

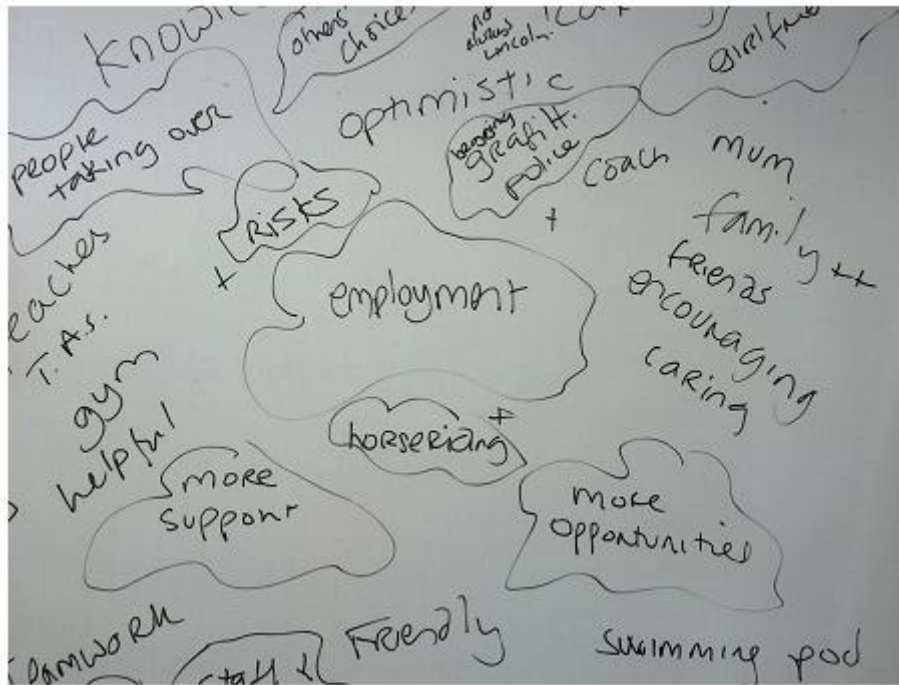
# Lincolnshire's All-Age Autism Strategy 2015-2018



*Providing fulfilling and rewarding lives for people with autism of all ages*



Devised by Edana Minghella & Rich Watts at the National Development Team for Inclusion (NDTi) in collaboration with people living with autism, family carers and multi-agency key stakeholders in Lincolnshire.



Our support, our issues, our priorities – produced during engagement activity by people with autism in Lincolnshire



**NHS**  
**Lincolnshire East**  
**Clinical Commissioning Group**

**NHS**  
**Lincolnshire West**  
**Clinical Commissioning Group**

**NHS**  
**South Lincolnshire**  
**Clinical Commissioning Group**

**NHS**  
**South West Lincolnshire**  
**Clinical Commissioning Group**

## Forewords

**To be completed post consultation by the following;**

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Representatives of the Autism Partnership Board

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## 1. Introduction

*Fulfilling and rewarding lives*, the Government's strategy for adults with autism in England, was published in 2010 with the following key aims;

- To help adults with autism to access the services they need easily and free of discrimination
- To improve diagnosis
- To increase awareness of autism across health, care and community services

Autism is a lifelong condition which can be very disabling. It is a spectrum disorder. This is because everyone that has autism experiences it differently and is affected in different ways. There are some things that all people who have an autism spectrum disorder will have difficulties with. These include:

- Social Communication
- Social Interaction
- Social Imagination

People with an autism spectrum disorder often experience sensory difficulties such as over- or under-sensitivity to sounds, touch, tastes, smells, light or colours. It is also more likely that people who have an autism spectrum disorder will experience higher levels of stress than someone who does not have an autism spectrum disorder. This makes mental health problems more likely.

Many people with an autism spectrum disorder are able to live independent lives. Others may need some support or to access services to achieve their full potential. It is common to have accompanying learning disabilities and whilst with reasonable adjustments many people can access mainstream services, some people will require specialist support.

A study cited by the National Autistic Society suggests there are over 700,000 people in the UK with autism – more than 1 in 100 individuals. In 2011, the Office for National Statistics estimated there were at least 623,000 people with autism living in the UK, many of whom will require access to mental health, learning disability and social care services at some point in their lives.

In response to the national strategy, along with the recent refresh, *Think Autism*, published in 2014, Lincolnshire decided to establish an All-Age Autism Strategy. This Strategy covers children, young people and adults living with autism in Lincolnshire (including those placed out of county) and their families/carers.

This strategy also applies to people who have autism alongside other conditions, for example a learning disability and/or mental health problem. The aims of this Strategy are:

- To share an ambitious model for promoting and enabling the best care, support, enablement and social inclusion of people with autism of all ages and their families / carers in Lincolnshire

- To inspire commissioners and providers in the local authority, health and non-statutory sectors to commission and deliver a better future for local people living with autism
- To ensure Lincolnshire reflects national policy and adheres to current legislation
- To ensure Lincolnshire uses resources efficiently and effectively

## 2. Local challenges

It is estimated that nearly 6,000 people in Lincolnshire have an autism spectrum disorder, a figure which is predicted to increase. By including people such as family members, carers, friends, professionals in health, social care and education, and other members of the community, the numbers affected by an autism spectrum disorder are much greater.

Determining the exact number of people living with an autism spectrum disorder in the county is extremely difficult, as very little data is available. A key issue is the gap in terms of estimated numbers of people with autism and the capacity of the NHS to offer diagnosis. It is estimated that around 50% of people with autism do not have a learning disability and many of these are at present unknown to the NHS or to the local authority. It is also recognised that there may be many people who are not disabled by their traits of autism spectrum disorder and so would not benefit from a diagnosis.

