behaviour. The Partnership aspires to provide services which are able to support individuals at these most difficult times by providing person-centred support which ensures routine, structure, consistency and predictability and leads to an increased quality of life.

The Partnership will promote a culture where individuals, family/ carers and other stakeholders can expect commissioners of support packages to work closely with them to plan the introduction to a new service/ staff, ensuring the transition is sensitive to the users' needs and paced to achieve minimal disruption.

On completion of the transition, the Partnership and its contractors will be responsible for delivering the full package of care and support and will comply with all statutory responsibilities including ensuring the provision is appropriately registered with The Care Inspectorate.

5.2 Person-Centred Services.

Argyll & Bute Partnership will procure person-centred services not only to identify the needs of individuals, but to ensure individuals consider that their service is appropriate for them. By working in partnership with individuals the aim is to:

- Develop and agree individualised support for each person we support.
- Provide a safe home environment.
- Provide support with all aspects of daily living, ensuring full and active lifestyles are achieved.
- Promote each individual's ability to communicate and make their own choices about the way they wish to live.
- Promote opportunities for individuals to realise their potential.
- Provide a wide range of opportunities for each person to participate in their local community.
- Support people to understand their own needs and how these can be met.
- Consult with service users, families and stakeholders to inform the service and develop outcome focused support plans.
- Regularly review provision to ensure outcomes are being achieved.
- Empower and uphold the rights of each individual as citizens at all times.
- Ensure that individuals and care managers are fully involved in all aspects of their support.
- Provide a well trained and knowledgeable staff team that will provide high quality service provision.

Every Person-Centred Support Plan is developed following person-centred planning principles as follows:

- Key-workers should be responsible for ensuring the service user is listened to and is encouraged to identify their own aspirations which can be developed into achievable outcomes within the plan.
- Service providers should embrace the principles of personalisation and advocate for individuals to direct their support, encouraging creativity from individuals regarding their service needs/plans and respecting individual choice.
- An individual's support provision should be continually reviewed to ensure we are maximising both potential and independence, with the individual and their family are at the core of this process.

5.3 Working in Partnership.

The Council recognises the value and importance of working in partnership with key agencies that are important in individual's lives. Individuals should not be supported in isolation, and service providers should work closely with partners to plan provision

and respond to individual need and changing circumstances. Input from families and carers is valued and service providers should work hard to develop positive working relationships, with other key agencies.

5.4 Communication.

It is recognised that individuals on the autism spectrum can experience difficulties with communication and will therefore require support to express their wishes and be involved in all decision making. Service providers must be committed to establishing clear communication systems and will utilise existing skills to maximise communication whilst, where appropriate, exploring new and enhancing communication methods. These may include the use of:

- Verbal and Written
- Picture Exchange Communication System (developed by Bondy and Frost in 1985)
- Talking Mats
- Object Signifiers
- Social Stories™ (Gray 2010)
- Photographs/Symbols
- “Tablet” computers and Apps
- IT – Touch screen computer
- DVD/Audio

These communication aids will support the individual to communicate and comment about the service as well as provide staff with the means to communicate effectively. Service users will be encouraged to exercise their right of choice, and express their wishes and desires using their preferred communication method.

Argyll & Bute Partnership recognises that communication extends beyond language and an important task for service providers will be to build relationships with each individual so they understand and respond appropriately to non-verbal communication. All those involved will be responsible for developing ongoing relationships with individuals and their families promoting effective communication and facilitating open and honest exchanges between all parties.

5.5 Supporting Independent Living.

It is recognised that some individuals may require support to live full and rewarding lives. With this in mind, support will be constructed in a way that ensures each individual is supported to maintain existing skills and develop new skills. It is vital, for each individual the Partnership supports, to agree aims, expectations and outcomes from the outset and for these to be regularly reviewed and modified.

Person-Centred Support Plans should be developed in consultation with each service user and the significant people in their lives. Agreed outcomes should be realistic and achievable, whilst acknowledging aspirations and hopes for the future.

The Partnership recognises the importance of maintaining existing skills as it is known that some individuals with autism lose skills quickly if they are not given opportunities to practice them.

Argyll & Bute Partnership aims to maximise the potential for each individual we support, and is committed to reviewing and adapting support to ensure this occurs.

5.6 Existing Service Delivery within Argyll & Bute.

Due to the service profile it is recognised that adults with autism were likely to be under-represented in the National Autism Mapping Project.

The mapping project identified a number of key issues for Argyll & Bute Partnership (www.autismargyll.org.uk/autismargyll/News/Entries/2014/1/1_Autism_Mapping_Project.html)

. The top three actions identified by Parents/Carers included:

1. Education – more training awareness/better provision specialist and mainstream
2. Better Support to Carers and families
3. More and better service provision.

Many carers reported that they did not feel equal partners in the provision of support to their children. An improvement in inclusion and communication would be welcomed by parents and carers. Further suggestions for improvement included:

- A lead professional with Health and Social Care experience who could work at planning level.
- Ongoing multi-agency working around national developments, with lessons for local processes clearly planned, implemented and reviewed.
- Increased knowledge and understanding at middle/ senior management/ commissioner level

Both carers and professionals would benefit from having a clear point of contact for information and signposting which would ensure that information was kept up to date and coordinated. Whilst in relation to early intervention, a proactive approach rather than the crisis driven reactive approach was deemed desirable by parents and carers. Furthermore it is vital to ensure that people on the spectrum do not slip through at vital transition phases, whether this be from primary school to Secondary, or from moving on from College to securing a work placement.

