

# Perth & Kinross Autism Strategy 2016 - 2021

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## PERTH & KINROSS AUTISM STRATEGY

The purpose of this strategy and associated action plan is to set the strategic direction for improving outcomes for people with Autism and their families/carers across the lifespan in Perth & Kinross. The content of the strategy and action plan is based on a mapping out of existing service provision and identifying priority areas for action reflecting local need to inform future shaping and co-ordination of services. Specific and measurable actions have been recommended in the action plan, on the basis of evidence, parental/carer/user consultation and a localised mapping analysis.

What words do people prefer to use to describe people on the autism spectrum? The language we use is important because it embodies and can therefore help change attitudes towards autism. <http://www.autism.org.uk/about/what-is/describing.aspx> recent research (NAS 2015) confirmed that there is no single term that everyone prefers. However, they suggest a shift towards more positive and assertive language, particularly among autistic communities where autism is seen as integral to the person. In light of this Perth and Kinross council are not using the term disorder and using the broad descriptor of Autism Spectrum Condition, and as being autistic for adults and on the autism spectrum for children.

## WHAT IS AUTISM?

There is no one answer to this question because the way autism impacts on each individual are unique. No two people are exactly the same. Autism is a difference in the way a person thinks, perceives and therefore understands the world and others. This results in difficulties or differences in communication, social interaction, and thinking and in sensitivity of the senses. Therefore autism poses many challenges that are often multi-faceted and complex, requiring a range of services and sectors to work together and clearly understand and ensure that individual needs are properly assessed and addressed.

## BACKGROUND

In 2010, a draft autism strategy was consulted on widely, and the development and creation of the new Scottish Autism Strategy (2011) <http://www.gov.scot/Resource/Doc/361926/0122373.pdf> for Autism was identified as being vital to ensuring that progress is made across Scotland in delivering quality services. Its 26 recommendations (see appendix) are far-reaching and will impact upon all professions, across all disciplines involved in the provision of public services.

The Strategy sets out a **10 year agenda for change** that addresses the entire autism spectrum and the whole lifespan of people living with ASD in Scotland which will give **individuals on the autism spectrum a meaningful and satisfying life built on:**

- people being given the care and support they need in a way which promotes their **independence and emotional well-being** and **respects their dignity**;
- people being 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**;
- services being **personalised** and based on the identified needs and wishes of the individual;
- people being supported to feel **safe and secure** without being over-protected;
- people having **the opportunity to achieve** all they can;

## SCOPE AND STRUCTURE OF THE STRATEGY

In December 2015, the Scottish Government developed its '**Scottish Strategy for Autism Outcomes Approach: Priorities 2015-2017**' document. This specifies four Strategic Outcomes (SOs) with a descriptor of what requires to be done to achieve each of the outcomes. The Scottish Government have advised us to consider and site the 26 recommendations within a broader framework, for the purpose of being clearer about intended outcomes that can result from the implementation of the Scottish Strategy for Autism at a local level. The introduction of national health and wellbeing outcomes, along with the integration of health and social care, will bring changes to how services for people with Autism and others will be planned and developed and the national strategy has been reframed to align with the four priority outcomes whilst remaining linked to the original Scottish Autism Strategies whole-life journey goals (see appendix 1).

### STRATEGIC OUTCOMES 2015 -17:

**A Healthy Life:** People with autism enjoy the highest attainable standard of living, health and family life and have timely access to diagnostic assessment and integrated support services.

Linked goal - Improve access to integrated service provision across the multi-dimensional aspects of autism.

**Choice and Control:** People with autism are treated with dignity and respect and services are able to identify their needs and are responsive to meet those needs.

Linked goal - Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas.

**Independence:** People with autism are able to live independently in the community with equal access to all aspects of society. Services have the capacity and awareness to ensure that people are met with recognition and understanding.

Linked goal - Capacity and awareness building in mainstream services to ensure people are met with recognition and understanding of autism'.

**Active Citizenship:** People with autism are able to participate in all aspects of community and society by successfully transitioning from school into meaningful educational or employment opportunities.

Linked goal - Improve access to appropriate transition planning across the lifespan.

### PERTH AND KINROSS HEALTH AND SOCIAL CARE PARTNERSHIP

Health and Social Care changed in April 2016 health and social care services are now provided through the Perth and Kinross Health and Social Care Partnership. In Perth and Kinross, we recognise that people who are ill, vulnerable or have disabilities, often need support from a number of services to enable them **to live as independently as possible** and to prevent unnecessary stays in hospital or in residential care. Autism is acknowledged as presenting a rising demand and placing a pressure on services within the Perth and Kinross Health and Social Care Strategic Commissioning Plan 2016-19.

<http://www.pkc.gov.uk/CHttpHandler.ashx?id=36538&p=0> "Prevalence of Autism is likely to be higher than we are currently aware and increased rates of diagnosis for young people will impact on adult services".

Perth and Kinross Health and Social Care Partnership recognise the distinctive needs of different areas of Perth and Kinross and the need to take account this in planning our services. We value the **diversity** of the communities of Perth and Kinross and will work with them to make sure we have an integrated health and social care system that **is inclusive and accessible**. We will work together to make sure people are supported to lead as independent, healthy and active lives as possible in their own homes. Children and young people's services are not formally included in the Health and Social Care Partnership and we will continue to work collaboratively with the Children, Young People and Families Partnership to meet the needs of the whole community.

Our commitment to the Public Service Reform agenda is articulated in our Community Plan/Single Outcome Agreement 2013-2023 <http://localapps.pkc.gov.uk/internet/flashmag/Community%20plan%202013/index.html>. This sets out a vision of a confident and ambitious Perth and Kinross, to which everyone can contribute and in which all can share. Through our strategic objectives we aim to maximise the opportunities available to people to achieve their potential, at every life stage and there are cross cutting themes that will underpin the work of the Health and Social Care partnership.