Until adequate data sets are developed, the Department of Health national prevalence study, published by the Projecting Adult Needs and Service Information Systems (PANSI), offers the most comprehensive guide to potential numbers. The total projected number of people in Lincolnshire with autistic spectrum conditions aged 18-64, with equivalent data for England, published by PANSI shows the following:

Year	2012	2014	2016	2018	2020
<b>Projected number 18-64 in Lincolnshire</b>	4,191	4,237	4,288	4,343	4,381
<b>Projected number 18-64 in England</b>	330,100	333,209	336,987	340,327	342,917

Source : Projecting Adult Needs and Service Information Systems (PANSI), 2013

In terms of those under 18 years of age, it is projected that there are 1737 living with an autism spectrum disorder. This is based on the national research indicating that 1.1% of the UK population has an autism spectrum disorder and applies this prevalence rate to the population of Lincolnshire using data from the Office for National Statistics population estimates for mid-2013.

### 3. The journey for Lincolnshire so far

The Lincolnshire Autism Partnership was formed in 2010, following the publication of the national strategy, *Fulfilling and rewarding lives*. It was set up to advise on all aspects of implementation associated with national and local autism policy and is made up of people with autism, carers, representatives of community and voluntary groups and professionals from the statutory sectors.

On 17 February 2012, Lincolnshire County Council and NHS Lincolnshire gave approval for the development of a countywide strategy for adults with autism.

Engagement with individuals who have lived experience and those who have accessed services is key to a successful strategy. The first stage in this was a 3-month public consultation, which was conducted at the beginning of 2013. Having comprehensively evaluated all of the feedback from the consultation a number of key themes arose. One area which received repeated discussion and focus was the transition from children's to adults' services. We recognise that transition is often a very difficult time for individuals with an autism spectrum disorder and as such it is critical that improvements are made to enable a more seamless service so that individuals feel sufficiently supported through the transition from children and young people to adult services.

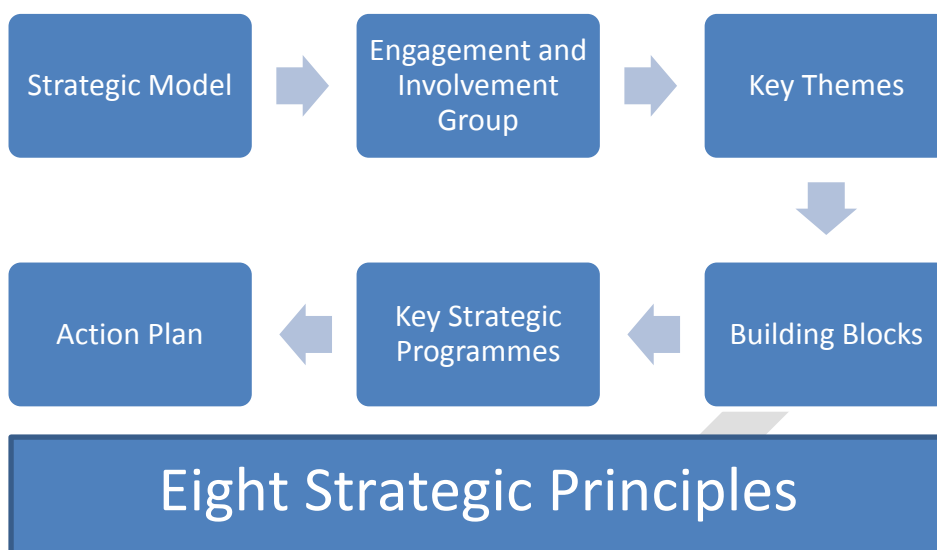
With this in mind Lincolnshire took the proactive decision to develop an all-age autism strategy. The introduction of the Children and Families Act (2014) highlights the need to consider the difficulty transition causes, as the legislation includes support for children and young people with special education needs up to the age of 25.

A Head of Commissioning for Autism has been appointed within Lincolnshire. Sharon Jeffreys, who has recently commenced in post, is an autism diagnostic practitioner who previously worked as a Nurse Consultant specialising in autism within both mental health and learning disability service provision.

A further engagement process commenced in 2014 conducted by the National Development Team for Inclusion (NDTi), which additionally incorporated themes and key stakeholders representing children and young people, as well as adults. This included two engagement events (held in Grantham and Lincoln) for people with lived experience of autism, family carers and multi-agency stakeholders. Specific engagement was targeted with Health Leads from each of the four CCG's within Lincolnshire and with officers from Children's Services at Lincolnshire County Council. Additionally, an Autism Strategy Involvement Group was established consisting of a variety of people with lived experience of autism or a family member of someone with autism. This strategy has, therefore, been devised in collaboration with a host of key stakeholders.



Figure 1: Development of the Strategy



A number of actions in response to the national strategy are already underway or have in fact already been implemented. Some of these are detailed below. These will be built upon further as the action plan for Lincolnshire's All-Age Autism Strategy is delivered.

What we have achieved so far and how it links to our key strategic programmes:

What We Did	Key Strategic Programme
GP's attended a regional training event in May 2012 aimed at improving access to primary health care services for adults with autism. Work is underway to incorporate autism into the monitoring of treatment and co-morbidity by GP practices	Awareness raising and training
Improved diagnostic services were piloted by Lincolnshire Partnership NHS Foundation Trust for an 18 month period to October 2013	Service provision
A 3-month public consultation was completed at the beginning of 2013 to gain feedback from key stakeholders to help inform proposals for an Adults Autism Strategy for Lincolnshire	Involvement and collaboration with people with lived experience and carers at every stage
Lincolnshire County Council commissioned a series of awareness-raising sessions for staff across health and social care and provides training and e-learning materials for partner agencies	Awareness raising and training
Basic autism awareness is now part of mandatory training provided to mental health services	Awareness raising and training



<p>Following an evaluation of the proposed Adults Autism Strategy, it was agreed that this would be adapted into an All-Age Autism Strategy and further engagement work has been conducted with key stakeholders during 2014 to help formulate the Strategy</p>	<p>Involvement and collaboration with people with lived experience and carers at every stage</p>
<p>A booklet of top tips for GPs for diagnosing, supporting and meeting the needs of people on the autistic spectrum has been developed and distributed to GP surgeries throughout the county</p>	<p>Awareness raising and training</p>
<p>Autism has been specifically defined as a key element to the role of one of the heads of commissioning in Lincolnshire. The person appointed to this role has previously worked as an autism specialist practitioner and has lots of experience of developing services for and working with people who have an autism spectrum disorder. We feel that this demonstrates the seriousness with which autism has been prioritised in Lincolnshire</p>	<p>Service provision</p>

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## 4. Our vision

The national strategy for adults with autism, *Fulfilling and rewarding lives*, sets out the Government's overarching vision;

'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.'