While there was some good progress particularly with children and young people, gaps were identified across a number of areas:

- There was a lack of clear referral pathways, training, awareness and continuity of targeted support
- Coordination was not always consistent, with the geography determining which agency or professional would lead. This resulted in some inconsistent multi agency working.

- Multi agency pathways stop at assessment.
- Carers said that there was a need for better coordination between services particularly post diagnosis.
- On-going specialist training on ASD is required.

However, because of its rural nature staff working in the remote communities of Argyll & Bute often have to think differently and can often come up with very personalised and creative solutions. Access to the range of direct provision which is available elsewhere in Scotland is not so well established within Argyll & Bute. Careful consideration therefore must be given to the nature of support and services to both service users and their families, who often live in remote areas with limited access to physical resources, staff, and transport.

Perhaps a starting point to addressing many of these issues, which highlight the dependence on carer support is to ensure that Carers fully understand their rights and are aware of the right questions to ask of the professionals.

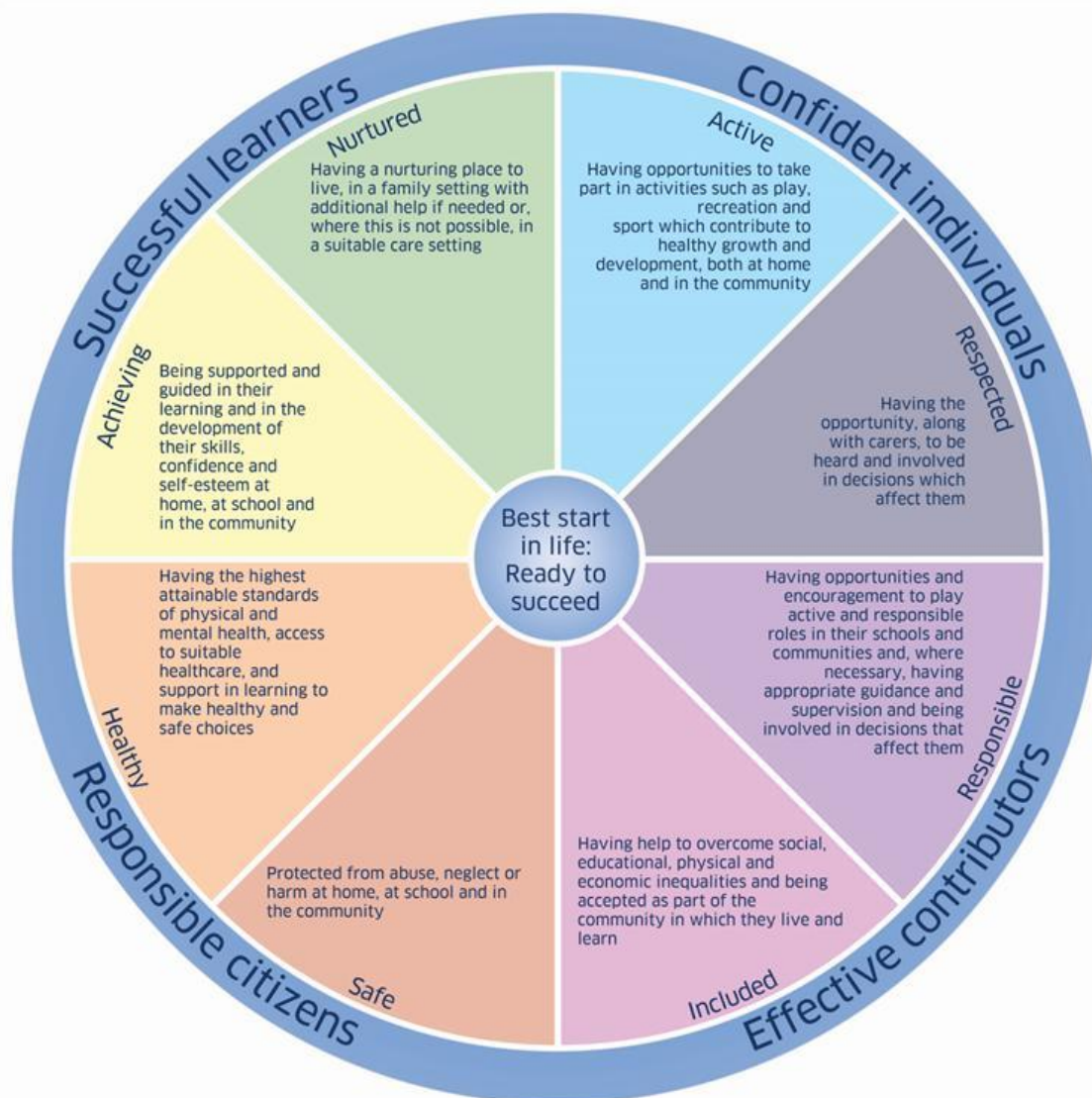
6. Education.

In all Scottish Schools, the Scottish Government, through documents such as GIRFEC (getting it right for every child), The Curriculum for Excellence, the Journey to Excellence and The National Care Standards (in residential schools) has set out entitlements, targets and a broad range of educational experiences for all children in Scotland.

The wellbeing of children and young people is at the heart of getting it right for every child. The eight indicators for well being are safe, healthy, achieving, nurtured, active, respected, responsible and included (SHANARRI). These eight areas are set in the context of the 'four capacities' which are at the heart of the Curriculum for Excellence.

