

Northamptonshire All Age Autism Strategy

2024-2026



**ACTING TOGETHER FOR AUTISM
NORTHAMPTONSHIRE**



Image by Otto Morrison – Young Person

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Where are we now?



Graphic: Amber Miller

The words autistic individuals associate with autism. (Difference, overload, transitions, frustrated, misunderstood, time blind, theory of mind, outcast, human, communication, neurodiversity, brilliant, incapable, care, anxiety, minority, stress, invisible, isolation, confusion, slow, angry, behaviour, language, bullied, sensory processing, unique, emotional, gifts, dysregulation, central coherence, structure, monoperceiving, vulnerable, planning, fluctuating, immature, dramatic, aggressive, sensitive, control freak, weird, prove ourselves, not normal, not listened to, not believed, lost, useless, lonely, hard, emotionless, difficult, naughty, stubborn, lazy, left out, time consuming, manipulative, boring, selfish, gullible, super powers, stupid, obsessive, sensitive, disabled, struggle, smart, struggle, dumb, vulnerable, high expectations.)

The strategy

This strategy aims to address the diverse and complex needs of autistic individuals and their families in Northamptonshire. The focus on a life-course approach underscores the commitment to supporting autistic people at every stage of their lives. It recognises autism affects people differently and touches many aspects of their lives.

The three-year timeframe aligns with the government's national strategy and emphasises the importance of continuous review and evaluation, ensuring that the strategy remains responsive to evolving needs and challenges. The involvement of a diverse group of stakeholders, including the autistic community, in the development

and review process is a key strength that promotes inclusivity and ensures that the strategy remains person-centred.

The emphasis on joint ownership and leadership across multiple organisations underscores the collaborative nature of the strategy, recognising that addressing the needs of autistic individuals requires a unified and concerted effort from various sectors. Furthermore, the strategy's co-production with the Autism Advisory Panel, Young Person Autism Advisory Panel, Autism Enabler Group, and Autism Champions underscores the commitment to the principle of "Nothing About Us Without Us," ensuring that the voices and perspectives of the autistic community are at the forefront of decision-making processes.

There is an emphasis on collaboration and partnership with various organisations and stakeholders demonstrating a concerted effort to ensure comprehensive support and inclusivity.

The holistic approach outlined in the strategy, encompassing various aspects such as health services, education, employment, independent living, and the criminal justice system, reflects a comprehensive understanding of the multifaceted challenges faced by autistic individuals. This approach is poised to create a more supportive and inclusive environment that fosters the well-being and empowerment of the autistic community in Northamptonshire.

Vision Statement

"Autistic people are recognised, heard, valued, able to thrive and reach their full potential".

Our vision statement was created with the input of autistic people embodying our commitment to 'Nothing About Us, Without Us' principle.

Mission

Our work, goals and achievements are guided by our vision to make Northamptonshire a better place for autistic people and encourage others to follow our lead. Our mission describes how we plan to achieve this and was developed by the Autism Champion Network.

A	Across organisational boundaries.
U	Understanding of autism improved.
T	Thoughtful processes and pathways developed.
I	Improving collaboration.
S	Sharing knowledge.
M	Making experiences better for autistic people.

Priority Outcomes

The strategy demonstrates a clear commitment to addressing the priorities and needs of the autistic community in Northamptonshire. By co-producing the strategy with the Autism Advisory Panel, Young Autistic Advisory Panel, Autism Enabler Group, and Autism Champions, the voices and perspectives of the autistic community have been incorporated into the Priority Outcomes and high-level goals.

Aligned with the national government themes, the strategy's Priority Outcomes reflect a comprehensive approach to addressing various aspects of the lives of autistic individuals. These outcomes, along with the corresponding high-level goals and action plans, are designed to deliver meaningful and sustainable improvements in the quality of life and well-being of autistic people and their families.

They are: -

1. **Planning and Governance that delivers improved outcomes.**
2. **Involvement, information and access that delivers results.**
3. **Increase service training, development and collaboration between services which, improves understanding and acceptance of autism within society.**
4. **Improving autistic children and young people's access to education and supporting positive transitions into adulthood through assessment, early intervention and planned support for key transition stages**
5. **Supporting more autistic people into employment and to retain employment.**
6. **Reduce health and care inequalities for autistic people.**
7. **Have the right support in the community and inpatient care.**
8. **Improved support within the criminal and youth justice systems.**



Image: A group of people with signs calling for better support for the disabled community.
By Cheryl Stafford – Adult

The emphasis on planning and governance to deliver improved outcomes signifies a commitment to effective coordination and management of resources to ensure the successful implementation of the strategy. Furthermore, the focus on involvement, information, and access underscores the importance of promoting inclusivity, accessibility, and transparency in all aspects of support and services for the autistic community.