We have an ambitious vision for Lincolnshire, which includes expanding on the national vision to achieve fulfilling and rewarding lives for people with autism of all ages. We want to build the capacity and understanding of our community and services to deliver the best possible experience for people living with autism and to enable them to fulfil their potential as local citizens.

Our vision is for a strategic model that has the lives of people living with autism and their family/carers at its heart. It takes into account common life events and domains, and the life journey from cradle to the grave, providing a set of clear points of possible support and intervention to help prevent problems and damaging crises, or to reduce the impact of the crisis if it cannot be avoided. It is a model that recognises everyone's fundamental needs, rights and aspirations and features a number of critical building blocks, all underpinned by eight core principles, as shown in Figure 3: Our strategic principles.

Figure 2: Our strategic model



The vision is as challenging as it is ambitious. It challenges us to work together in partnership with each other as commissioners and providers across a number of agencies in statutory and non-statutory services, with people and their families living with autism and with our community at large.

This strategy was developed through consultation, engagement and sharing ideas and experiences with key people in services and communities: commissioners and providers from health, social care, education, criminal justice, housing, employment and other care services in the statutory and voluntary sector. Most significantly, an Autism Strategy Involvement Group, composed of a wide variety of people with autism or with a family member with autism, was set up expressly to support the development of the strategy.

## 5. Our strategic principles

Eight strategic principles underpin the strategy and are critical to understanding it. These principles also operate as a template to help us implement our action plan. The principles are shown below.

Figure 3: Our strategic principles



Each one of these principles has a critical significance in the development, implementation and evaluation of the strategy and is explored in more detail below.

### Strategic Principle 1: Equalities-based

- People with autism have the same rights to access available services and opportunities as anyone else in the county
- People with autism have the same rights as everyone else for housing, employment, education, training, money, meaningful activity, health and wellbeing and relationships
- All citizens with autism, regardless of their ability or disability, age, gender ethnicity, sexuality, or faith are entitled to equal access to services

### **Strategic Principle 2: Reflects parity of esteem**

- People with autism and their families have access to services to enable both physical and mental wellbeing
- If people with autism become unwell their mental health problems and/or learning disability needs are treated on a par with physical health problems and needs

### **Strategic Principle 3: Strengths-based**

- People with autism are citizens with qualities, strengths, gifts, skills and capabilities to offer to the community.
- Service development, improvement, delivery and training will be enhanced and improved with the contributions of people living with autism.

### **Strategic Principle 4: Person-centred**

- Our approach will be person-centred, both for people living with autism and for families
- Everyone is unique; services will be tailored to need, preferences and aspirations and focused on person-centred outcomes
- The autistic spectrum is itself diverse and there is a wide variety of issues, needs, capabilities, etc. within it
- The person with autism has a right to their own voice, needs, wishes and preferences
- Families' and carers' needs and aspirations must be taken into account
- Families and carers are a valuable resource and support for people with autism
- Families and carers should be seen as partners in the provision of care

### **Strategic Principle 5: Proactive and preventive**

- The life course presents a natural and relatively predictable journey to enable key support to be provided in a timely and proactive manner, to anticipate difficulties, prevent crises and prevent issues early on leading to further problems later in life
- Early intervention is essential, with or without a formal diagnosis
- Services will be geared to understanding current needs, thinking ahead, anticipating change, and planning for the future

### **Strategic Principle 6: Safe**

- Safeguarding children and adults who may be vulnerable is a priority in Lincolnshire
- This includes protecting people with autism and their carers within Lincolnshire or placed out of county
- Children and young people with autism have the right to thrive in school without fear of bullying

- Community safety is a key issue for people living with autism
- Safety and risks must be balanced against the desire for independence of each individual
- Independent advocacy, including peer advocacy, is a key way of ensuring safety and support for people living with autism who meet the respective eligibility criteria to receive this service

### **Strategic Principle 7: Local, mainstream and inclusive:**

- Services should be mainstream and local as the default
- Specialist education support should be available to children and young people throughout their education, taking into account the particular requirements of young people living with autism (such as need for consistency) to enable them to thrive in and contribute to mainstream education where possible
- Mainstream health services, including primary care, should be accessible to all, including those living with autism
- Specialist health services should be available at times of greatest need, with a clear focus, remit and timescale
- Specialist health and social care services, if needed, should be provided close to home where possible
- Services need to ensure they make reasonable adjustments to enable people with autism to be heard, contribute and benefit from universal health, education and care services

