

Strategic Delivery Plan

Autism and Learning Disability

Perth & Kinross Health & Social Care Partnership

2022-2025



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INTRODUCTION

Autism is a developmental disorder of variable severity that is characterised by difficulty in social interaction and communication and by restricted or repetitive patterns of thought and behaviour.

Learning disability is a reduced intellectual ability and difficulty with everyday activities. People with a learning disability may take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.

Some people have autism and a learning disability. Both are lifelong conditions.

National context

For nearly three decades the strategic direction for health and social care in Scotland has been to support people with autism and/or a learning disability to remain in their own homes rather than institutional care. More recently, greater emphasis has been placed on increasing choice in the types of support available and supporting the individual to have more control.

The Scottish Strategy for Autism 2018-21, The Keys To Life Strategy 2019-21 and The Coming Home Report have general themes which are reflected throughout policy and legislation which is focused on promoting and protecting people's rights to enable them to live healthy, productive lives. This is underpinned by living independently; fair access to support and treatment at the right time, having access to education and employment opportunities and being able to actively participate in communities.

There are some known health inequality issues associated with people who have a learning disability which we must acknowledge and plan to address. People with learning disabilities have a different pattern of health and shorter life expectancy than the general population. People with learning disabilities also experience high levels of multi-morbidity (two or more physical and/or mental health conditions in addition to a learning disability) which is related to poor clinical outcomes including lower quality of life, increased prevalence of long-term conditions and physical disability. People with learning disabilities also face barriers in accessing health services. Increasing access to high quality health care services is vital to reducing health inequalities for people with learning disabilities.

Local context

In Perth and Kinross, our ambition is to enable people with autism and/or a learning disability to have the same life chances as the general population, live as independently and healthily as possible with as high a quality of life as possible and reduce reliance on acute health services and institutional care.

Historically, services have often failed to be available early enough to provide the right support to maximise the person's independence. They were often inflexible and not designed to meet the individual's needs. For people with more complex needs services have frequently failed to identify and address underlying causes of behavioural issues and, instead, provided large amounts of social care to try and 'manage' behaviours. This often did not support the person to achieve their desired outcomes and did not provide best value financially.

Over the past decade there has been significant progress in implementing personalised support for people with autism and/or a learning disability through developments such as Self Directed Support and Day Opportunities. There has been an increase in the number of people with autism and/or a learning disability living in a community setting and a reduction in the number living in a care home. However, further work is required, especially for people with complex needs. To address this the Complex Care Transformation Programme was initiated along with ongoing action plans to support the local implementation of the national autism and learning disability strategies.

BACKGROUND

Life expectancy for people with a learning disability has increased in recent years, although it should be noted it is still 14 years shorter than the general population. There has also been an increase in numbers of children born with a Profound and Multiple Learning Disability (PMLD) surviving into adulthood. Both of these developments are to be welcomed. However, together with increasing numbers of people being diagnosed with autism (probably due to improved access to diagnosis rather than increased prevalence) and older parents no longer able to care for their adult children, there is increased pressure on services.

Year	Number of LD clients P and K
2010	685
2020	1,010

Year	Ratio Children Diagnosed with Autism in UK
2000	1 in 150
2021	1 in 57

There are currently over 250 people with complex needs being supported in Perth and Kinross. The total annual cost is £23,579,60. The most expensive individual package of care is £331,189 per year.

Every year over £1million needs to be added to existing budgets to meet increasing demand for care packages. The main reasons for this are:

- young people transitioning to adulthood
- increases in existing packages due to carer breakdown or a deterioration in the person's condition.

Approximately 100 young people with autism and/or a learning disability are supported each year to move into adulthood. Roughly one in five of these young people has complex needs. The number of young people with complex needs is increasing significantly year on year. In 2012 ten young people with complex needs required support to transition and in 2021 this number had risen to twenty four.

In Perth and Kinross there is a specialist Learning Disability Health Team which provides support with diagnosis, specialist health interventions, Positive Behavioural Support and independent living skills. There is no specialist Social Work support for people with a learning disability.

There is currently no specialist, statutory service for people with autism based in Perth and Kinross. There is a specialist team which has a Tayside wide remit but resources are limited and there are often long waiting times to access support from it.