The framework of the Scottish Autism Strategy (2011), along with **Perth & Kinross's Community Planning Partnership – Community Plan (2013 - 2023)** has guided the preparation of this strategy. This will ensure that the expectations of the strategy remain the focus of development and improvement of services for people with autism, whilst linking with the values and priorities of the local community plan, which sets out **5 strategic objectives for Perth and Kinross**:

- **Giving every child the best start in life**
- **Developing educated, responsible and informed citizens**
- **Promoting a prosperous, inclusive and sustainable economy**
- **Supporting people to lead independent, healthy and active lives**
- **Creating a safe and sustainable place for future generations**

This strategy and associated action plan includes reference to both adults and children and whilst there are some common themes across all age groups, the legislative and organisational context is quite distinct for adults and children's services. Therefore the report acknowledges the importance of several key documents and areas of guidance that are applicable to the entire autism spectrum and the whole lifespan of people living with ASD in Scotland (see appendix 2).

The National strategy is in its fifth year of implementation, however Perth & Kinross's action plan was not written until 2014 and although that may appear delayed we were in fact more prompt in producing this document than many other areas, as a consequence our action plan was written to align with the original Scottish Government guidance, since then and as detailed previously the National Strategy has altered its approach and therefore we as an authority have decided to consult once more and re draft our original document, to ensure congruence with the National direction.

We have consulted the local autism community, we asked those with an ASC their families and carers to comment on the four outcomes as identified by the Scottish Government, the feedback we have received will direct our future work and ensure that we as an authority are basing our plans on the needs of this group by ensuring autistic individuals, their families and carers remain an active participant in service development and improvement for those with an autism spectrum condition within Perth & Kinross.

In relation to each outcome we will detail:

- **What we will do**
- **Why we need to do this**
- **What we have achieved**
- **What we will do next**

# 1

STRATEGIC OUTCOME - A HEALTHY LIFE – PEOPLE WITH AUTISM ENJOY THE HIGHEST ATTAINABLE STANDARD OF LIVING, HEALTH AND FAMILY LIFE AND HAVE TIMELY ACCESS TO DIAGNOSTIC ASSESSMENT AND INTEGRATED SUPPORT SERVICES.

## WHAT WE WILL DO

Improve access to integrated service provision across the multi-dimensional aspects of autism.

## WHY WE NEED TO DO THIS

For people with autism getting an assessment of autism is the first step to accessing services they need to meet their personal outcomes.

## WHAT WE HAVE ACHIEVED:

**CAMHS:** - NHS Tayside CAMHS provides specialist assessment and treatment for children and young people aged up to 18 years who have or are suspected to have mental health difficulties. They work as part of a multi-disciplinary team of Child & Adolescent Psychiatrists, Clinical Psychologists, and Clinical Associates in Applied Psychology, Family Therapists, Specialist Nurses, Psychotherapists, Occupational Therapists, Primary Mental Health Workers, Social Workers, Speech & Language Therapists and administration staff. They also work in partnership with other agencies that provide health, social care and education services. Their aim is to ensure that they deliver the best or most appropriate services possible to meet the particular mental health needs of the child or young person. A small amount of outreach is also provided to Community Paediatrics to support diagnosis of autism in pre-schoolers.

Since December 2015, Tayside CAMHS has achieved the Scottish Government standard of 90% of referrals accessing treatment within 18 weeks of referral. More efficient and patient centred processes have been put in place to try to ensure that children and their families have the opportunity to work with a clinician who has the right skills to help them from the start of their journey through CAMHS. However, many children will still experience a lengthy wait following initial assessment and care before a diagnosis can be confirmed or excluded by an autism specialist.

**CHILD DEVELOPMENT TEAM:** - Primarily provides assessment for pre-five children, you can be referred to this team via a variety of sources, they are a multi-disciplinary team with a substantial amount of expertise and time spent working with children who have an ASC. **Parent to Parent** support parents of children undergoing assessment for ASD/ADHD offering emotional support while the child is waiting to be assessed. For children displaying challenging behaviour the support worker will help parents to implement boundaries and strategies.

# 1

Parent to Parent will accompany parents to assessment and feedback visits if required and if a diagnosis is given will help parent access other appropriate provisions.

**ADULT LEARNING DISABILITY TEAM:-** Comprises of a multidisciplinary team and is based at Murray Royal Hospital, Perth including: Psychiatrists, Learning Disability Nurses, Psychologists, Physiotherapist, Occupational Therapists, Speech & Language Therapists, Dietitians, Music Therapist and Art Therapist. This team accept referrals for those with autism as long as they have a comorbid Learning Disability. Included within this service are the Learning Disability Intensive Support Service (LDISS) who offer an assessment and treatment service for Adults who have a Learning Disability and who may also have associated health needs in relation to a variety of issues e.g. Mental Health, Epilepsy, Autism, Exhibiting behaviours which can be challenging, this can be either at LDISS or in a community setting which meets their needs e.g. their own home.

They offer a person-centred flexible approach to healthcare, encouraging individuals to achieve their potential in an environment which is safe and therapeutic and offer support, education and advice to clients, their families / carers and to partner agencies e.g. behaviour support plans. The learning disability team and pathway is very clear and works well, they offer autism specialism and are highly regarded.

**CMHTs:** - People with autism are provided with diagnostic assessment from their local CMHT and/or from the Specialist Team. Interface relationships continue to mature and most referrals are discussed together to ensure that the correct service is providing the diagnostic assessment. There is a clear increase in joint working with individuals to ensure both diagnostic assessment and integrated community mental health support. People are provided with information regarding No3 this support is displayed within our waiting areas.