These are illustrated in the "Wellbeing Wheel"

(www.scotland.gov.uk/Topics/People/Young-People/gettingitright/well-being)



'National Priorities in Education' have been defined, expected 'outcomes' and 'experiences' clearly identified and every child in Scotland will be enabled to become 'Confident Individuals', 'Effective Contributors', 'Successful Learners' and 'Responsible Citizens' as shown below (www.educationscotland.gov.uk):

successful learners	confident individuals	responsible citizens	effective contributors
<p>attributes</p> <ul style="list-style-type: none"> enthusiasm and motivation for learning determination to reach high standards of achievement openness to new thinking and ideas <p>capabilities</p> <ul style="list-style-type: none"> use literacy, communication and numeracy skills use technology for learning think creatively and independently learn independently and as part of a group make reasoned evaluations link and apply different kinds of learning in new situations. 	<p>attributes</p> <ul style="list-style-type: none"> self-respect a sense of physical, mental and emotional well-being secure values and beliefs ambition <p>capabilities</p> <ul style="list-style-type: none"> relate to others and manage themselves pursue a healthy and active lifestyle be self-aware develop and communicate their own beliefs and view of the world live as independently as they can assess risk and make informed decisions achieve success in different areas of activity. 	<p>attributes</p> <ul style="list-style-type: none"> respect for others commitment to participate responsibly in political, economic, social and cultural life <p>capabilities</p> <ul style="list-style-type: none"> develop knowledge and understanding of the world and Scotland's place in it understand different beliefs and cultures make informed choices and decisions evaluate environmental, scientific and technological issues develop informed, ethical views of complex issues. 	<p>attributes</p> <ul style="list-style-type: none"> an enterprising attitude resilience self-reliance <p>capabilities</p> <ul style="list-style-type: none"> communicate in different ways and in different settings work in partnership and in teams take the initiative and lead apply critical thinking in new contexts create and develop solve problems

This has become a mantra in schools where all aspects of learning, all aspects of school life can be reflected back to the Curriculum and measured against the standards set and agreed specifically as 'Learners'. This might seem obvious and it is emphasised here as an alternative to the still commonly held view of young people with ASD as having behaviour disorders, communication problems etc.

It is the view of the Partnership that the educational, emotional and social needs of all pupils with autism can be best served by **adopting**, not by **adapting** the Curriculum for Excellence.

To quote from the Curriculum for Excellence documentation:

All children and young people are entitled to experience:

- A coherent curriculum from 3 to 18
- A broad general education and outcomes across all curriculum areas. This should include understanding of the world and Scotland's place in it and understanding of the environment
- A senior phase which provides opportunities for study for qualifications and other planned opportunities for developing the four capacities
- Opportunities for developing skills for learning, skills for life and skills for work

- Opportunities to achieve to the highest levels they can through appropriate personal support and challenge
- Opportunities to move into positive and sustained destinations beyond school”.

These are lofty ideals. The important fact to consider, however, is that they are **entitlements**. What then happens to these ‘entitlements’ when pupils leave school; what then happens to the skills gained; what then happens to the expectations of parents/carers/professionals; and, most crucially, what happens to the increased expectations and aspirations of the young people themselves?

Education for children with autism in Argyll & Bute will seek to promote the following:

- Skills for independent living
- Developing the capacity for coping/resilience
- Opportunities for engaging with communities (including when teaching and learning takes place within a special needs unit)

Children and young people will progress differently, depending on their circumstances but every child and young person has the right to expect appropriate support from adults to allow them to develop as fully as possible across each of the well-being Indicators and have access to a broad curriculum of experiences.

The Scottish Strategy for Autism points out that some children will have been identified as likely to require additional support before they start nursery school. In these circumstances education authorities should seek and take account of relevant advice and information from appropriate agencies and individuals at least six months before the child is expected to start nursery. This advice and information will help the education authority to establish the child’s additional support needs and to determine the provision and adequacy of additional support required. A similar process must be undertaken before a child with additional support needs transfers from pre-school provision to primary school and from primary school to secondary school. However, the timescale for the planning of a transition is longer and the duty to seek and take account of relevant information and advice from appropriate agencies or persons should be completed no later than 12 months before the transition.

The Scottish Government commissioned and published an Autism Toolbox in 2009. This is currently being revised and updated. Written by a professional multi-agency team its aim is both to support education authorities in their planning of services for children and young people with autism and practice in the classroom.

This will be central to Argyll & Bute’s strategy for education for young people with autism.

7. Employment.

Many of the domains of quality of life described earlier are directly addressed by a person being in meaningful employment, and many people on the autism spectrum aspire to be part of their community and contribute to society in this way.

Large autism charities such as Autism Initiatives, Scottish Autism and the National Autistic Society do provide work opportunities, sometimes as “Social Firms.” For local authorities the focus must be on creating routes to employment within their own areas.

There is no easily defined work type which can be classified as suitable for people with autism. As shown earlier, the range of capability, intelligence, education and skills is very wide within the autism community. Meaningful employment is possible for some, but not all.

The Partnership’s strategy will be to:

- Create supported routes to further higher education, vocational training and employment which results in the fulfilment of support needs (which might be minimal);
- Buy into training, awareness of, and understanding of autism;
- Actively encourage meaningful buy-in from relevant sectors – Partnership offices and services, further education and the NHS within its area of responsibility.

The departments of the Partnership that deliver employment related services will be actively encouraged to engage with the strategy in relation to developing an awareness and understanding of the needs of people with autism in the area of employment.

The Partnership will seek to explore effective models of supported routes to employment e.g. project SEARCH (www.sclid.org.uk/sclid-projects/project-search) with a view to expansion when the financial environment improves.