### **Strategic Principle 8: Ambitious but sustainable**

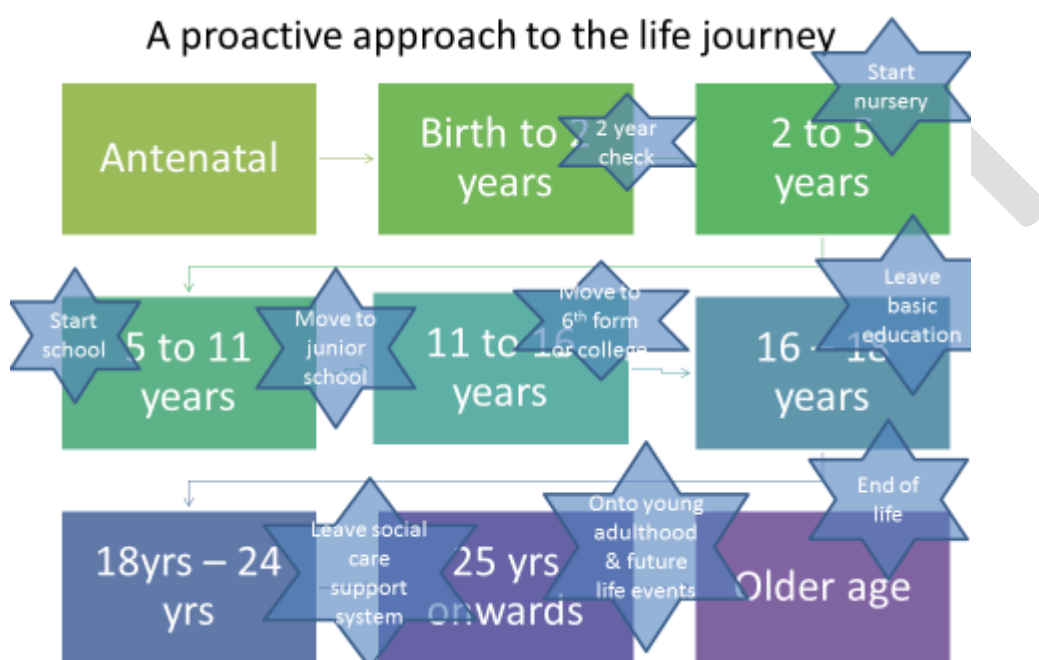
- Lincolnshire's Strategy aims to embrace the vision within the national strategy but to go beyond it by providing fulfilling and rewarding lives for people with autism of all ages. We want Lincolnshire to be the best county in the country for people living with autism, who will have the opportunity to co-produce local policy and practice and be welcomed as active members of our community
- We will make sure our approach to autism is forward thinking and sustainable and planned with forthcoming policy and legislation in mind
- Sustainability includes embedding change through training and awareness raising, that will be co-produced and co-delivered by people living with autism
- Sustainability also includes building on existing good practice and positive services and ensuring they are fit for the future

## 6. The life journey: a proactive approach

A central part of our strategy is the concept of the life journey. Although everyone is an individual, there is some predictability to the life journey and the events that act as markers of change along the way.

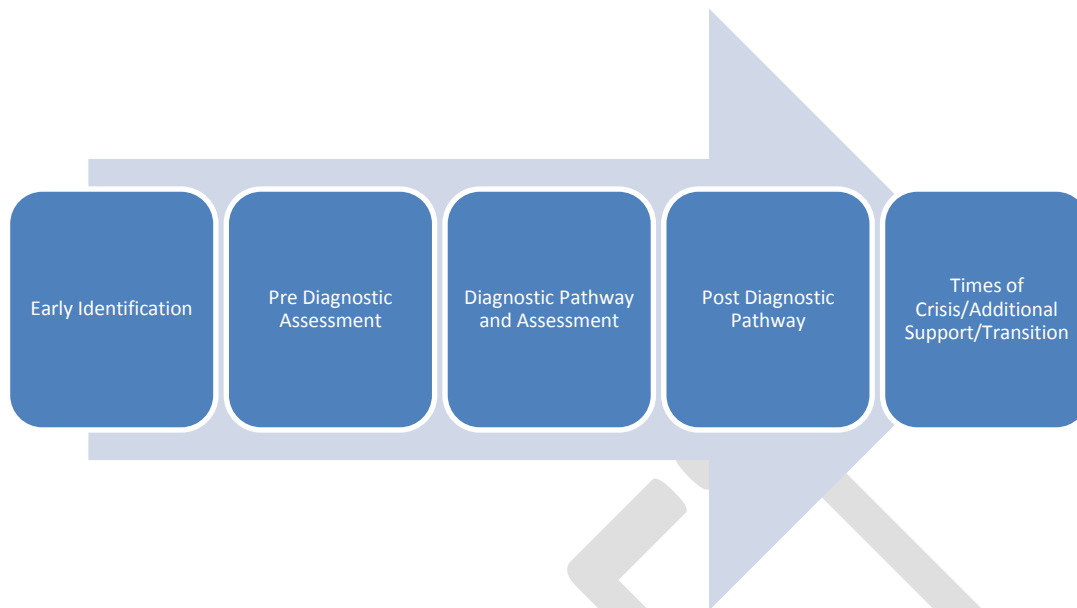
Taking a life journey approach allows us to anticipate possible hurdles, support families through potentially difficult periods, work proactively to prevent problems getting worse and becoming crises. Transitional moments identified in the life journey are opportunities to provide help and support and target resources to times that are likely to represent most need.

Figure 4: The life journey with transitional moments



Reflecting *Think Autism*, at the core of the strategy is the person with autism (and their family / carers) and their life journey, presenting windows of opportunity to provide the “right support at the right time”, proactively and preventively.

Figure 5: The Autism Journey



As mentioned throughout the strategy, how an autism spectrum is experienced and impacts on an individual can be very varied. It is therefore really important that individuals can access the right support at the right time for them. This means that the autism journey runs alongside the life journey shown in figure 4 and can occur at any stage of the transitional moments described.



## 7. Existing service in place across Lincolnshire for Autism Spectrum Disorder

One of the key messages from the engagement activity was that many individuals and their families had difficulty in accessing services. All services have a legal requirement to make reasonable adjustments for those who require it. This includes reasonable adjustments for individuals with an autism spectrum disorder. One of the aims of this strategy is to work towards services being easily accessible for people with an autism spectrum disorder.

We want to work closely with primary care services including GP's and mainstream health services to promote accessibility for all and raise awareness of autism. We aim to ensure involvement from education within our action plan and to have representation from schools and colleges within the Autism Partnership Board.

Mental health and learning disability services will need to ensure that they are making reasonable adjustments for people with autism. We recognise that this will only be possible if all services have autism on their agenda and if the awareness and profile of autism is high. One of the key roles of this strategy and the Autism Partnership Board will be to make sure all services are aware of their responsibilities around people with autism and ensure that the voice of those with lived experience is heard.