STRATEGIC PRIORITIES

In order to meet increasing demand, provide high quality, effective support for people with autism and/or a learning disability and meet the objectives in the Strategic Commissioning Plan (2020-25), Perth and Kinross HSCP will work with clients, carers, partner organisations and other key stakeholders to:

- Support people to live independently in the community
- Ensure people have equal access to all aspects of society
- Ensure people have access to high quality, personalised support when they require it
- Transform support for people with autism and/or a learning disability who have complex needs.

PROGRESS TO DATE:

Actions to support people with autism and/or a learning disability have been delivered through The Keys to Life and Autism Strategy Groups.

Keys to Life Strategy

The local Keys to Life Strategy for people with a learning disability has seven priority themes:

- Ensure a greater voice for people with learning disabilities in society
- Provide accessible information and early intervention and support to reduce barriers to employment and address health inequalities
- All people with a learning disability have the right to live as independently as possible in their community with personalised support
- Support people with learning disabilities to participate in their communities
- People with learning disabilities are central to, and involved in, their life plans
- Provide access to a greater range of quality 'short breaks'
- Transformation of support got people with complex care needs.

A Charter of Involvement is being developed to ensure people with a learning disability are fully involved in service developments.

Information relating to learning disability, including how to access services and supports, is available in Easy Read versions. A number of HSCP staff have been trained in Easy Read so all relevant documents, leaflets etc can be translated and made accessible.

A number of Small Group Living Units for people with a learning disability are available across Perth and Kinross which enable them to live in their own community as independently as possible. Personalised packages of care using all of the Self Directed Support options can be accessed by people with a learning disability to maintain their own tenancies, access employment, Further Education and leisure facilities in their local area. Day opportunities also provide the opportunity to access a range of learning and leisure activities either buildings based, in the community or virtually.

Actions to improve access for people with a learning disability to health services have been taken along with development of bespoke services such as a specialist clinic for people with Downs Syndrome and LD Liaison Nurses who support people with a learning disability when they are in hospital.

A range of support is also available for people who care for someone with a learning disability including outreach, respite, alternative therapies and peer supports.

Autism Strategy

The Autism Strategy has six priority areas:

- Strategic Leadership
- Achieving Best Value
- Collaboration and involvement in decision making
- Cross agency working through stronger networks
- High quality diagnosis, intervention and support
- Wider opportunities

A range of services and supports are available across Perth and Kinross to support people with autism and their carers similar to those listed above for people with a learning disability.

There are specialist services from people with autism in Perth and Kinross run by Third Sector organisations including a 'One Stop Shop' in Perth that provides help finding employment, accommodation, leisure activities and coping with a diagnosis in adulthood, specialist supported accommodation for people with autism in Bridge of Earn, autism specialist carers and support for children with autism and their families.

Impact

These developments listed above have helped people with autism and/or a learning disability lead more independent lives. For example, in Perth and Kinross:

- Over the past ten years there has been an 83% reduction in the number of people with autism and/or a learning disability in residential care
- over the past ten years there has been a 10% increase in the number of people living in supported accommodation
- there has been a 21% increase in people with autism and/or a learning disability accessing packages of care through Option 1 since the implementation of SDS in 2014.

NEXT STEPS:

Over the next three years the Autism and Keys to Life strategy groups will continue improve services and supports for people with autism and/or a learning disability. As stated above, a key area for development is improving support for people with autism and/or a learning disability who have complex needs. To address this the Complex Care Transformation Programme has been initiated.

Complex Care Transformation Programme

This transformation programme aims to develop a sustainable model of care that provides high quality support for people with autism and/or a learning disability who have complex needs.

The Complex Care Programme aims to put in place the services and supports that will allow for earlier intervention to maximise people's independence and address underlying causes of behavioural issues and in doing so reduce the need for more intensive, expensive, and sometimes intrusive interventions. This seeks to improve individual's outcomes and deliver best value.