**TAACT:** - The Tayside Adult Autism Consultation team were set up in January 2014 and received recurring funding in September 2015, they are a multi-disciplinary team comprising of (psychology, occupational therapy, SALT and nursing input) with a psychiatrist joining the team imminently. They have provided a much needed diagnostic and consultancy service; they have worked with 202 referrals since February 2015 and tend to diagnose the more complex cases of autism that present. Notably their number are comprised of approximately 50% females, which is interesting given the established male/female ratio 1:4 and would indicate a better understanding of how autistic women present.

**PERTH AUTISM SUPPORT:-** Perth Autism Support, support over 550 families throughout Perth & Kinross, taking a full family approach to their support they promote the highest attainable standard of living, health and family life which families can access not only when they have received a diagnosis of autism but throughout the assessment period.

**AUTISM INITIATIVES:** - Number 3 supports individuals aged 16 and over to navigate the diagnostic process. From pre-diagnostic information about autism and what the assessment process is to supporting the individual to attend their GP, to seek a referral then if needed supporting the person to attend assessment appointments with the relevant service (Adult LD Team, Community Mental Health Team or Tayside Adult Autism Consultation Team). Follow up appointments are essential to help the individual to understand the process at all stages. Post diagnostic support is provided in the form of 1:1 appointments with individuals and family if required and through the "Late Diagnosis Group", an 8 session course specifically designed to support individuals understanding of their diagnosis. Number 3 have supported more than 20 adults to navigate through the diagnostic process with a further 38 being referred to our service for post diagnostic support following an adult diagnosis. Number 3 is an integral part of the diagnostic pathway for adults living in Perth & Kinross.

# 1

## WHAT WE WILL DO NEXT?

We are working to improve joint working methods with our colleagues in health CAMHS, Child Development Team, CMHTs and TAACT to ensure individuals and their carers/families find the diagnostic process before, during and after as efficient and stress free as possible. Additionally we want to ensure that all parties involved contribute to the assessment process in an appropriate and constructive manner with the aim of ensuring we have an accurate picture of the young person's presentation and that the views and perspectives of families, carers and professionals are equally respected.

**CAMHS:** A number of factors have led to children still facing a lengthy (although improved) waiting time for diagnosis of autism, including internal bottlenecks resulting from the huge numbers of children seen during the drive to reduce the waiting time for accessing CAMHS, year on year increases in demand for CAMHS; and a local and national shortage of child psychiatrists. To address this problem, CAMHS are developing a standard autism diagnostic pathway based on national guidance so that children receive a high standard of care regardless of where in Tayside CAMHS they are seen, or which clinician they are seen by.

CAMHS is also working with Community Paediatrics to find more efficient ways to work across both services, making best use of skills, and avoiding duplication of work. In addition, CAMHS is investing in training more non-medical staff to be able to diagnose autism. CAMHS is developing links with the Tayside Adult Autism Community Team (TAACT) to promote successful transitions between child and adult mental health autism services when young adults need this. CAMHS recognises the need for all agencies to work together for the benefit of children and their families, and will be contributing to multi-agency planning for autism services in Perth, Dundee and Angus localities going forward.

**TAACT:** - Have developed a new pathway that should make the referral process clearer and therefore efficient.

Referral can come from CMHT - if a specialist consultation is felt necessary.

Referral can be made to the team if the individual has a complex differential diagnosis, previous trauma, schizophrenia, OCD but with the understanding that the CMHT have screened the individual.

Referral can be made by a GP straight to the TAACT team if the individual presents with no previous or current comorbid mental health issues and believes they may have an ASC.

Additionally the team provide flexible post diagnostic support, looking at what the individual's autism means for them individually and strategies for moving forward. They provide training and support to other teams including psychology, criminal justice services, social work teams and the CMHTs.

**PAS & AUTISM INITIATIVES:** Their priority is to ensure that they secure ongoing funding to sustain and allow them to deliver services continuously to families throughout Perth & Kinross.

# 1

**FEMALE PRESENTATION OF AUTISM:** - A recurring theme in our consultation across all age ranges is a lack of specialism and understanding of a female presentation of autism. We seek to improve this by:

Providing a range of resources including front line training and a dedicated section on our Perth Autism website [www.autism-perth.org.uk](http://www.autism-perth.org.uk) PAS have run a joint event with the Curly Hair Project [www.thegirlwiththecurlyhair.co.uk](http://www.thegirlwiththecurlyhair.co.uk) and will continue to work closely with them. The Scottish Women's Autism Network (SWAN) has a local group which is run at Autism Initiatives. The TAACT specialise in diagnosing women with autism.

Timely identification and subsequent formal diagnosis of autism are surely the most basic of building blocks for an effective and cost effective autism strategy. In an ideal world, identification of needs should be sufficient for action to be taken, but in practice a diagnosis is often required to access support and services. Identification and diagnosis open the door to assessment of an individual's needs for support, and of how their personal strengths and preferences might affect what should be done.

## CONSULTATION FEEDBACK IN RESPONSE TO OUTCOME 1:

*"Reduced waiting time needed at CAMHS for access to Drs and assessments".*

*"Living with autism is exhausting and the last things people want are complicated procedures, lots of reading and forms to fill out. It would be better to have one point of call for everything, and possibly to be referred on to an agency/support group who can help from there".*

*"Advice and support post diagnosis particularly with entrenched behaviours needed".*

*"Options for parents/carers to access overnight respite even if this involves a cost".*

*"Family life can be put under severe strain without adequate respite care being available. It shouldn't take crisis point to happen before help is available".*

*If it wasn't for my referral to Perth Autism Support via Parent to Parent I dread to think where we would be relying on the state.*

*"Important to have plenty support".*

# 2

## CHOICE AND CONTROL – PEOPLE WITH AUTISM ARE TREATED WITH DIGNITY AND RESPECT AND SERVICES ARE ABLE TO IDENTIFY THEIR NEEDS AND ARE RESPONSIVE TO MEET THOSE NEEDS.

### WHAT WE WILL DO

Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas.