The local authority and Clinical Commissioning Groups in Lincolnshire are in the process of developing an 'Expert by Experience Practitioner' to lead by example and promote co-production at every stage of the commissioning cycle. If approved, this role will be instrumental in the promotion and awareness raising of the autism strategy and the delivery and monitoring of the action plan.

The table in Appendix C details a selection of the current autism service provision in Lincolnshire across health, social care, provider and voluntary sectors. Please note that this is not a definitive list and is the starting point to maintaining a live document of service provision that is both accessible and meaningful for people with autism and their families.

## 8. Action plan and developing local offer

The consultation and engagement process completed with people with lived experience of autism and other stakeholders has highlighted the key issues that form the basis of our Strategy. Details of the aspirations identified by key stakeholders through this piece of work and the emerging themes are detailed in Appendix B. This has resulted in the development of building blocks for action, which incorporate all of these themes, many of which are overlapping and have things in common, and will inform how and what we deliver locally for our citizens living with autism. The approach is underpinned by our eight strategic principles.

Figure 6: Building blocks for action



We have translated our building blocks into a local offer and a clear action plan. The action plan incorporates four key strategic programmes to deliver the Autism Strategy, and has underpinning measurable objectives. It will be overseen by the Autism Partnership Board, which will take a leadership role and be accountable for the delivery of the plan.

Figure 7: Our four key strategic programmes to deliver the Autism Strategy



A key facet to the action plan for delivery of the strategy will be to establish working groups for each of these four strategic programmes to push the agenda forward in each specific area. An appropriate Lead for each programme will need to be assigned, along with key stakeholders who can provide the necessary skills and knowledge to help deliver the agreed actions. For each of the four working groups we will establish the following:

- An agreed agenda and set of outcomes for each working group to be structured utilising the strategic model
- Terms of Reference that will include the 8 strategic principles
- Updates from each working group will be fed into the Autism Partnership Board, who will oversee progress and delivery of the overall Strategy and Action Plan

Examples of what these four working groups will focus on is provided in more detail below.

### **Awareness raising and training**

We will develop a tiered programme of awareness-raising and training that will be co-developed and co-delivered with people with lived experience of autism. Target audiences with clear learning outcomes will be identified.

In line with *Think Autism*, awareness training will be offered beyond 'services' and extend into communities to build and strengthen community capacity to support people with autism. This will link in with our development of autism-friendly communities. Equality and diversity training will be integrated into our awareness and training programme.

We propose to seek funding and/or sponsorship to develop community awareness training and provide support opportunities for the community, including employers, education, criminal justice

system, clubs and cinemas and universal services, such as banks and public transport to help create autism friendly communities.

## **Involvement and collaboration with people with lived experience and carers at every stage**

We propose to build on and strengthen the existing Autism Partnership Board. We aim to do this by:

- Broadening the remit to include children and adults
- Reviewing and widening the membership to include partners from children's services, education, paediatric, GP's and other clinicians, criminal justice (including police and probation) and other relevant colleagues and ensuring there is senior representation regularly in attendance
- Increasing membership of people with autism and inviting young people with autism to join the Board
- Alternating the time and venue of the Board to give more opportunities for members to attend
- Reviewing the terms of reference in order to focus the Autism Partnership Board on being accountable for delivering Lincolnshire's Autism Strategy and its key programmes.

We propose to ensure that people with lived experience and carers are involved at each stage of service development, delivery and review. This may include for example:

- Recruitment
- Training
- Service delivery
- Outcome measurement
- Service user and carer feedback

## **Data systems and information gathering**

We will develop improved data systems across health, mental health and social care to ensure we capture the right information to enable commissioners and providers to understand needs, service use and costs.

We will establish a partnership between Public Health, social care, primary and secondary healthcare and local groups to develop better ways of recording and collecting data specified here.

## **Service provision**

We will carry out a service review to identify strengths, gaps, overlaps and areas for development, looking at services for people with autism and for carers and families.

We anticipate that the service review will enable us to see the priorities for development of service provision, which is likely to include pathways for:

- Diagnostic assessment
- Post diagnostic support
- Access to services when needed (such as health, social care, times of crisis)
- Access to support for carers

We will develop a central information hub for people with autism to provide information and advice about autism and local service availability, in a variety of media and formats and co-produced with people living with autism.

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## 9. Lincolnshire's All-Age Autism Strategy – Initial Action Plan

Task	Timescale	Key Strategic Programme
<p>Establish working groups for each of the four key strategic programmes, to include the following;</p> <ul style="list-style-type: none"> <li>• Appoint a working group Lead</li> <li>• Appoint working group members with appropriate interest/skills/knowledge</li> <li>• Establish Terms of Reference</li> <li>• Each working group will draw up their own specific agenda and agreed outcomes</li> </ul>	June 2015	All
<p>Strengthen the Autism Partnership Board to ensure that it is fit for purpose in leading on and overseeing the implementation of Lincolnshire's All-Age Autism Strategy. This includes ensuring consistent representation from key stakeholders and ensuring additional representation from schools and clinical services. As part of this process, a re-launch of the Autism Partnership will commence in 2015.</p>	June 2015	Involvement and collaboration with people with lived experience and carers at every stage
<p>Undertake an autism awareness and training needs analysis to provide a baseline to monitor progress and development, and to strengthen training expectations and opportunities across health, social care and partner agencies.</p>	Ongoing	Awareness raising and training
<p>Provide basic autism awareness as part of mandatory training to mental health services. To develop a range of training opportunities that local employers can access or purchase for their workforce and to provide training materials for carers and other stakeholders.</p>	Ongoing	Awareness raising and training
<p>Work towards the development of shared health, education and social care assessments and accompanying shared documentation in place for people with autism.</p>	March 2016	Service provision
<p>We will aim to agree mechanisms for pooled budgets for Specialist Adult Services to facilitate integrated health and social care for people with autism.</p>	March 2016	Service provision
<p>We aim to understand what the offer is for people with autism within generic service provision, which will include a review of all service specifications that we commission to ensure that they are fit for purpose for people with autism.</p>	March 2016	Service provision