8. Autism Awareness and Training.

Ensuring staff at all levels across all disciplines have knowledge and awareness of autism commensurate with their involvement in the lives of people with autism is a challenge for all Scottish local authorities. The National Training Framework for Autism (MacKay & Dunlop 2004) provides a rationale for the range of training available and gives indicative guidance as to who would benefit most from the range of opportunities available. Appendix 3 outlines the types of training opportunities that were available across Scotland at the time the document was published. Since then some authorities such as Edinburgh and Glasgow have developed e-learning resources that address needs at an awareness level. Voluntary organisations have also developed resources such as the National Autistic Society's "Ask Autism" resource and Scottish Autism's "Right Click" programme which is free to parents who have children on the autism spectrum.

Other parent training resources have been made available as a result of the Development Fund linked to the National Strategy.

The rationale and framework for awareness raising and training is clearly set out in the National Training Framework. The challenge is to operationalise this in a way that is strategic and measurable.

The Argyll and Bute Partnership will work towards adopting the national training framework as the basis of our local training strategy. Aspects of the outputs may be achieved by liaising with Partnerships and the voluntary sector to maximise the use of resources that are already developed and that are available free of charge or with minimal cost. Such resources can be cross-referenced with the framework; targets relating to staff and parent training can be set and measured over time.

It is also important that, in the longer term, local capacity in relation to training is identified and built. As part of the development funding stream the charity Scottish Autism is developing The Autism Trainer Award. The aim of the award is to drive up the standards of non award bearing training that forms the vast majority of training undertaken by local professionals. This ranges from awareness training to more specific topic based training such as supporting behaviours that challenge or communication. Argyll and Bute, along with all other Scottish Partnerships will be offered a place, free of charge on the pilot delivery of the award which will commence in the autumn of 2014.

Appendix 1: The Chronology of Key Autism Policy & Related Initiatives in the Scottish Context.

Publication	Summary of Focus	Outcomes/Conclusions
Scottish Government (2000) <i>The Same as You? A review of services for people with learning disabilities</i> . Edinburgh: Her Majesty's Stationery Office	National review of Learning disability. (Includes Asperger's Syndrome)	29 recommendations made. E.g. Establishment of "Partnership in Practice" agreements. Development of a National ASD network Right to a "personal life plan" if desired.
Public Health Institute of Scotland (2001) <i>Autistic Spectrum Disorders- Needs Assessment Report</i> . Glasgow: PHIS /NHS Scotland.	National Assessment of the Needs of people with autism and their families. Includes pre and post diagnosis, services, information and professional training	32 recommendations made in key areas of: <ul style="list-style-type: none"> • Standards & Monitoring • Matching resources to need • Training • Research • Diagnosis & Assessment
Barnard, J., Prior, A. & Potter D (2000) <i>Inclusion in Autism is it Working?</i> London The National Autistic Society	A survey of its members conducted by The National Autistic Society that focuses on their experiences of inclusion. Provides 1000 examples of inclusion in adult life and education.	A national survey with results differentiated to reflect views on experiences of inclusion in education and wider society in the various regions of the UK. Includes needs across the spectrum and the lifespan.
Barnard, J., Broach, S., Potter, D & Prior, A. (2002) <i>Autism in Scotland's Schools Crisis or Challenge?</i> London: The National Autistic Society	A survey seeking the views of teachers on numbers of children on the autism	Range of recommendations in areas of: <ul style="list-style-type: none"> • Diagnosis & Assessment • Research to establish

	spectrum and the education provision made available to them.	<p>minimum standards of education for children with ASD</p> <ul style="list-style-type: none"> • Training • Improved inter professional collaboration.
Mackay, T.A.W.N. and Dunlop, A.W. (2004). <i>The Development of a National Training Framework for Autistic Spectrum Disorders. A study of Training for Professionals Working in the Field of ASD in Scotland</i> . Glasgow: National Autistic Society and University of Strathclyde.	A national survey of the training undertaken by and training needs of a range of professionals from health, education and social work and social care disciplines. Parents, family members and individuals on the autism spectrum are also included.	<p>A “state of the nation” overview of the range and level of training undertaken by a range of professionals and individuals with a personal interest in ASD.</p> <p>21 recommendations in areas relating to:</p> <ul style="list-style-type: none"> • Developing a national training framework • Training providers • Local training strategies • Implementation
Her Majesty’s Inspectorate of Education (2006) <i>Education for Pupils with an Autism Spectrum Disorder</i> . Livingston: HMIE	A review of the range of educational provision available to children on the autism spectrum. Including mainstream provision, units within or attached to mainstream schools and autism specific schools.	<p>8 key recommendations:</p> <ul style="list-style-type: none"> • Education authorities should know the numbers of children in their area and have details of provision. • Education authorities should have varied forms of provision • Schools should use and regularly review individual education plans. Local authorities should work with Scottish