The strategy's focus on reducing health and care inequalities, ensuring appropriate support in the community and inpatient care, and improving support within the criminal and youth justice systems highlights a commitment to addressing systemic challenges and promoting equity and fairness for the autistic community across various Sectors.

Overall, the strategy's comprehensive approach, in conjunction with the involvement of the autistic community in its development, positions Northamptonshire to make significant strides in improving the quality of life and well-being of autistic individuals and their families.

What is Autism?

My Kaleidoscopic Perspective

By C.R. Eede

May this poem offer an insight into my personal experience of living with autism.

Through a different lens, I perceive,
An array of thoughts, I've come to believe,
Sensory concertos, both tender and noisy,
Autism's canvas, a gentle pillow ever so cosy.

A wondrous journey, glowing in my delight,
Autism's embrace, unfolding with great might,
I see, I hear, I feel, I touch,
Surrounded by life, it becomes too much.

Through routines and structure, there is comfort I find,
A sanctuary of composure, a safe and serene mind,
Empathy and understanding, deep and profound,
Understanding emotions, innate echoes resound.

I wish to be heard, to be loved, to be seen,
Not treated as lesser, or even a machine,
I deserve to be happy, live a good quality of life,
Must my mind balance on the tip of a knife?

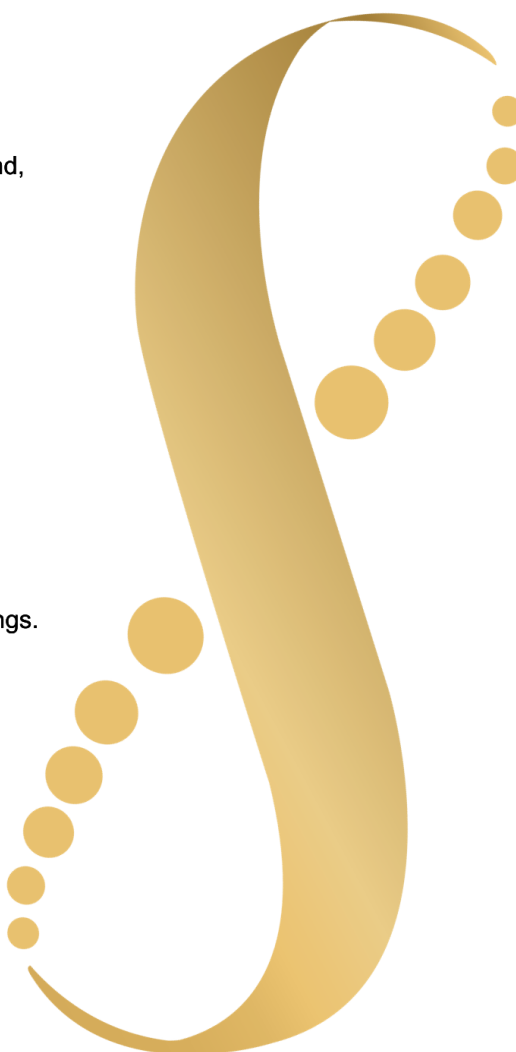
Embracing the details, such beauty they hold,
Autism's masterpiece, my story untold,
I struggle to navigate a world of feelings,
As people use metaphors, applying different meanings.

Communication, a slow dance of its own,
Words may escape me, but connection is shown,
Expressions and gestures are all so true,
My autistic language, an inner bond that grew.

Inclusion and acceptance, the path I must tread,
Shattering barriers, too many times I have fled,
Equality and understanding, it's all I seek,
But the world around me views me as weak.

I am a raging phoenix, revolutionary and fiery,
No one can obscure me, not people, not society,
In love and acceptance, more people unite,
Autism's message, my beacon of light.

This is my epilogue, I say to you,
Look into my eyes; with life I pursue,
I see colours and words, swirling as a collective,
Inside my mind, a kaleidoscopic perspective.



This poem serves as a powerful reminder to embrace the kaleidoscopic perspectives that shape our world, recognising the richness that lies within each unique experience. It invites readers to pause, reflect and appreciate the profound depth of emotion and understanding that exists within the journey of autism. Thank you for sharing your poignant reflection.