Introduce an efficient diagnostic pathway for children and adults, recognising that the earlier the diagnosis the better for the person. It will be possible for the pathway to be fast tracked for adults to avoid lengthy and costly processes and long waiting times. The pathway will be co-designed by a multi-disciplinary team and people living with autism.	March 2017	Service provision
Our ambition is to promote community networks and the wide range of support that people with lived experience and their carers can provide to each other. This is likely to be an outcome of the transformation of the Autism Partnership Board. In addition, we will work with existing information sources to develop a local information hub where families and people with autism can access advice and information about autism and local autism services and other services that they may require.	March 2017	Service provision
Introduce autism champions within every local school and community who will work together with children, young people and adults with autism and their families to create autism-friendly environments, tackle bullying, increase social inclusion and support the talents and contributions of people with autism. In addition, all the services that we commission will be expected to identify a local autism champion.	March 2017	Involvement and collaboration with people with lived experience and carers at every stage
Develop an ongoing local autism friendly community, demonstrated in a range of ways such as shops displaying autism friendly signs, autism friendly cinema screenings , local autism champions in key universal services (banks, libraries, CJS, police stations, public transport, taxi services, sports and leisure centres).	March 2018	Awareness raising and training
Establish integrated information and intelligence across Adult and Children's Services enabling us to know and understand our local population and their care needs and pathways and local spend.	March 2018	Data systems and information gathering
The progress of the strategy and action plan will be reviewed annually by the Autism Partnership Board and updates made available to all relevant stakeholders.	Annually	All
Develop a range of measures which will enable us to evaluate the impact of our strategy for people living with autism in our communities.	April 2018	All



## Acknowledgements

Following the engagement activity led by the National Development Team for Inclusion (NDTi), they have requested acknowledgements and special thanks to the following:

- All individuals and organisations who have been involved in the engagement events during 2014 to help inform the adaptations to produce Lincolnshire's All-Age Autism Strategy
- All the members of the Autism Strategy Involvement Group (actual and virtual) whose sharing of their experience and ideas from the position of lived experience of autism has had a major impact on this work
- Debbie Marshall
- Andrew Wells

The owners of this strategy would like to thank the following for their hard work and dedication to the development of this strategy and innovative thinking that has formed the action plan:

- Everyone who participated in the public consultation conducted in 2013 for the original Adults Autism Strategy for Lincolnshire that was proposed for implementation
- All members of the Autism Partnership Board

Special thanks to Edana Minghella and Rich Watts at the National Development Team for Inclusion for capturing the aspirations and vision of people living with autism, family carers and multi-agency key stakeholders in Lincolnshire, which forms the basis of this strategy.

## Appendix A: Policy Drivers

The following are the key, current national policy drivers that form the framework for autism in England.

The National Autism Strategy *Fulfilling and Rewarding Lives* (2010) was refreshed in 2014 with the publication of *Think Autism*, and which will be supported by a Code of Practice, due to be published in early 2015. Both apply to adults with autism.

Key actions and challenges from both include:

- Increasing awareness and understanding in services and in the community
- Developing timely diagnostic pathways
- Increasing access to mainstream services
- Building local capacity and capability
- Improving access to work
- Improving social inclusion
- Listening to the views and aspirations of people living with autism.

For children, a Multidisciplinary National Autism Plan was introduced in 2003 to improve assessment, diagnosis and interventions for children.

The NICE guideline of 2013 focuses on developing early recognition, referral and diagnosis of children and young people, through a local pathway overseen by a multi-agency board. The guideline includes recommendations regarding, for example, data collection and audit of the autism pathway.

There are two other significant national policy drivers that affect the lives of children and adults with autism:

- The Children and Families Act (2014) introduces a system of support for children and young people with special educational needs from 0-24, focusing on outcomes, engagement and participation of parents and young people, joint commissioning, coordinated Education Health and Care (EHC) plans and personalisation
- The Care Act (2014) includes Local Authorities' duty to assess and address the needs of adults in need of care and support (including those transitioning from children's services) and their carers, promote wellbeing and provide preventative support, integration with NHS and information.

## Appendix B: Aspirations, Key Themes and Building Blocks for Action

### 1. Person-centred aspirations

Working from a person's perspective rather than from a service's perspective we co-devised person-centred outcomes with people living with autism and their families, as well as practitioners. These outcomes are what people in Lincolnshire want their all-age autism strategy to achieve, and so are captured in the first person 'I' for the person with autism or a parent/carer.

The person-centred outcomes are of two kinds: outcomes at key life stages during childhood and young adulthood, and then outcomes in key life areas when someone is an adult.

#### Antenatal and birth

- As a parent, my increased chances of having a child with additional needs (for example due to premature birth, low birth weight or having other children with additional needs) are recognised and supported by my antenatal team
- As a new parent, I know that my midwife, health visitor and GP will be made aware of my increased chances of having a child with additional needs and know how to help prepare and support me and the family

#### Birth to 5 years (examples)

- As a parent, I am confident that my concerns about my child's different development will be heard by my child health team
- As a parent, I will get the support and parent training needed to help me recognise my child's differences and cope with any unusual behaviours
- As a parent I will get timely effective support to manage my child's difficulties with basic needs, such as problems with sleeping, eating, and toileting, so that these are less likely to become long-standing problems that will affect future education and socialising

#### The school years

- I am confident that if my child is presenting traits of autism I will have the opportunity to access a timely full assessment and diagnostic pathway
- With or without a diagnosis of autism I will have an education, health and care needs assessment and a care plan focused on outcomes that will take into account my views, interests and aspirations. This will be reviewed and change over time as I develop
- I am confident that if my behaviour affects my ability to get the most out of school (e.g. not attending), this will be noticed early on and I will get timely support to get back on track to prevent problems escalating
- I know I will get the right support with my education to support my learning and this will take into account some of the specific issues related to how my autism presents, such as an individual plan showing how I cope with change
- I am confident that teachers and other staff, not just specialist SEND practitioners, have good awareness and understanding of autism
- I am confident that I need not fear bullying at school. If I do experience bullying my teachers will provide me with the best possible support and prevent further bullying