		<p>government to ensure co-ordination of support.</p> <ul style="list-style-type: none"> • Schools should provide appropriate opportunities for pupils with ASD to develop life skills. • Schools should maximise opportunities for social inclusion • Education authorities should ensure parents have access to information about provision. Authorities should involve parents in training where appropriate • Education authorities should ensure teaching and support staff have access to training and professional development opportunities • Collaboration between education authorities and other agencies to ensure a co-ordinated approach <p>This report led to the formation of the Autism Education Working group formed by Support for Learning Divisions,</p>
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		Schools Directorate. Scottish Government.
Batten, A. and Daly, J. (2006) <i>“make school make sense.” Autism and education in Scotland: the reality for families today.</i> Glasgow: National Autistic Society	Survey report conducted as part of The National Autistic Society campaign aimed at improving educational provision for all children on the autism spectrum.	This report also influenced the development of the working group mentioned above. The report resulted in a call for: <ul style="list-style-type: none"> • The right school for every child with autism • The right training for every teacher • The right approach in every school
Marwick, H. and Tait, C. (2006) <i>Evaluation Report of the Glasgow Autism Resource Centre.</i> www.scotland.gov.uk	An evaluation of the perceived efficacy of a Scottish Government funded initiative. Includes the views of staff and service users as well as professionals who engage with the service for training or advice.	Evidence as to the efficacy and service user satisfaction levels with this model of provision for adults on the autism spectrum.
Marwick, H. and Tait, C. (2007) <i>Evaluation of ‘No. 6’: the One-Stop-Shop for Adults with Asperger’s Syndrome and High Functioning Autism, in Edinburgh and the Lothians.</i> www.scotland.gov.uk	An evaluation of the perceived efficacy of a Scottish Government funded “one stop shop” initiative. Includes the views of staff and service users as well as professionals who engage	Evidence as to the efficacy and service user satisfaction levels with this model of provision for adults on the autism spectrum.

	with the service for training or advice.	
<p>Scottish Intercollegiate Guideline Network (SIGN) (2007) <i>Assessment, Diagnosis and Clinical Interventions for Children and Young People with Autism Spectrum Disorders</i>. (SIGN Publication 98) Available at: www.sign.ac.uk/pdf/sign98.pdf Retrieved March 2010</p>	<p>Review of high level research evidence available relating to diagnosis, assessment and interventions for children and young people on the spectrum up to 18 years of age.</p>	<p>Guidance regarding diagnostic protocols. Recommendations re appropriate tools for diagnosis and assessment. Recommendations re a range of interventions based on a review of available evidence. Outcomes available in a range of formats including a booklet that aimed to be accessible for children and young people on the spectrum.</p>
<p>Scottish Government (2008) <i>Commissioning Services for People on the Autism Spectrum. Policy and Practice Guidance</i>. Edinburgh: The Scottish Government.</p>	<p>Guidance aimed at improving the range of services provided to adults with autism where such services are specifically commissioned by local authorities for individuals or numbers of people on the spectrum.</p>	<p>Details on areas that should be considered before commissioning services for people on the spectrum. Includes models of good practice.</p>
<p>Daly, J. (2008) <i>I Exist</i>. Glasgow: The National Autistic Society</p>	<p>Survey report resulting from The National Society campaign to bring attention to the needs of adults on the autism spectrum if they are to be meaningfully included in society. Addresses</p>	<p>A survey of National Autistic Society members in Scotland aimed at identifying issues for adults on the autism spectrum. 7 recommendations made:</p> <ul style="list-style-type: none"> • The Scottish Government should ensure local authorities implement “The Same as

	<p>issues such as housing, employment, friendships and relationships.</p>	<p>You?”</p> <ul style="list-style-type: none"> • Establishment of local data bases • Produce and promote guidance for commissioners • Guidance on how local authorities should bridge the gap between learning disability and mental health services • Staff training particularly for those conducting needs assessments • Training for social care staff • Clear routes to assessment for people on the spectrum
<p>A Guide to Getting it right for every child (GIRFEC) (2008)</p> <p>www.scotland.gov.uk/Topics/People/childrenservices/girfec</p>	<p>Provides a consistent way for people to work with all children and young people. It's the bedrock for all children's services and can also be used by practitioners in adult services who work with parents or carers.</p>	<p>The approach helps practitioners focus on what makes a positive difference for children and young people – and how they can act to deliver these improvements. <i>Getting it right for every child</i> is being threaded through all existing policy, practice, strategy and legislation affecting children, young people and their families.</p>
<p>Dunlop, A.W., Tait, C., Leask, A., Glashan, L., Robinson, A., and Marwick, M. (2009). <i>The Autism Toolbox: An Autism Resource for Scottish Schools</i>. Edinburgh: Blackwell</p>	<p>Resource produced as a result of a working group formed by The</p>	<p>A national resource containing practice and policy guidance aimed at improving the inclusion of pupils</p>

	<p>Scottish Government Support for Learning Division, Schools Directorate to address the recommendations made in HMIE review of provisions and “make school make sense” campaign report.</p>	<p>on the autism spectrum in mainstream schools. A copy sent to every nursery, primary and secondary school in Scotland.</p>
<p>Dunlop, A.W., Tait, C. and Robinson, A. (2009) <i>Policy into Practice: Supporting the Development of ASD Accreditation Standards for Trainers and Developing Personal Accreditation Routes for ASD Training Participants</i>. Edinburgh: The Scottish Government.</p>	<p>Policy into practice project report on the outcomes of a 2 year Scottish Government funded collaborative project between The Scottish Society for Autism and The National Centre for Autism Studies. The aim of the project was to develop a system of accreditation or approval for award and non- award bearing training in autism and autism trainers.</p>	<p>Continuing development of an autism training approval scheme via the development of a customised award; The Autism Trainer Award. This award is to be developed by Scottish Autism and validated by The Scottish Qualifications Authority.</p>
<p>The Scottish Government (2011) <i>The Scottish Strategy for Autism</i> Edinburgh: The Scottish Government</p>	<p>10 year strategy</p>	<p>2,5 and 10 year goals and 26 recommendations aimed at improving quality of life of people on the autism spectrum</p>

<p>The Scottish Government (2013) <i>The Scottish Strategy for Autism: Menu of Interventions</i> Edinburgh: The Scottish Government</p>	<p>Guide to interventions and supports for people on the autism spectrum</p>	<p>Developed in response to Recommendations 10 and 11 of the national strategy it is intended as a guide to interventions required by people with autism across the lifespan and ability range.</p>
<p>The Scottish Government (2013) <i>The Scottish Strategy for Autism: National Autism Mapping Project</i> Edinburgh: The Scottish Government CDROM</p>	<p>Map of services and service pathways across Scotland</p>	<p>A local map of services for every local authority in Scotland indicating what is working well and identifying gaps</p>

Appendix 2: The Theory of Operations.