Definition

The definition of Autism changes as our knowledge continues to expand. The National Autistic Society currently defines Autism as “a lifelong developmental disability which affects how people communicate and interact with the world”. Autism, sometimes known as ‘Autism Spectrum Condition’ (ASC) or ‘Autistic Spectrum Disorder’ (ASD) is considered a neurodivergence, signifying a different functioning of the brain. While it is recognised as a lifelong developmental disability, it’s important to acknowledge that not all individuals with autism view themselves as disabled.

For diagnostic purposes, Northamptonshire refers to the World Health Organisation’s (WHO) International Classification of Diseases 11th edition (ICD11 2019) Framework and the 2013 American Psychiatric Association released the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders (DSM-5).

With an estimated 700,000 autistic adults and children in the UK, it is likely that most people have some connection with someone who is autistic. Additionally, there are around 3 million family members and carers of autistic individuals in the UK, as reported by the National Autistic Society. Autistic individuals experience the world in a distinct manner, perceiving, hearing, and feeling differently compared to others. Autism’s wide-ranging effects have led to its characterisation as a spectrum condition, with varying levels of support needed throughout individuals’ lives.

Autism is neither a learning disability nor a mental health condition however mental health issues are more prevalent among autistic individuals. Although autism is not a learning disability, around 4 in 10 autistic individuals have a learning disability.

Diagnosis

Autism is a relatively ‘modern’ diagnosis; the term ‘autism’ only came into common clinical use in the 1960s and whilst most diagnosis now occurs in childhood; many adults remain undiagnosed. Demand is increasing as there is a greater awareness of neurodiversity.

Getting a diagnosis can be a crucial milestone for autistic people; many have felt different and unable to “fit in” for all of their lives.

Decisions as to which terms to use with regard to someone who has a diagnosis of autism, identity first (autistic individual) or person first (individual with autism) are always difficult as they have subtle differences in meaning and can elicit strong feelings. There is no single universally accepted description that is agreed upon in the UK. We use the identity-first language preferred by many autistic individuals (Kenny *et al.* 2016).

Schrodinger's autism



All autistic enough to have a diagnosis
but not autistic enough for people to believe them
or offer reasonable adjustments

By Cheryl Stafford – Adult

Impact

Autism, while a medical diagnosis, encompasses a range of challenges that individuals with this condition may encounter. These challenges **can** include:

- Camouflaging or masking behaviours to conform and fit in.
- Identification as a social minority group, highlighting the need for understanding and acceptance.
- Living with a lifelong and complex condition, requiring ongoing support and accommodation.
- Managing an invisible disability, leading to potential misunderstandings and misconceptions.

It is crucial to recognise that autism presents with diverse profiles and support needs. Each autistic individual is unique and their requirements may vary. Autism is a spectrum and not linear, influenced by factors such as the environment and stress levels. While some autistic individuals may require minimal or no support, others may rely on daily assistance from a parent or caregiver.

Support needs can encompass a wide range of aspects, including establishing friendships, navigating educational settings, adapting to the workplace, and participating in community activities. This strategy emphasises the concept of neurodiversity, which recognises the different ways the brain can function and

process information, highlighting the importance of accommodating and embracing diverse cognitive processes.



By Cheryl Stafford – Adult

Covid



Artwork Cherl Stafford

The COVID-19 pandemic and previous pressure on the NHS have had a profound impact on various aspects of healthcare services, including those for individuals with autism. As a result, several challenges have emerged, contributing to a notable shift in the landscape of autism support and diagnosis. Some of the key impacts include:

1. **Waiting List Surge:** There has been a staggering increase in the number of individuals on the waiting list for autism assessments, with a reported rise of 200% for children and young people and 500% for adults. This surge has resulted in extended waiting times, leading to delayed access to crucial diagnostic evaluations and subsequent support services.
2. **Shortage of Practitioners:** The pandemic has exacerbated the existing shortage of healthcare practitioners specialising in the autism pathway. The reduction in available professionals has further compounded the challenge of managing the surge in service demand, contributing to longer waiting times and delays in accessing essential support.
3. **Extended Waiting Times for Diagnosis:** The substantial increase in waiting times for autism diagnoses has created additional stress and anxiety for

individuals and their families. Prolonged delays in accessing timely assessments and interventions have implications for early intervention strategies, potentially impacting the overall well-being and development of those on the waiting list.

4. **Hospital Admissions and Support:** The pandemic has also seen fluctuations in the rates of hospital admissions for individuals with autism, potentially due to the challenges in accessing necessary support services and disruptions in routine care. Navigating hospital environments during the pandemic has posed additional difficulties, especially for individuals with sensory sensitivities or specific support needs.