- I have the opportunity for mixing with other children and young people outside of school and taking part in the same ordinary out of school activities that other young people enjoy
- If I need extra help with my mental health needs I can get timely access to children's and young people's mental health services. These services will make reasonable adjustments to meet my needs and have knowledge and expertise in working with autism
- As a parent I am confident that there are good channels of communication between the teachers and the family so that critical information about my child's progress and school experience can be shared and that my input and needs as a carer are recognised

### **At times of transition (for example, moving schools or moving onto college or sixth form)**

- I am informed about and have had the opportunity to discuss the educational choices available to me for college or further education
- A transition plan is developed which reflects my individual needs. For example; I have had an opportunity to visit my preferred college and to familiarise myself with it, including the journey to it
- As a parent I will be able to access a school for my child where teachers and other staff are aware of the differences in a child who may have autism and know how best to support the child's learning, development and play

Based on the engagement conducted, the following section details the outcomes people living with autism and their families want the strategy to support them to achieve across different aspects of their adult lives.

### **Housing**

- I will have the opportunity to live and participate in my local community
- If I need daily living support I know I will receive the support I need to enable me to live as independently as I can and wish to
- If I live in the family home, I and my family are confident that if and when my parents or family are no longer able to support me, I will be able to access alternative options for supported accommodation close to home, depending on my needs

### **Health and Wellbeing**

- I am confident of having the right type and level of support I need at the right time to promote and maintain my mental and physical health, wellbeing and safety
- I am confident I have the same choices and opportunities to access mental and physical health and wellbeing services as the rest of the population and that having autism will not preclude me from accessing services, as reasonable adjustments will be made to reflect my individual needs
- I am confident that any mental health or learning disability needs I have will be treated with parity of esteem with any physical health needs I may have

- I am confident that health professionals are aware of how I may experience pain and health problems because of my autism (for example I may find it difficult to recognize pain or to explain how I am feeling) and if necessary will put in place extra safeguards to ensure my wellbeing and that the way I experience pain and health problems is understood
- I am confident health professionals will see beyond my autism to any other health conditions I may have, for example that health professionals are aware that my autism may mask health problems I am experiencing
- I am aware that if I meet the eligibility criteria through a social care assessment I have a right to access advocacy whenever I want it
- I know how to get an eligibility assessment, which may provide opportunities for respite to enable us to maintain a health family life
- I know where to get help and advice to enable me to go about my daily life and access services and opportunities

## Money

- I have the same opportunities to earn money as everybody else
- I am confident of being able to access the financial support and state benefits I am entitled to, to enable me to be as independent as possible
- I am confident that if I need it, there will be support to help me manage my money and that if my financial affairs go awry because of my autism, there will be a safety net for me
- I am protected from people or organisations who may wish to exploit my autism for their financial gain
- As a parent, I know my son or daughter will be able to access financial support regardless of my own status

## Work

- I can be confident that I will have a fair and equal opportunity to get and keep work
- I can be confident that I will be paid the right level of money for my skills, commensurate with colleagues doing the same work
- There is the right kind of support available for me to get and keep a job, including support for applications, interviews and when facing difficulties at work
- I am confident that there is support available to me to manage discrimination and bullying in the workplace
- I am confident that there is support available for people who employ me or work with me
- Employers and my colleagues are supported to understand that time is needed for me to meet expectations in the workplace

- Employers are supported to recognise that I could be the best person to employ for some types of jobs

### **Education and Training**

- I will have a regularly updated health, education and care needs assessment, which will take into account my needs, abilities and aspirations
- I am confident I will get the help and support I need to make the most of my school education
- As I leave statutory education, I can be confident of getting the advice and support I need to enter further education or training depending on my needs and aspirations
- I will get support to stay in further education or training to give me the best chances of employment afterwards
- As a parent I will be able to access parenting skills courses to help me support my child, manage difficult behaviours and look after myself

### **Relationships and Social Inclusion**

- I am confident that it is me who determines what I want to do, not someone else
- I have as many opportunities to socialise as other people without autism, irrespective of where I live in the county
- Social activities and opportunities available to me match my age and/or interests, and are not simply determined by my having autism
- I know that if I need it, I will have support to access social situations
- In social situations it is recognised that because of my autism, I may need space and time to reflect or do other things that make me feel more comfortable and enable me to enjoy and contribute more fully
- I am confident that I can access support, such as buddy schemes, to help me make and sustain relationships
- I am confident that I will be able to get help to extricate myself from relationships where I am at risk of being exploited or of inadvertently coming into contact with the Criminal Justice System
- My value as a person is recognised by services who seek and support my involvement in co-producing services, information and advice and training

### **Throughout the life journey (examples of aspirations that should be available at any point)**

- As a parent or an individual wishing to access an assessment, I am confident that there is a clear, timely and effective pathway to being able to receive an assessment to consider a diagnosis of autism

- As a parent, carer or an individual with a diagnosis I am confident that post-diagnostic support is available. To help me understand the diagnosis and how the condition will affect me or the person I am caring for
- As a parent/ carer I will be able to access education for my child (including nursery) where the staff are aware of the differences in a child who may have autism and know how best to support the child's development
- As an individual with an autism spectrum disorder, carer or parent, I know where to go to get information and advice about autism and local autism services for myself or my child

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## 2. Themes and building blocks for action

Whilst producing this strategy, a number of themes emerged from our work with partners, colleagues and people with autism and their families. For example, it was clear that people wanted much more awareness and understanding about autism in the community at large and amongst professionals and services. This increased awareness and understanding would underpin many of the other themes identified, such as equality of access to services and opportunities, proactive interventions and social inclusion. More service-oriented themes included the need for a clear diagnostic pathway – and this was something both professionals and people living with autism called for.

Figure 5: Themes arising from the person-centred outcomes that inform strategic actions needed



Some of these themes overlap with each other or have things in common with each other. As such, we have developed a number of building blocks for action, which need to be in place to turn this strategy into a reality.