### WHY WE NEED TO DO THIS

People with autism tell us that they experience variation in access and how services respond to their needs. Professionals must be able to understand autism and develop services that are responsive to the needs of people with autism.

### WHAT WE HAVE ACHIEVED:

The National Institute of Health and Care Excellence (NICE) have produced materials to support diagnosis and multi-agency assessment, as well as recommendations for commissioning support. All diagnostic services within Perth & Kinross apply the same quality standards as required by NICE. Staff will have, or be supervised by staff who have specific knowledge and skills outlined in the Scotland Autism Training Framework. These standards are reinforced in the NES Autism Training Framework and Menu of Interventions document.

<http://www.gov.scot/Resource/0043/00438221.pdf> , these documents have been circulated and all diagnostic teams made aware of this work and up to date research on reducing waiting times, PUBLISHED BY Autism Achieve Alliance.

<http://www.autismnetworkscotland.org.uk/files/2014/11/AAA-ASD-Waiting-for-Assessment-Executive-Summary.pdf>

**PAS:** Support just under 200 young people on a weekly basis; they work on an individual basis with each child identifying needs and developing plans for each young person taking in to consideration their thoughts and views using the SHANARRI indicators to keep this in line with other support services. Their individual plans look at the young person's life as a whole and not just their time within PAS services. Their service is flexible to the needs of each young person and they can tailor and adapt groups as appropriate. Through their family support and school liaison team's information is shared with families and education colleagues to allow a streamlined, consistent approach to the support of every young person who accesses their services.

**AUTISM INITIATIVES:** - Number 3 provides a complete 'One Stop Shop' service for individuals with an ASC where communication and interaction can be the biggest barrier to accessing support. Individuals with an ASC can build a relationship with a team of staff who has a specialist understanding of their condition that is able to support them and their families with any difficulties and challenges in their lives.

# 2

Number 3 offers a safe haven for adults with an ASC, available on an as required basis, meaning individuals can access support when they need it with all aspects of life. The main areas of support provided are with benefits, housing, employment, relationships, life skills and mental wellbeing. The Number 3 service provides direct support and also enables adults with autism to access services elsewhere effectively by supporting communication between the individual with autism, their families and other services. Number 3 employees use their knowledge, understanding and experiences of autism and appropriate guidance (SIGN, NICE, Menu of Interventions) to bridge the gap between individuals with autism and mainstream services. Number 3 is used by 247 adults with autism (178 male and 69 female).

**PERTH & KINROSS COUNCIL:** - Perth & Kinross Council promotes learning for everyone and works to keep our vulnerable residents safe and protected, the priorities for **Education & Children's Services** are:

Raising achievement for all;

Supporting vulnerable children and families;

Improving the quality of life for individuals and communities; and

Enabling the delivery of high quality public services

Working in partnership with Angus and Dundee City Councils, NHS Tayside and colleagues from the independent school sector, we have developed a shared format for a single Child's Plan as well as multi-agency guidance to support their effective creation. This format is being used to coordinate plans for all children and young people who need one, including children and young people who are looked after or are in need of protection. The specific focus of our Child's Plan meetings is now to improve outcomes for children, young people and families. The plan format gathers information about progress made, identifies what needs to be different and better, and details the actions we will put in place to make those improvements. Use of the agreed Child's Plan format is leading to fewer meetings for families and a greater focus on partnership working as we meet the needs of the children, young people and families we serve.

In addition to the multi-agency guidance, education specific guidance has been produced and training in the use of the Child's Plan format has been rolled out to all relevant staff in Education Services. The Tayside Child's Plan format and guidance will be evaluated and reviewed by June 2017. Getting It Right for Every Child (GIRFEC) approaches, including use of the Wellbeing Wheel and the Child's Plan format, are well embedded across our schools and centres. In most schools children, young people, parents and staff are developing a shared understanding of wellbeing. With the publication of *How Good Is Our School?* We have further strengthened the focus of schools on wellbeing and equality and this is helping to ensure that all our children and young people have appropriate opportunities to develop as successful learners and confident individuals.

**Housing and Community Care:** Housing & Community Care provides housing services and services for older people and vulnerable adults. We help people, wherever possible, to live independently within their own homes. We support communities across Perth and Kinross by working to reduce re-offending and increase public safety and protection. We match support to people's need, so provide support such as home care, day care and residential services, respite or advocacy.

# 2

With specificity to autism we employed an autism coordinator who has ensured through the production of our action plan and strategy and ongoing joint working with relevant partners that we are focussing our work on the recommendations of the Scottish Autism Strategy and have ensured our work is aligned with all relevant National Developments of particular note:

The Principles of Good Transition 3 (The Autism Supplement)

The NES Training Framework

Menu of Interventions

New Autism Outcomes and Priorities Approach 2015-17

## WHAT WE WILL DO NEXT?

Autistic people often express the wish for greater autonomy - more choice in the opportunities available to them and greater control over decisions that affect their lives – but empowerment may be pointless unless there are effective supports and structures in place for some people, these structures are influenced by good practice guidance.

We will continue to apply best practice, guided by national health, education and social care guidelines and hence ensure any work moving forward is enriched by:

Providing appropriate training for our staff

Providing specific support mechanisms for engaging in the workplace

Providing enhanced transition (as detailed in outcome 4)

By working in a truly joined up manner with our colleagues in health, social care, education and the third sector.

By addressing funding gaps we aim to create more sustainable autism specific services that more effectively meet the needs of this complex group of individuals.

Our Ease the Move project as detailed in Outcome 4 is a good example of how we have already started to move forward in our thinking around how we provide Autism specific services and encapsulates all of the above mentioned working methods.