Malcolm K. Sparrow is Professor of the Practice of Public Management at Harvard's John F. Kennedy School of Government. He is Faculty Chair of the school's executive programmes on regulation and enforcement, corruption control, policing, and counter-terrorism. In March 2010 he was appointed by President Barack Obama to the Recovery Independent Advisory Panel, to advise the Recovery Board on protecting the integrity of the economic stimulus package.

Professor Sparrow is no stranger to Scotland, having given lectures and run workshops on regulation, the control of "harms" and in refining the business model for SCISWIS, where he delivered a Scrutiny Reform Master Class. He has worked extensively with the Scottish Environmental Protection Agency in refining that agency's approach to "Better Regulation." The Scottish Government's response to the Crerar Report was also informed by reference to Professor Sparrow's work, in particular his book *The Character of Harms: Operational Challenges in Control*, Cambridge University Press, 2008.

It is his thinking set out in this book which led to the Scottish Government and Scottish Autism jointly funding a workshop in Edinburgh in December 2012 – "The Scottish Strategy for Autism: Structuring Services and Harm Reduction Work for the ASD Community."

Much of this theory is directed towards what Sparrow describes as "sabotaging harms." The word "harm" is perhaps inappropriate in the context of autism, but the theory is readily adaptable to many complex issues facing government organisations. First, consider the levels at which "harms" could be addressed:

Levels at which "harms" could be defined and addressed:

Level:	Object:	Comments:
1-Highest	Broad categories of harm, addressed at the level of nations.	<ul style="list-style-type: none"> • Macro-level analyses • "General theories" compete at this level • Lower level texture not visible from here
2-High	Specific harms that have escalated to crisis proportions	<ul style="list-style-type: none"> • Problem politically visible and urgent • Failure to control would be embarrassing • Combination sufficient to produce action
3-Medium	Anything in between!	<ul style="list-style-type: none"> • Small enough to be optional • Large enough to require organizational systems • Many agencies lack any apparatus for this
4-Low	Problems small enough to be addressed by highly motivated individuals or teams	<ul style="list-style-type: none"> • Preserve of self-motivated volunteers • Represent departures from normal practice • Heralded as "innovations"
5-Lowest	One specific incident, report, or case.	<ul style="list-style-type: none"> • Handled through routine processes • Unit of work is how workload is measured • Object not a collection of lower level objects

Autism could be said to spill over into level 2, but fits best in level 3. Expanding this view:

Levels at which "harms" could be defined and addressed:

Level:	Object:	Comments:
1-Highest	Broad Categories	
2-High	Visible Crises	
3-Medium	Anything in Between!	<ul style="list-style-type: none"> ▪ Small enough to be optional ▪ Large enough to require organizational systems ▪ Many agencies lack any apparatus for this ▪ Therefore "covered" by functions & processes
4-Low	Addressable by small teams	
5-Lowest	Individual incidents or cases	

Malcolm K. Sparrow

John F. Kennedy School of Government, Harvard University

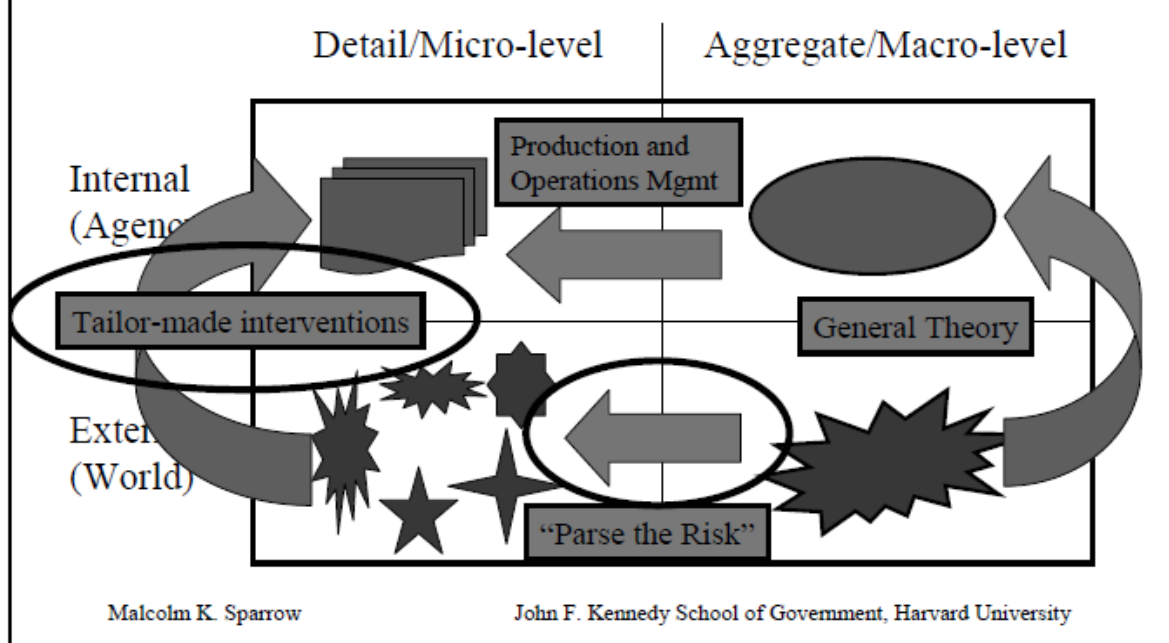
The result of this is that the majority of risk-control work is not organised around risk-concentrations (such as the unaddressed needs of people on the spectrum), but around functions, processes and agency structures.