We discuss each of these building blocks below. Some work has already started for some of the building blocks, which we highlight below where it has happened.

## Creating autism-friendly communities

*“I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism” – Think Autism*

Communities need to be better informed and more aware, so that they can understand, support and appreciate the value of people with autistic spectrum disorders

The community is defined as a geographical locality and the myriad of people who are linked to it through residence, work, business, education, training or regular visits. It includes within it ‘communities of interest’ such as faith communities and people from diverse groups.

Services within health and social care recognise the needs of people living with autism but we also recognise that it is in the wider community where people with autism live most of their lives. Our strategy therefore includes the whole community not just the parts of the community that identify as ‘services’.

## Information and data

*People with autism have been described as “some of the most excluded, and least visible, people in the UK” – Think Autism*

### Information and data at the individual level

Information about people living with autism is poor nationally; our position in Lincolnshire reflects that. *Think Autism* now requires local authorities to improve data collection.

In Lincolnshire, Public Health data shows there were 11.54 children with autism as the primary stated need per 1,000 pupils – higher than the national average. There are no figures available for adults with autism locally. Best estimates are 4,237 adults (18-64) in 2014 predicted to rise to 4,343 by 2018.

It is essential that we have more information about people with autism and their families, the care and services they access and their outcomes. We need more information on the needs of diverse groups of people with autism to ensure there is equality of access, experience and outcomes. We also need improved data to ascertain costs. Currently local spend on autism is impossible to quantify so we are unable to know whether we are using resources effectively and efficiently.

### Information and data at a service level

An initial mapping of services for this strategy revealed that a range of services and opportunities are available for people with autism in Lincolnshire but:

- There is a risk of fragmentation, lack of co-ordination, gaps and overlaps

- Many people, including other services, do not know what is available and there is no central service map
- Many services – even those within the statutory sector – rely on passionate individuals and goodwill and are therefore unsustainable
- Some services – especially those that are user-led – are run with little or even no funding
- Services tend to be focused in Lincoln or Grantham and much of the rural part of the county is poorly served.

Information about services, rights, resources and facilities is also needed by families and people living with autism to ensure they can access the services they need when they need them.

### Partnership and leadership

We already have an Autism Partnership Board with a broad multi-agency membership, including some members living with autism, which provides us with a good foundation. However, it is limited in its population remit (adults only), focus, membership and authority, and we recognise that we need to develop the Board in these areas in order to ensure that we have the necessary strengths within the Partnership to achieve and build upon the vision and aims of the Strategy.

There are also other local ‘partnership’ groups that have been established, for example led by Lincolnshire’s paediatric lead for autism, which we need to work in conjunction with, incorporate into the Partnership itself and ensure that we are not working towards any conflicting goals or causing confusion amongst people living with autism.

### Awareness and training

The groundwork for developing this Strategy highlighted a strong need for increased awareness of autism and improved training to improve the skills of staff in mainstream services in recognising, supporting and caring for people with autism.

A training group reports to the current Partnership Board and currently includes people with autism. The training group’s remit and objectives need to be broadened, strengthened and clarified to reflect this Strategy.

### Co-production

*“It is central... that all actions, nationally and locally, should be taken forward in a co-productive way that involves and engages people with autism and their families and carers as partners, respecting the insight and expertise that their experience and lives bring” – Think Autism*

By co-production we mean working with people with autism as partners in:

- Their own care
- Developing policy
- Designing and delivering training
- Designing and delivering services
- Evaluating policy, training and services.

There is evidence that engaging people as active participants in their own care and in service development can achieve a variety of benefits including improving care and experience, ensuring care systems are accountable and responsive and making better use of scarce resources.

Lincolnshire has a strong presence of people living with autism influencing policy and developing service. People with autism and their families are keen to be further involved and this strategy reflects how we want and intend for people who are personally affected by autism to be involved.

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## Appendix C: Existing service in place across Lincolnshire for Autism Spectrum Disorder

The table below details a selection of the current autism service provision in Lincolnshire across health, social care, provider and voluntary sectors. Please note that this is not a definitive list and is the starting point to maintaining a live document of service provision that is both accessible and meaningful for people with autism and their families.

Service	Do services have or provide the following types of skills/assistance?					
	Diagnostic accredited practitioners	Make reasonable adjustments	Specialist care and interventions	Staff receive specific training in ASD	Social inclusion opportunities (housing, education, employment)	Support for families and carers
Green Light Team	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
LD Health Liaison Nurses	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Inpatient Assessment Treatment Unit		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Locked Rehab		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Low Secure Rehab		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
CAST (Community Assertive Support Team)		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
CRHT (Crisis Resolution Home Treatment Team)		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
CMHT (Community Mental Health Teams)		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
IAPT (Improving Access to Psychological Therapies)		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
CAMHS (Child & Adolescent Mental Health Services)		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Inpatient Team		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>
ESCO (Early Support and Care Coordination)		<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Birth to Five Team		<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
TAC (Team Around the Child)		<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Autism Pathfinder Outreach		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Autism Care		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Action for Children		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Adult ADHD Lincolnshire (ADHD & Autism)		<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Boulevard Care		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
CANadda		<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>

Service	Do services have or provide the following types of skills/assistance?					
	Diagnostic accredited practitioners	Make reasonable adjustments	Specialist care and interventions	Staff receive specific training in ASD	Social inclusion opportunities (housing, education, employment)	Support for families and carers
Dimensions		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
GAIN (Grantham Autistic Information Network)		<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>
HASS (Housing and Support Solutions)		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
Heritage Care		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Home From Home Care		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
Kisimul Group		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
Lincolnshire Autistic Society		<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>
Linkage Community Trust		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Mencap		<input checked="" type="checkbox"/>			<input checked="" type="checkbox"/>	
Navigation Support Care Services		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
PAACT (Parents and Autistic Children Together)		<input checked="" type="checkbox"/>				<input checked="" type="checkbox"/>
Thera Trust		<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Voyage Care		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>