The Programme has six workstreams

Workstream 1 SCOPE - formation of an integrated, multidisciplinary team, called SCOPE, to support people who have autism and/or a learning disability and complex needs. The team will consist of a range of professions including Psychology, Social Work, Occupational Therapy, Physiotherapy, SALT (provision to be provided through the wider Tayside service, linking into SCOPE) Community Learning Disability Nurses and Support Workers. The team will work closely with all relevant professionals and organisations in the statutory and independent sectors.

Workstream 2 - Overnight Responder Service: There are currently over 100 people receiving overnight support in Perth and Kinross. Much of this support is provided on a 1-1 basis and creates a 'false environment' where a person has a paid carer in their accommodation while they are sleeping. To enable people to be more independent a TEC/Overnight Responder Service is being developed.

Workstream 3- Day Opportunities, Respite: Day Opportunities are being reviewed to ensure they are appropriate for people with complex needs. This will include reviewing the current levels of 1-1 support for people attending Day Opportunities. The review will ensure that an ethos of lifelong learning is embedded in Day Opportunities. This work is supported by Perth and Kinross involvement in the iHub Collaboration. Respite provision is also being reviewed and consultation has been undertaken with clients and carers.

Workstream 4 - Transitions: Transitions processes for young people moving into adulthood are being reviewed and improved to support young people. family members/carers and professionals. This work is supported by The Principles in Practice, Good Transitions 3, developed by Scottish Transition Forum. Perth and Kinross is part of the pilot.

Workstream 5 - Positive Behavioural Support: PBS helps identify underlying causes of behavioural issues and ways to address them without resorting to physical restraint and overuse of social care. PBS is available in Perth and Kinross but resources are finite and there can be issues accessing it at the appropriate time. Work has commenced with CALM, who provide training and support to organisations to enable delivery of PBS.

Workstream 6 - Core and Cluster Models: Core and cluster accommodation has been identified as the preferred option by most people with autism and/or a learning disability in a recent consultation. Eight Core and Cluster projects have been identified across Perth and Kinross offering different levels of support. It is anticipated the first will be ready for occupancy December 2021 with further projects coming on line in 2022.

FINANCIAL FRAMEWORK

REVENUE

We have developed below a Financial Framework for the PKHSCP Autism/Learning Disability Services to support the development of an affordable Strategic Delivery Plan. This sets out the current recurring budget for dedicated Autism/Learning Disability services and supports delivered by PKHSCP, the future proposed investment and the funding available to support this investment.

Overall, a budget of £25,233m currently supports services across Perth & Kinross. The recurring budget does not include the services delivered in an Inpatient setting which are not within the scope of the strategy.

Current Recurring Budget 2021/22

Service	Funded From	Recurring Budget £000
Learning Development	Health Core Budget	889
Complex Care	Health Core Budget	999
Supported Living/Placements/Respite/Learning & Development	Social Care Core Budget	23,345
	Total Current Budget	25,233

The investment requirements to meet demand anticipated within the next 3 years and deliver on wider strategy objectives are set out below along with the significant planned from transformation.

	2022/23 Year 1	2023/24 Year 2	2024/25 Year 3	Total
Social Care	£'000	£'000	£'000	£'000
Investment				
Learning Disability/Autism Transitions	567	611	566	1,744
Learning Disability/Autism Increased Demand	576	400	400	1,376
Transformation Investment	411	75	-	486
Total Social Care Investment	1,554	1,086	966	3,606
Disinvestment				
Transformation of Complex Care	(439)	(405)	(405)	(1,249)
Total Social Care Disinvestment	(439)	(405)	(405)	(1,249)
Sub-Total Social Care Shortfall	1,115	681	561	2,357
Health				
Investment				
Legacy Deficit	475	-	-	475
Learning Disabilities Increased Demand	52	52	52	156
Total Health Investment	527	52	52	631
Sub-Total Health Shortfall / (Surplus)	527	52	52	631
Sub-Total Shortfall Health & Social Care	1,642	733	613	2,988

The Strategic Delivery Plan sections above set out the demand anticipated over the next 3 years from both transitions and the general adult population in Perth & Kinross. For health services, this includes a legacy deficit of £0.475m. The 3 year Financial Plan, approved by the IJB, for 2019/20 to 2021/22 detailed savings of £1.1m from the Complex Care Transformation Programme. As of September 2021, £0.6m of this saving has been achieved, with the remainder expected to be achieved in 2022/23. In addition, the programme described in this plan expects a further £1.249m to be achieved by 2025/26.