# 2

## CONSULTATION FEEDBACK IN RESPONSE TO OUTCOME 2:

*"Better communication from CAMHS".*

*"These services must employ people who truly understand the nature of autism though, and be able to be flexible enough to accommodate individual needs, as all autistic people have different characteristics. I see very few professionals who truly seem to understand my child's condition - indeed, some people who have not been 'trained' can be more empathetic".*

*"More training for school staff in supporting young people on the spectrum".*

*"I agree we have a very positive experience so far".*

*"When you get access to a service people are increasingly respectful, however getting access to services to identify needs is very difficult as services are stretched to the limit and have very long waiting times".*

*"There needs to be a council wide subtle way of communicating that a person has autism at every reception desk for example (Dr surgery/hospital /council leisure facility etc.) so that information can be passed over easily about what may help them".*

*"The staff make me feel that being 'Different' is not a bad thing, they make you feel as though you have a purpose in the world."  
(No3)*

*"Number 3 rescued me from a very low point in my life and has helped turn my life around"*

# 3

INDEPENDENCE – PEOPLE WITH AUTISM ARE ABLE TO LIVE INDEPENDENTLY IN THE COMMUNITY WITH EQUAL ACCESS TO ALL ASPECTS OF SOCIETY. SERVICES HAVE THE CAPACITY AND AWARENESS TO ENSURE THAT PEOPLE ARE MET WITH RECOGNITION AND UNDERSTANDING.

## WHAT WE WILL DO

Capacity and awareness building in mainstream services to ensure people are met with recognition and understanding of autism

## WHY WE NEED TO DO THIS?

People with autism experience barriers accessing community facilities. Having the right support and knowledgeable workforce to deliver services are important aspects on an independent life.

## WHAT WE HAVE ACHIEVED

**Education and Children Services:-** The creation of the additional posts of **Outreach Teacher** has allowed the outreach service to be enhanced with one teacher focussing primarily on primary schools and the other focussing on secondary schools they have provided a wide array of practical resources that are being put in place to support teachers, young people and their families.

The Outreach Teacher post has built up a wealth of materials for teachers, training courses and worksheets to help build knowledge and skills. The teacher also provides telephone support in respect of individual children. The Outreach Teacher has also been in close contact with parents, and has helped to build their knowledge and capacity or support them when things are not going well. This has required good interpersonal skills and the Outreach Teacher has been able to mediate where their school finds a child's behaviour particularly challenging. This activity was reported to reduce exclusion of children and young people from school, thus reducing stress and distress for children, young people and their families as well as helping to prevent children being placed in specialist or residential provision. The Outreach teacher post has also worked to change cultures and influence thinking within schools about children with Additional Support Needs.

**The Educational Psychology Service** provides consultation with key school professionals for 365 children and young people. The focus of these consultations included anger, aggression, bereavement and loss, transition, wellbeing and sexualised behaviours. The most commonly reported immediate impact was consultees feeling that they had a plan to meet their need.

# 3

**Housing and Community care and Education services** recruited an **autism coordinator** in August 2013, who wrote our original action plan and newest updated version. Since then the coordinator has actioned many of the areas of need as identified by the original plan, has accessed Scottish Autism Development Funding to create two bespoke autism specific transition services for young people between the ages of 16 and 25 and has created an Autism specific modern apprentice scheme supported by Perth Autism Support and Autism Initiatives No3. Worked jointly with a parent to create an Autism Perth Website and run a wide array of courses including autism awareness, how to manage behaviour and cognitive affective training. In addition the coordinator provides one to one support and consultation for those with an Autism Spectrum Condition and their families/carers, whether it is in the family home or in a work environment, the coordinator provides appropriate strategies and support enabling the individual to work or just be safe in the community.

The coordinator is a member of Autism Strategy Lead Officers Collaborative and sits on the Scottish Government Working Group two looking at the Goal: Access to appropriate transition planning across the lifespan and as a consequence is up to date with national developments and able to translate and apply them to a local context.

Many autistic people have a strong interest in **technologies** that has been linked to clarity in demands (and absence of social demands), immediate, predictable and repeatable responses, use of visual cues, and diminished sensory stimuli. Technologies may be used to support functional skills such as interventions aiming to improve activities of daily living, social participation, communication skills, spatial and temporal planning and recognition of emotions.

**Perth & Kinross council** are investing a small amount of funding in **Brain in Hand (BiH)** smart web-based software that helps users achieve greater independence, manage mood problems and reduce reliance on support. It synchronises with a smartphone app so it is always available and simple to use. It is based on well-established therapeutic principles such as CBT, solution focused therapy, and recovery based rehabilitation allowing the learning from these approaches to be turned into a set of patient centred strategies.

Brain in Hand enables the service user access to:  
Instant access to pre-planned coping strategies  
A diary to structure their time and “recipes” for difficult to remember tasks  
A monitor to track anxiety levels  
A system for users to request support if things don’t go to plan  
A secure website where they can review their use and identify new issues.

We are proposing a 10 user program that we believe would provide Perth and Kinross Council with large enough cohort of service users to demonstrate how this would deliver both improved outcomes for a much larger number of service users across many different services such as older peoples services, Children and young people services as well as reducing costs in the delivery of existing support services.

Outcomes that BIH have already seen within other deployments are:  
Enabling service users to live more independently.  
Reinforcing other adaptations and programmes already on offer by encouraging the outputs to be utilized within Brain in Hand  
Providing support to travel training.  
Reducing sleeping and waking night support.

# 3

**PAS:** *“Our ethos at Perth Autism Support is not that our children require autism specific services for the rest of their lives but to ensure that we can develop communication and social skills within an autism friendly environment at the pace that is right for each young person which in turn we would hope means that when they move into adult services there will be less reliance on service and that they will be able to achieve any goal they wish to strive for in life and be an active and independent member of the community with less barriers faced when accessing mainstream services, based on the idea that early intervention is key to better longer term outcomes for our young people. Although our groups are fun they are very structure based working on some of the challenges the young people are facing but in a fun, non-confrontational “real” way”.*

PAS spend a lot of time raising autism awareness in the community and this includes delivering training to our colleagues in both Perth & Kinross Council and NHS Tayside. This also includes the wider community remit of supporting organisations who may be working with our young people in other settings and with employers in the area who are working with our Employment Co-ordinator to deliver Modern Apprenticeships or work experience opportunities. They provide a wide array of learning opportunities locally and nationally with the aim of providing autism specific training that meets the needs of professional, carers/families and individuals on the autism spectrum.