This has several important implications. In the diagram below the horizontal dividing line separates the external world (below the line) from the internal world (above the line). The vertical dividing line separates macro-level considerations (on the right) from detailed or micro-level ones (on the left).

The starburst on the lower right represents a global concentration of risk/harms – in our case the entire needs of the ASD population. In response to this government creates one or more agencies to address this and this is represented by the oval in the top right corner.

The governing body now needs to decide what might be done, which Sparrow calls the *theory of operations*. Usually the general method of operations is set out in the governing/delivering body's policies or authorising legislation – but not always.

Theory of operations



Often the *theory of operations* represents an entrenched tradition which has never been questioned. This is perfectly normal and understandable – governments, local or national, need to plan for the delivery of services and are required to show fairness and objectivity as well as being efficient and providing value for money.

This approach is represented as the “General Theory” in the diagram and is perfectly adequate for most of the population.

However the problems and issues associated with autism exist in the outside world and are *independent* of the structures Partnerships put in place to address them. The core of the problem is that with something as complex and multidimensional as autism for a significant minority of individuals there is a misalignment between the “standard” processes any Partnership has in place and the problem itself.

This works on two different scales:

- 1: On the autism population as a whole - recognising that autism is not a single specific issue – say a generic learning disability – but a series of “populations” of which the analysis in Chapter 2 of this strategy could be one possible classification; and
- 2: On the individual on the autism spectrum recognising the complexity inherent in co-morbid conditions, sensory issues and the presentation of that individual’s autism.

Therefore the “starburst” in the Theory of Operations diagram could represent either the issues facing the entire autistic population or multiple issues faced by an individual with ASD.

Functional organisation is important but not sufficient because it leaves no-one in charge of processes which straddle multiple functions. This is not to imply that there is some form of conflict between processes owners (e.g. health and social care), just a lack of consideration of the individual’s interaction with the other process. The process owners may have markedly different views on how to proceed.

This can result in the individual being classified e.g. as a “patient” or as a “service user” according to where he comes to the attention of government services, and his/her other needs are not addressed.

The logical implication is that the issues are better focused on the individual than on the mainstream processes. Sparrow’s analysis concludes (P57) *“that focusing on processes and focusing on problems produces two quite different patterns of thought and action.”*

Addressing the various elements of a complex harm naturally produces a series of tailor-made interventions which are outside the normal policies and procedures of the Partnership.

Conventional quality improvement policies in local government tend to focus on *process* improvement i.e. they are managerial tools for improving the Partnership’s processes. By contrast a *problem-solving* approach is an operational way of working on external harms.

This suggests additional resources specifically to manage all the various requirements of complex individuals. This is clearly not practicable in the current economic climate. The Partnership therefore recognises that for such a complex multidimensional phenomenon as autism, staff in all disciplines must recognise that they may only be seeing one facet of the individual’s condition and adopt an individual-focused approach (i.e. a problem solving approach) if all the individual’s needs are to be met and quality of life maximised.

Appendix 3: The National Training Framework.

LEVEL	TYPE OF TRAINING	FOR WHOM	WHERE
12) Postgraduate	PhD	Grads & postgrads	Universities
11) POSTGRADUATE AWARDS	Certificate, Diploma and Master's in Autism	Specialist practitioners and managers of services who hold first degrees or equivalent - range of disciplines	University of Strathclyde - on campus and local outreach. University of Birmingham Distance Education programme
11) PROFESSIONALLY SPECIFIC POST-GRADUATE AWARDS	MSc Educational Psychology Clinical psychology	Educational & clinical psychology trainees	Various universities
10) PROFESSIONAL AND STATUTORY BODY QUALIFICATIONS	Core or option element on autism in initial undergraduate vocational degrees	Teachers, speech & language therapists, nurses, doctors, social workers, occupational therapists	Faculties of education, medicine, health studies, social work - various universities
CPD - LOCAL AUTHORITY AND HEALTH BOARD	In-service, local authority training provided by LA personnel & speakers outwith	Usually targeting single professional groups	In local centres
9) BA DEGREES	Non-vocational degrees, eg psychology	Major project and undergraduate dissertation students	Universities
8) HEI	HE undergraduate certificates and diplomas with option elements	Those exiting before degree status.	Universities and higher & further education colleges, ACE in Autism
6) & 7) FE	PDA awards students, SGA students		FE colleges
5) HNC AND NC	Social Care awards - non-specific	Career pathway in social care, childcare and education	FE colleges
4) SVQ	Levels 3 & 4 SVQ cluster skills set, in preparation	People who prefer a practical way of learning	Learning activities undertaken in the workplace
3) COMMUNITY LEARNING	Reflection on personal development	People working in a range of community care settings	Community-based learning
2) IN-HOUSE	Building a portfolio of experience and training, shadowing, planned	All employees in a given setting	Workplace learning

	learning opportunities		
1) INITIAL PRACTICAL EXPERIENCE IN COMMUNITY OR WORKPLACE	Informal life and work experience	Volunteers, work experience students, returners, parents	Informal learning through observation and experience

Appendix 4.1: Mapping the Two Year Goals in the National Strategy against the Good Practice Indicators and the Argyll & Bute Action Plan.