There is currently a total shortfall of over £2.9 million over the three years. The 2022/23 Draft Budget to be considered by the IJB in March 2022, proposes that higher than anticipated Scottish Government funding for Integration for 2022/23 be used to meet the shortfall in Year 1. However the need for net investment in Autism/Learning Disability services in future years is a key discussion with NHS Tayside and Perth & Kinross Council. Over the last 5 years significant savings have been delivered by PKHSCP across Autism/Learning Disabilities Services with further savings planned. However, the extent of demand means additional investment is likely.

As well as improving the quality of care and support available and delivering a significant reduction in spend on social care this Programme will enable the discharge of long stay patients within Inpatient learning Disabilities Services and people currently placed out of area due to lack of suitable services to return to Perth and Kinross. The wider development of a Tayside Financial Framework for Mental Health and Learning Disability should expect to set out a shift in the balance of resources from inpatient services to support community costs.

PERFORMANCE FRAMEWORK

The strategic delivery plan sets out our approach to improving the lives of our clients. To provide the necessary assurance that our actions are making the impact so desired we have developed a strategic, outcomes focussed, performance management framework. This framework considers the key outcome deliverables from the SDP and links them directly to Key Performance Indicators which are themselves linked to the overall National Health and Wellbeing Outcomes.

The table below demonstrates how we will measure our progress towards the outcomes we seek to deliver. It is our intention that these performance measures will be used, along with supporting narrative and wider contextual information, to provide the necessary assurance that appropriate progress is being made. Where this isn't the case, or isn't possible, we will set-out what further actions we seek to take.

NATIONAL HEALTH and WELLBEING OUTCOMES

		NATIONAL HEALTH and WELLBEING OUTCOMES								
STRATEGIC OUTCOMES	KPI's	1	2	3	4	5	6	7	8	9
To Support People to remain at home or in a homely setting	1) % of service users supported at home who agree that they are able to maximise their health, indepenence and maintain their quality of life. 2) Reduction in occupied bed days (Long stay) 3) Reduction in Out of Area Placements		0							
2. Reduce the over reliance on Social Care	Overall reduction in the average cost of care per patient package	0	0							0
Service users have access to support by appropriately trained workforce.	1) % of staff who have completed mandatory training. 2) % of staff trained in positive behavioural support.								0	
Ensure people can live well in their communities and have access to accommodation which is suitable for their needs and where they are supported to live as independently as possible.	1) % of people who agree they live in suitable accommodation at home and within their community. Being able to live as independently as possible. 2) % of people who agree that their Health and Social Care support helped to maintain their quality of life. 3) Reduction in OOA placements for service users who wish to remain in P&K.		0		0	0				
Ensure people are able to participate in their communities.	Increase in the percentage of service users who access "Day Opportunities" & "Fun Network" Services				0					
 Individuals will have greater opportunities to be involved and participate in decisions that affect their lives. 	% of service users who agree they had a say in how their Health or Social Care support was provided			0		0				
7. Improve access to quality and meaningful employment opportunities.	% increase for clients / service users in employment % of service users in further education				0	0				

CAPITAL

The Strategic Delivery Plan sets out the intention for Core and cluster developments to be built across Perth and Kinross to provide accommodation and care for people with a range of needs including people with complex support requirements. The developments will vary in size with a number of units for clients and one unit for staff. This will enable people to have their own tenancies and receive appropriate support. It will create a less artificial environment than current 1-1 support provided in individual tenancies and reduce costs due to economies of scale. In addition to the above, the use of TEC will be optimised to reduce the reliance on social care. Digital TEC solutions have been developed and will be integrated into all the Core and Cluster developments.

Capital Investment will be required to deliver on strategic objectives. A Strategic Outline Case for essential capital investment in a flagship Core and Cluster model has been assessed and approved by the PKC Strategic Investment Board (SIIB). This will be further assessed by the SIIB Sub-Group before final approval is sought at the PKC Strategic Policies & Resources Committee (SP&R).