**Autism Initiatives** launched the Perth and Kinross One Stop Shop (**No3**) in 2013 which is for people aged 16+ living in Perth & Kinross with autism. No 3 is a free, person-centred support service for adults with an autism spectrum disorder (ASD) living in the Perth & Kinross region. It offers a wide range of advice, information, activities and support services.

The work No3 do is focussed on positive mental wellbeing, not only for adults with ASC but for their families and those close to them. They provide an all-round service including but not exclusive to pre diagnostic information, attendance to and advocacy at appointments, post diagnostic support, problem solving and life skills support, relationship issues and self-awareness. They aim to provide a safe autistic space where people can build their self-esteem, sense of self and appropriate strategies with the support of knowledgeable staff and others in a similar position.

**SALT & OT:** - Speech and language therapy and occupational therapy staff within paediatrics and adults (Mental health and Learning disability) have been integral to training in relation to various elements of autism. They have worked jointly with the third sector to provide flexible, autism specific learning opportunities, for professionals, carers and individuals on the autism spectrum. Both these services are highly valued and their ongoing contribution has meant that jointly Perth & Kinross are able to offer high quality, up to date autism specific training.

## WHAT WE WILL DO NEXT

We are keen to develop more experiential learning opportunities for professionals within schools and community care. The local authority, the NHS, PAS and No3 currently provide a wide range of training opportunities and there is no doubt that this learning is valuable but how it is applied to practice is something we could improve on.

A growing body of research suggests that we should be linking strategies for intervention with the settings in which we hope interventions ultimately will be used. Specialist interventions that work in a clinical environment don't work in community settings, for them to be successful we need improve joint working mechanisms and accurately assess the skills of those expected to make these interventions work in a different context.

# 3

This will help facilitate the successful adoption, implementation, and maintenance of interventions that have already been developed, and to develop new interventions in collaboration with communities to ensure that the interventions meet the community's needs and capabilities, thereby increasing the likelihood of successful diffusion". Dingfelder and Mandell 2010. With public sector resources so very stretched, actions need to be affordable. Effective interventions and support are needed and will continue to be needed at all stages of life, whether these are remediating the effects of earlier poor care or not. These issues mean that a cradle to grave model of support could be most effective.

Perth & Kinross are currently looking at possible long term models of support, were we to go down a whole life route we would want a provider that recognizes the need for early intervention, ensuring individuals are supported from childhood into adulthood, in turn lessening costs and pressure on adult services, support should be provided as a preventative measure and not when irreversible damage has been done and families find themselves in a crisis situation.

They should truly understand the nature of autism and what makes a meaningful difference. We should not be aiming to just keep people safe, or to find somewhere for people to go each day with no real outcome other than just filling time. We should be aiming to increase the skills of these individuals to ensure they have access to the same things you and I do, to be employed, to access education, to have their own home to have a social life/relationships. These are all entirely possible for a large proportion of this population and should be where we aim to work, thus improving outcomes not only for the individual but their families and society as a whole.

## CONSULTATION FEEDBACK IN RESPONSE TO OUTCOME 3:

*"Access to appropriate support at every stage of life".*

*"This is an admirable goal, but needs the community to fully understand the complex nature of autism (and its many associated variations) in order to work. This kind of work is already being undertaken by the NAS, but it is a huge undertaking, and much publicity is still needed. In the end it benefits the community as much as it does the ASD person, as it broadens their understanding and tolerance of social behaviours".*

*"More supported living options for young people transferring from children's services to adult services".*

*"Education and awareness to everyone. Supermarkets, chemist, retailers because everyone can do something to help even if it's giving someone a kind words to a stressed out mother dealing with a meltdown in a supermarket".*

*"Well where do I start? Number 3 has helped me enormously. If it was not for the staff at Number 3 I would still be living a reclusive life by not going out or meeting new people. They have also helped me get a flat so that I can live independently as I can."*

# 4

CITIZENSHIP – PEOPLE WITH AUTISM ARE ABLE TO PARTICIPATE IN ALL ASPECTS OF COMMUNITY AND SOCIETY BY SUCCESSFULLY TRANSITIONING FROM SCHOOL INTO MEANINGFUL EDUCATIONAL OR EMPLOYMENT OPPORTUNITIES.

## WHAT WE WILL DO

Improve access to appropriate transition planning across the lifespan

## WHY WE NEED TO DO THIS?

People with autism can experience barriers to participation in aspects of community life including education, employment opportunities and social activities. A good transition plan from school will enable young people with autism to plan their future participation in and contribution to their community.

## WHAT WE HAVE ACHIEVED

It was recognised that children with additional support needs, particularly those with Autistic Spectrum Disorders have difficulty with changes and transitions in their lives. Perth and Kinross created the Transitions in the Community project in 2012, including three areas; Building Family Support (including Woodlea and Child Health team), Transitions Team and Enhanced Educational Provision who deliver a number of different services, interventions and activities.

To keep children and adults in their own homes wherever possible.

Children, young people and adults are 'included' and benefit from a personalised approach to meeting need in line with 'Getting it Right for Every Child' and the personalisation agenda.

Services are more sustainable and cost effective.

A range of learning, achievement and employment opportunities is made available and accessible to children and adult service users; Parental confidence is increased.