Links to National Strategy goals – Foundations: by 2 years	
<ul style="list-style-type: none"> • Access to mainstream services where these are appropriate to meet individual needs. • Access to services which understand and are able to meet the needs of people specifically related to their autism. • Removal of short-term barriers such as unaddressed diagnoses and delayed intervention. • Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis). • Implementation of existing commissioning guidelines by local authorities, the NHS, and other relevant service providers. 	
Good Practice Indicator	Strategic Action
10. A self-evaluation framework to ensure best practice implementation and monitoring.	The authority will seek to identify a relevant and effective means of self evaluation in relation to best practice within autism service delivery across health, education and social care.
<p>2. Access to training and development to inform staff and improve the understanding amongst professionals about ASD.</p> <p>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.</p>	<p>Develop a cross agency, sustainable, training plan that meets the existing and future training needs in relation to ASD. This will be a 3 tiered plan. Monitor the use and application of The Autism Toolbox as a resource that supports good practice in mainstream education settings.</p> <p>We will work to implement the National Training Framework for Autism in all relevant sectors of the authority</p> <p>We will monitor the uptake and impact of autism training particularly at awareness level.</p> <p>We will seek to collaborate with other local authorities and the voluntary sector to identify training resources that can be shared and can be readily accessed e.g. e-learning resources.</p> <p>We will work to build local capacity by taking advantage of initiatives linked to the national strategy such as The Autism Trainer Award.</p>

<p>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.</p> <p>3. A process for ensuring a means of easy access to useful and practical information about ASD.</p>	<p>The authority intends to develop a database and data collection methods that enable interagency data sharing in order to plan and target support for people with ASD. Particular attention will be paid to how information on adults with ASD is collected and collated.</p>
<p>6. A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.</p> <p>1. Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD.</p> <p>7. A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.</p>	<p>Develop a clear consistent pathway for adults to receive a diagnosis of autism and appropriate support following a diagnosis.</p> <p>We will seek to identify opportunities to maximise supported employment opportunities for people across the spectrum.</p>

Appendix 4.2: Mapping the Five Year Goals in the National Strategy against the Good Practice Indicators and the Argyll & Bute Action Plan

Links to National Strategy goals – Whole Life Journey: by 5 years	
<ul style="list-style-type: none"> • Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism. • Access to appropriate transition planning across the lifespan. • Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas 	
Good Practice Indicator	Strategic Action
10. A self-evaluation framework to ensure best practice implementation and monitoring.	<p>The authority will seek to identify a relevant and effective means of self evaluation in relation to best practice within autism service delivery across health, education and social care</p> <p>Establish the ongoing evaluation of the “ASD Multi-disciplinary Protocol and Pathway” for identification of ASD in line with the SIGN guidance.</p> <p>To work toward the implementation of NICE Guideline (Assessment, diagnosis and clinical interventions for people with autism spectrum disorders) to ensure more evidence based diagnosis.</p>
<p>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.</p> <p>9. Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.</p>	<p>The authority will ensure that planning meetings for all children with an ASD moving from early years to primary education are in line with the ASL Act (2004)(2009). Planning meetings will include all multi-agency partners, parents and the individual.</p> <p>Individual educational plans will be person centred and will encompass the wellbeing indicators in line with GIRFEC principles and guidance. This will ensure monitoring of progress and identification of further areas for intervention.</p> <p>Review reports will reflect the well being indicators of GIRFEC ensuring that each child or young person is at the centre when developing a shared understanding within and across agencies.</p> <p>We will promote ASD aware</p>

	<p>environments in schools to take into account any sensory issues experienced by the individual.</p> <p>There will be a review of the existing transitions guidance, incorporating ASD and ensure the development of good practice transition guidance across all partner agencies and organisations to ensure appropriate support for individuals with ASD through life stage transitions.</p> <p>We will ensure Getting It Right at Post School Transition guidance includes those individuals higher functioning on the spectrum.</p> <p>We will monitor the outcomes of projects funded via the national strategy development fund to identify cost effective models of professional and parent training that can be implemented in Argyll and Bute.</p>
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Appendix 4.3: Mapping the Ten Year Goals in the National Strategy against the Good Practice Indicators and the Argyll & Bute Action Plan

Links to National Strategy goals – Holistic personalised approaches: by 10 years	
<ul style="list-style-type: none"> • Meaningful partnership between central and local government and the independent sector. • Creative and collaborative use of service budgets to meet individual need (irrespective of what the entry route to the system is). • Access to appropriate assessment of needs throughout life. 	
Good Practice Indicator	Strategic Action
<p>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.</p> <p>5. A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication.</p>	<p>The authority will develop a clear communication strategy to ensure that all developments and service implications are communicated to stakeholders</p> <p>The authority will seek to improve parental and carer support during and post diagnosis</p> <p>The authority will work to establish partnerships and or support initiatives that provide adequate access to information and support for adults with ASD and families to understand the implications of their diagnosis.</p>
<p>9. Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.</p>	<p>The authority will work to enable people with ASD and their families can choose from a wide range of affordable and achievable options. This includes promoting choice and control through Self Directed Support.</p> <p>The authority will work to ensure (and monitor) that all statutory services consult the Scottish Government ASD Commissioning Guidelines when commissioning services.</p>

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