To address these challenges, it is imperative to adapt and innovate in the delivery of autism support services, ensuring that individuals on the waiting list receive adequate support and care. Developing support services, streamlining assessment processes, and prioritising high-risk cases can help mitigate the impact of the pandemic on autism care and support services. Moreover, investing in training programs and initiatives to expand the pool of practitioners with knowledge of autism care and support, can help alleviate the strain on the Diagnostic Pathway and improve access to timely assessments and interventions.

Where are we going?



Graphic: Amber Miller

Words used by autistic individuals to describe how they feel they want to be viewed. (Empowered, life chances, trail blazers, reach full potential, heard, quality of life, thrive, empathy, respect, equality, diversity, validated, connected, understood,

compassion, proactive, positive, lasting, safe, valued, visible, included, fulfilled, accepted, wellbeing, hope, supported into adulthood, believed, good, supported, seen, recognised, strong, creative, understood, different- not less, observant, thoughtful, worthy, outside the box, gifted, resilient.)

Core Values and Guiding Principles

In pursuit of Northamptonshire's vision to become an autism-inclusive community, the strategy emphasises the importance of fostering a supportive and inclusive environment that promotes equal opportunities for autistic individuals. To achieve this local vision, the following key principles and initiatives have been identified:

1. **Collective Responsibility:** Recognising that supporting autistic individuals is a shared responsibility, the strategy advocates for collaborative partnerships among various agencies and stakeholders, foster a collective approach to addressing complex challenges.
2. **Early Support and Intervention:** Prioritising early identification and intervention for autistic children, young people, and adults, the strategy emphasises the need for a skilled and confident workforce equipped to identify and provide timely support for individuals displaying autistic traits.
3. **Inclusion and Localisation:** Ensuring access to universal services with reasonable adjustments, the strategy underscores the importance of creating an inclusive environment where autistic individuals can participate fully in their local communities, accessing relevant services tailored to their needs.
4. **Personalisation of Support:** Adopting an individualised approach that emphasising choice, control, and reasonable adjustments, the strategy aims to empower autistic individuals by providing tailored support that respects their preferences and autonomy.
5. **Co-production and Partnership:** Encouraging active participation and decision-making by autistic individuals, the strategy promotes the principle of "Nothing about us without us," advocating for the inclusion of their perspectives in the developing and shaping of services.
6. **Integration and Coordination:** Emphasising the importance of collaborative integration, joint commissioning, and coordinated approaches, the strategy seeks to facilitate improved outcomes for autistic children, young people, and adults through cohesive and integrated service delivery.
7. **Cultural Shift and Flexible Approaches:** Encouraging a shift in cultural perspectives and the adoption of flexible delivery methods, the strategy advocates for innovative and adaptable approaches to better support the diverse needs of autistic individuals, fostering a more inclusive and responsive environment.



By Cheryl Stafford – Adult

Identification of Needs/ Population Data

Understanding the prevalence and impact of autism within the community is crucial in shaping effective strategies and support systems. Current estimates suggest that Between 1.5 and 1.76% of children and young people and 1 and 1.3% of adults are autistic. We estimate there to be between 8,514 and 11,032 people with autism in Northamptonshire, although variations may exist due to different diagnostic criteria, service availability, and public awareness. The experience of autistic individuals, particularly in educational and social settings, underscores the need for comprehensive support and understanding. Some notable statistics from the National Autistica's research highlight the challenges faced by autistic individuals:

- 34% of autistic children report experiencing bullying at school.
- 70% of autistic adults express dissatisfaction with the support provided by social services.

- A significant portion of autistic individuals experience mental health conditions, with high rates of anxiety and depression and other comorbidities.
- Employment opportunities for autistic adults remain limited, with only 16% in full-time paid positions.
- There is a significant underdiagnosis of autism in females compared to males.

The National Institute for Health and Care Excellence (NICE) estimates that around 70% of autistic people have an additional condition, which is “often unrecognised”. The main conditions that co-occur more frequently in autistic people compared with the general population include:

- Mental health conditions Research suggests that 70% of autistic people have a mental health condition and that 40% have two or more.
- Autistic people are up to four times more likely to have anxiety disorder and twice as likely to have depression.
- Research has shown that autistic people are more vulnerable to negative life experiences, which may also impact mental health.
- Compared to the general population, autistic people report having a lower quality of life.
- Research indicates that suicide is a major cause of early mortality in autistic people.

In Northampton, data on the autistic population is gathered from various sources, including the Joint Strategic Needs Assessment (JSNA), national prevalence figures, and submissions to Public Health England. Co-occurring conditions, including mental health disorders and neurodevelopmental challenges, are prevalent among autistic individuals, often posing additional hurdles to well-being and quality of life.