**The Building Family Support** service area incorporates a number of diverse services, many of which have been achieved through a reorganisation of services based at or delivered through Woodlea Cottage. This includes residential short breaks (respite care), various forms of family support, outreach work, and support for the acquisition of independent living skills.

# 4

**The Transitions Team** has been established to support young people and their families to be active participants in changes in their lives; this includes transitions into adulthood. The Transitions Team is managed through Housing and Community Care and includes workers from a range of different backgrounds. The aim of the team is to allow young people to experience smooth transitions and to provide them with support to achieve their ambitions and enjoy success. For some, this may eventually include training, further education, employment and independent living. Team members consider that to achieve these aims it is necessary to ensure that major shifts take place in service and community cultures. As well as mainstream local services and activities, the Transitions Team help to link families into initiatives which support the transitions process in practical ways:

**The Independent Living Skills Programme** has been developed in partnership with Woodlea Cottage and the Transitions Team. Eight students attend Woodlea Cottage at weekends to develop a range of skills such as cooking, shopping, planning meals etc. This service provides an example of Child Care and Adult Care services working together

**The Child Health Team and the Woodlea Outreach Team** worked together to develop child-centred programmes of individually tailored support for children and young people with complex needs and their families. By pooling resources and expertise, and working differently, they were able to develop programmes that did not create dependencies on the service, but altered expectations and ambitions, and developed children and family's confidence, skills and abilities to manage the challenges of daily life. The staff works in partnership with parents within the family home to address issues such as sleep, routine and eating which were often challenging in the home environment. The staff brought their skills and experience and intimate knowledge of the child and worked alongside parents to develop consistent approaches at home, school and respite. The number of children and young people receiving a service has been expanded and referrals from other agencies have increased. The team has shared the good practice of Intensive Family Support with delegations from other local authorities, head teacher groups, and external organisations.

**The Independent Travel Trainer** is part of the Transitions Team and works with primary and secondary schools to ensure that children and young people can learn and develop skills such as the use of public transport which will help promote independence. Apart from the confidence and self-esteem which this gives young people and their families, travelling independently also reduces the cost to the Council in respect of taxi fares and similar transport fees.

**Day Opportunities:** Over time, Perth and Kinross Council has tended to move away from centres for adults with learning disabilities. There are, however, three Day Opportunity Programmes within the area and a 'Joining-In Group' has been developed which provides a resource for some people who previously attended Day Opportunities but who no longer need such a service. At present, the Joining-In Group is supported by two staff from a Day Opportunity programme but it is hoped that this model can gradually be rolled out to other areas and become less reliant on the input of professionals.

**Further Education:** Dundee and Angus College state they are fully committed to providing high quality provision and services for students with additional support needs including physical and mental health difficulties, sensory impairment, physical and learning disabilities, and Autism.

# 4

Perth College (University of the Highlands and Islands) provide relevant courses and support for young people and work closely with the Transitions Team to identify opportunities and facilitate successful transitions. There are well established systems in place to successfully support students with a variety of personal and learning needs. They have experience of working with individuals affected by a wide range of health conditions, learning difficulties and disabilities including, Dyslexia, Autistic spectrum disorders, Visual impairments, Hearing impairments, Mobility or dexterity difficulties, Health or medical conditions, Unseen disabilities such as epilepsy and General learning difficulties.

## AUTISM DEVELOPMENT FUND

Perth & Kinross council recently secured funding from the Scottish Government Autism Development Fund to develop two projects the first of which is our **ASC Work Experience Coordinator post** which has been created to improve access to appropriate transition from senior school age to adult life, by providing work experience opportunities for those with an ASC in 4/5th year of all ten secondary school within Perth & Kinross. We provide work experience placements throughout the school year within Perth & Kinross council and these placements are supported by Perth Autism Support. This project is jointly run by Perth & Kinross, Education and Children's Services, Housing and Community Care and Perth Autism Support. We have existing strong links and will further build on this relationship, thus enhancing the opportunities available to young people with an ASC through Perth & Kinross. Perth Autism Support has evidenced clearly their capacity to support those on the autism spectrum and have existing relationships with the young people we will be engaging.

This project aims to:

Improve transition from school and into employment for those with an ASC.

Provide people with an ASC an employment opportunity allowing them to use their skills and to make a valuable contribution in the workplace. Allow those with an ASC to be an active and valued part of society affording significant psychological and social benefits.

Have a positive impact on the lives of people who have little or no experience in the workplace and to help them achieve their highest potential, as they interact with colleagues and grow to become more confident and competent in their abilities.

Acquire extended work experience, employment opportunities via the associated modern apprentice programme or by moving on to secure full-time jobs elsewhere.

**PAS:** - will tailor the support needed for each individual, ranging from one to one high intensity support to, independent travelling to, training and assisting PKC employees in understanding autism and how to get the most out of each student on placement.

We will ensure we job match specifically to the skillset of these individuals.

We will ensure our HR team are autism confident by providing bespoke training designed by Perth Autism Support and our Autism coordinator.

*"In creating sources of pride and a meaningful life, one of the biggest challenges will be to create job opportunities for autistic people. I am convinced that every autistic person can contribute to society and that this feeling of contributing is one of the main sources of wellbeing".*  
Peter Vermeulan (2016).

# 4

**Ease the Move Project:** Perth and Kinross Housing and Community Care staff are working jointly with Perth Autism Support to deliver this highly specialised and focussed provision, we receive additional support from the local school specialist provision, where many of these individuals would have been educated and supported in the secondary school years.

Ease the Move is based in an existing small day service in Blairgowrie; we were keen to target this area as our statistics currently indicate a larger proportion of young people with autism living in the North locality. Ease the Move has funding for two to three years and is aimed at young adults 16-25 in line with the Principles of Good Transition guidance, 10 places, with two reserved places for those who are currently inappropriately placed or out of area.

We provide a tailored day service which is completely autism specific in nature, highly structured and person centred, our service will examine closely the impact of Autism Spectrum Condition's (ASC's) upon the individual and devise strategies with them and their families that address issues they may have with for example emotional regulation, sensory issues, low self-esteem, depression, anxiety or distressed behaviour.

Individuals will benefit from a completely person centred approach, people can spend time in the centre if need be but also make use of local community activities and projects. Access to the service is through a management referral team who will be made up of education, social care and third sector staff (with an autism understanding/knowledge base) who will decide the suitability of each individual being referred. This ensures the needs of those already in the service is taken into account and that we do not disrupt or damage any of the existing good work already in place, but also to ensure the staff skill in place is sufficient to meet an individual's needs. We acknowledge that transition is a process that evolves over several years and therefore this project is looking at spending 1 – 2 years with individuals easing the move between children's and adult services. We aim to enable these individuals to go on to further education, independent living or supported employment opportunities, other more mainstream services or simply to lead happier more fulfilled lives.

Interventions that help to build resilience, or address mental health symptoms are also potentially very important. In addition, of course, changing the mind-set of employers could make a huge difference to the chances of autistic people getting and keeping meaningful employment. Housing and Community Care have created a bespoke **ASC Modern Apprenticeship scheme**, where young people with an ASC can access Modern Apprenticeship placements within PKC, but with support from our local third sector autism organisations Perth Autism Support and Autism Initiatives or our Autism Coordinator. They can have their hours adjusted to suit their needs, teams working with the young person will receive training and support and if a young person isn't quite ready for work we have linked in with a company called IDTC, who are funded by Skills Development Scotland and provide work readiness skills.

**AUTISM INITIATIVES:** - works in partnership with secondary schools, Perth Autism Support and Youth Services to ensure young people receive the correct support at time of transition from school. The service works with Higher Education facilities, mainly Perth and Dundee Colleges and supports individuals to access funding and financial support via the Student Awards Agency for Scotland and to access educational support the college's student support services and Disabled Students Allowance.

Number 3 works closely with Job Centre Plus, other local employment support providers (Check In/Giraffe, the Shaw Trust, Capability Scotland, Barnardo's) and with PKC Modern Apprenticeship scheme. For those who require additional support when they reach adulthood, Number 3 supports individuals to contact PKC's Community Care Access Team. Ensure individuals and families have a full understanding of SDS. Liaise with service providers. Provide a support & advocacy role at meetings then provide ongoing support to individuals, family and service provider once support package is arranged.

# 4

## WHAT WE WILL DO NEXT

Over the course of our lives, each of us will make many transitions, some of which go smoothly and some of which do not. They could include starting school for the first time or moving between schools, starting and leaving university, beginning our first job, losing a job unexpectedly, moving house, becoming a parent, coping with the death of someone close to us, or suddenly discovering that we have a serious illness.

*“Transitions of this kind can be stressful for anyone, but particularly so for an autistic person who seeks sameness, this may not be recognised by others or responded to adequately. Recognition and response may be even less likely if the professionals seen by an autistic person in the health, social care, education or housing sectors are themselves changing all the time”. (National Autism Project 2017)*

Some transitions in life are predictable and we should be able to plan effectively for these, apply autism thinking to the situation, be flexible in our approach, and be cognisant of the stress that any such transitions can cause autistic people, parents and other carers.

We aim to get better at providing the information required to help families prepare, fundamental to anyone with autism is how their transition from education to adult services is handled; the risks associated with an inadequate transition are high. The risks vary dependent on where on the spectrum the young person sits but if they are seen as having a high functioning condition, their needs are often not recognised and support is insufficient, leading to mental health issues, unemployment and dependence on their families. Those seen as having a more complex condition are often placed in services that are unable to cope with this complexity and therefore suffer situations that cause great stress and worsen their Autism often ending up in secure environments which are not designed to meet the needs of those with ASC.

Within Perth & Kinross we have paid a substantial amount of attention to these issues and invested in this area of provision, we will continue to do so in the coming years, we believe that a combination of early intervention a good quality transition will radically alter the experience many with autism experience, and as a consequence reduce the strain and stress felt by families.

## HOW DO WE MEASURE SUCCESS

Assessing success should take into account the perspectives of different stakeholders, seeking to achieve whatever is considered to be the right balance between the competing interests and commitments of autistic people, family members and other carers, public sector commissioners and wider society.

We have acknowledged that there is a need to move beyond ‘simply’ improving what might be considered ‘clinical’ outcomes, such as social interaction, communication skills and behaviours, these are important for many autistic people but don’t necessarily equate to happier lives.

We are aiming to improve outcomes for autistic individuals and the families/carers, not by making them less autistic but by understanding the unique presentation of their condition and what adaptations we can make to improve that individuals ability to be part of the community workplace and education system

*“Not less autistic, but autistically happy”*

Autisme Centraal

# 4

## CONSULTATION FEEDBACK IN RESPONSE TO OUTCOME 4:

*"I think that a lot of people with autism are missed and are not diagnosed properly and find these transitions harder than others".*

*"Greater opportunities for young people to undertake extended work experience placements whilst at school that extend beyond leaving school to support transition"..*

*"Recognising that people with Autism are capable of much more meaningful and range of employment with support".*

*"We have had no support with transition so far and don't know how to access help".*

*"I am researching what PAS in my local area can provide for my son now he has become a teenager as now he has moved into secondary I need to think about a career for him and how he can be supported in that. Again I would prefer to have the opportunity to have that information offered to me at the right time".*

*"Important that employers offer equal opportunities for everyone".*

*"Education and more awareness to as many people as possible. Understanding how to help and make them to feel included even though it can be extremely hard to interact and bring them out of their shells".*

*"Helped my son understand life from a different perspective, supported him with leaving school and into work, support to get PIP payments and free bus pass, entertainment/leisure, somewhere to go for advice...the list goes on"*