Collective Voices Stronger together



By Cheryl Stafford – Adult

To ensure a comprehensive and inclusive approach, the strategy emphasises the active engagement and participation of all members of the community, aiming to foster positive and empowering outcomes for everyone involved. Various forms of involvement, including engagement, consultation, participation, and co-production, have been crucial in developing this strategy, with a dedicated effort to ensure that the perspectives and needs of autistic individuals are at the forefront of decision-making processes.

Throughout the strategy's development, a priority has been placed on meaningful community involvement to establish clear and effective outcomes, goals, and actions that are responsive to the communities diverse needs. Respect for the unique needs of autistic individuals has been a guiding principle, leading to the adaptation of approaches and the provision of reasonable adjustments to facilitate their full and confident participation in a manner that best suits them.

In pursuing a comprehensive and well-informed strategy, information has been gathered from various stakeholder events conducted during the post-COVID period, ensuring that the strategy reflects the diverse voices and experiences within the community. This commitment to inclusive participation and collaboration underscores the strategy's dedication to creating a supportive and empowering environment for all individuals, including those with autism.

Gratitude is expressed for the courage shown by autistic individuals in sharing their experiences and stories, acknowledging the vulnerability inherent in such sharing. This recognition underscores the importance of creating a supportive and understanding environment that values the contributions and perspectives of every individual involved in the strategy development process.

Legal Background and Obligations

This strategy is being developed in parallel to legislation, Strategies and Guidance that impact the lives of children, young people and adults with autism and their families. These include:

- NHS Long Term Plan (2019)
- The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026
- Department of Health in 2010 (Fulfilling and Rewarding Lives; the strategy for adults with autism in England)
- National Institute Of Health & Care Excellence (NICE) Guidelines
- Special Educational Needs and Disability and Childrens and Families Act 2014
- The Autism Act (2009)
- Strategy for Adults with Autism 2010
- Learning Disability Mortality Review (LeDeR/ learning from lives and deaths)
- Think Autism 2014 and Statutory Guidance 2015
- Care Act 2014
- Equality Act 2010
- The Health and Care Act 2022
- Core Capabilities Framework for Supporting Autistic People 2019. The Department of Health and Social Care

How do we get there?

To ensure the continued relevance and effectiveness of this strategy, an annual review process will be implemented, engaging a diverse group of individuals, stakeholders, partners, and, significantly, autistic individuals of all ages, along with their families. Effective implementation of the strategy requires active participation and leadership at senior levels within various partner organisations, including West Northamptonshire Council, North Northamptonshire Council, Northamptonshire Health Care Trust, Northamptonshire Integrated Commissioning Board, NHFT, Northampton General Hospital, GH, Kettering General Hospital, Northamptonshire Police, and Voluntary Sector Partners.



By Cheryl Stafford – Adult

Given the multifaceted nature of the priorities outlined in this strategy, successful implementation hinges on shared ownership and collaborative leadership across all relevant organisations. The collaborative efforts of these diverse stakeholders will be instrumental in ensuring the strategy's meaningful impact and the effective delivery of its outlined objectives.

To effectively manage the progress of this strategy, a comprehensive monitoring and evaluation system will be established. The following measures will be implemented to ensure the strategy's success and its impact on the community:

1. **Establish Clear Metrics of Success:** Develop specific and measurable indicators aligned with the strategy's objectives to assess its progress and effectiveness.
2. **Regular Progress Updates:** Share timely updates and progress reports with stakeholders, partners, and the community to maintain transparency and accountability in the implementation process.
3. **Annual Review and Evaluation:** Conduct an annual review process to assess achievements, challenges, and necessary adjustments required to meet the evolving needs of the community effectively.

4. **Action Plan Development:** Work closely with designated action leads to develop a comprehensive action plan reflecting the strategy's priorities and initiatives, providing a clear roadmap for achieving the set objectives.
5. **Collaborative Approach:** Emphasise a collaborative approach to encourage effective communication and engagement among all stakeholders, ensuring that diverse perspectives are considered in the decision-making process.
6. **Effective Communication:** Implement a robust communication strategy to ensure that all relevant parties are well-informed and engaged throughout the implementation process.
7. **Flexibility and Adaptability:** Maintain a flexible approach to accommodate necessary adjustments and changes based on feedback received during the review process, ensuring that the strategy remains responsive to the evolving needs of the autistic community and their families.

By implementing these measures, the strategy's progress will be effectively managed, ensuring tangible and positive outcomes for the benefit of the autistic community in Northamptonshire.