

# **Growing Older Planning Ahead – For Adults with a Learning Disability**

Healthwatch Stockton-on-Tees  
October 2023

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# About Healthwatch Stockton-on-Tees

Healthwatch Stockton-on-Tees is the health and care champion for people who live and work in Stockton-on-Tees. As an independent statutory body, we have the power to make sure NHS leaders and other decision makers listen to people's feedback to improve standards of care.

We use feedback to better understand the challenges facing the NHS and other care providers locally, to make sure people's experiences improve health and care services for everyone.

We are here to listen to the issues that really matter to our local communities and to hear about people's experiences of using health and social care services.

We are entirely independent and impartial, and any information shared with us is confidential.

The Tees Valley Healthwatch Network is a collaboration of five autonomous Healthwatch who, when circumstances require it, work together to support, and promote the experiences of users of health and care services in the Tees Valley. It comprises the following Healthwatch:

Darlington

Hartlepool

Middlesbrough

Redcar and Cleveland

Stockton-on-Tees

# Executive summary

Tees Valley Healthwatch Network worked in partnership with North East Commissioning Support on behalf of the North East and North Cumbria Integrated Care Board (NENC ICB).

Our aim is to deliver a local review in response to the national requirement to improve planning process when families can no longer support their family member to stay at home.

The particular focus of this project is to improve support for family, carers, and older people with learning disability (aged 40+ to reflect the early onset of chronic health conditions such as dementia) by producing effective recommendations.

Our engagement took place from June 2023 until October 2023. The promotion of our work was supported by a wide range of partners, including Stockton-on-Tees Borough Council and the VCSE sector.

To ensure this research was accessible we used various methods of engagement to gather feedback including surveys, one to ones, focus groups and meetings with professionals and service users.

We spoke with Carers, Service Users, and Professionals to determine what their main concerns are when planning for the future, to inform how services can be improved, ensure a joined-up multi agency approach and ensure a person-centred approach in the decision-making and planning process.

We were given the opportunity to speak with residents at Accent Group – Argyl House Residential Provision, to get an insight into what residents' feel is a good provision, which enables them to live independently, while feeling safe and supported in a community they feel part of.

We found this topic to be particularly difficult for Carers and Service Users who had little awareness what services could be available in the future if circumstances changed, and additional support was needed. The happiness, safety and security of the service user was a clear priority, along with choice and control.

All the feedback gathered has supported the recommendations for the local area, this included residential provision to be available in the locality, clear communication and concise transition plans, together with a better understanding of what support could

be available to help with planning for the future. All information contained within this report will be embedded in an overarching report that will inform the future delivery of services across the Tees Valley.

# Introduction

Tees Valley Healthwatch Network worked in partnership with North East Commissioning Support on behalf of the North East and North Cumbria Integrated Care Board (NENC ICB).

Our aim is to deliver a local review in response to the national requirement to improve planning process when families can no longer support their family member to stay at home.

This is important because without adequate planning and preparation, when families can no longer support their family member to stay at home, there could be an increase in crisis placements. There is limited information available regarding experiences of family carers who are anxious and afraid about the future for their son or daughter and how this will affect a person with a learning disability.

There is little research regarding the lives of older people with learning disabilities, such as health issues, the illness or death of a family member and how this can affect a person with a learning disability and impact on their behaviour.

The particular focus of this project is to improve support for family, carers, and older people with learning disability (aged 40+ to reflect the early onset of chronic health conditions such as dementia) by producing effective recommendations.

This report focuses on the key societal challenges of:

- meeting the needs of people (and their carers) with learning disabilities **aged 40 and over** with increasing life expectancy.
- transition planning for people with learning disabilities as their carers age.
- the health and social care system's response to ageing carer breakdown / crisis arrangements.
- service planning to ensure sufficiency and adequacy of provision to meet complex needs.
- support and guidance for ageing carers.
- effective navigation of appropriate pathways for the cohort of older people with learning disabilities.
- assessment of risk of social isolation and loneliness for older people with learning disabilities.
- identification of inequities in the mental health and physical needs of this cohort.

# Methodology

Healthwatch Stockton-on-Tees used the Public Health Learning Disability Profiles for the area and worked with Stockton-on-Tees Local Authority to help identify current support services accessed by people with a Learning Disability, their families, carers and professionals. This formed the basis for mapping services in the area and informed plans to engage with professionals, carers and people with a learning disability to understand gaps in support and services.

At the time of this work being undertaken the number of adults (18+ years) with a learning disability receiving long-term support from Stockton-on-Tees Local Authority was 540 [Learning disabilities \(teesjsna.org.uk\)](https://teesjsna.org.uk).

Working together with the five participating Healthwatch teams in the Tees Valley Healthwatch Network and with the North East Commissioning Support team, we agreed a standard set of survey questions. Our questions sought to discover:

- How people feel they are currently involved in the planning of their own future care needs as they grow older.
- If carers feel able to discuss how their relative will be supported when they are no longer able to care for them.
- How carers want to be involved in planning for when they can no longer provide care for a relative, when it should start and carers expectations of health and social care services.
- A baseline of local people's current knowledge of these services.
- What good looks and feels like.

Our engagement took place from June 2023 until October 2023. To ensure this research was accessible we used various methods of engagement to gather feedback. Our mechanisms for gathering feedback comprised of:

- SmartSurvey – three surveys were developed to gain the different perspectives of service users, families and carers, and professionals. This was promoted throughout our networks, via our website, featured in our newsletters and ebulletins and shared widely with colleagues and partners with direct links to this service user group. This was to ensure that we could generate as much participation as possible for those who may not be able to attend in person or reached by usual engagement methods.
- We conducted Interviews to support information gathering with professionals.

- We attended day services within Stockton-on-Tees to provide face to face Interviews with carers.
- We provided face to face Interviews to support meaningful intelligence gathering from people with learning disabilities.
- We attended groups and service provision to carry out focus groups and gather additional case study information.

The number of people we were able to reach with the use of social media was:

- Newsletter – 890
- Facebook – 1,435
- Twitter- 1,146
- Direct engagement through our website – 90

The partners who supported the promotion of this workplan item are:

- Catalyst (VCSE)
- Stockton-on-Tees Borough Council Adult Learning Disability Service
- Pharmacy Express Eaglescliffe
- Stockton Adult Carers Support Service
- Tees Healthy Living Pharmacy
- Stockton Social Prescribing Link Workers
- Woodbridge PPG
- Cohen Court, Norton
- Billingham Environmental Link Programme (BELP)
- SBC Learning Disability and Mental Health manager
- Saint John of God (SJOG) - Head of Operations Complex Care
- Fairer Stockton
- Creative Village
- Department of Work Pensions (DWP) Stockton-on-Tees Locality
- Public Health Stockton-on-Tees
- Adult Social Care Stockton-on-Tees

Through focus groups and meetings with individuals and organisations we were able to engage with 205 people who were able to provide valuable information and help to promote this work plan item. These included.

- Carers Group Stockton-on-Tees Borough Council
- STEPS



- Project Choice
- TEWV Adult Learning & Disability Service
- NHS North Tees & Hartlepool Foundation Trust
- Groundwork North East
- Community Based Options – Billingham, Thornaby & Ragworth
- Starfish Health and Wellbeing
- Accent Group – Argyl House Residential Provision

In total we gathered **completed** surveys from

33 Cared for individuals.

The age profiles are as follows.

17 or under - 1

18 to 20 -2

21 to 29 -2

30 to 39 – 7

40 to 49 – 6

50 to 59 – 7

60 or Older 8

12 Carers

5 Professionals

# Survey findings: Summary

## What matters most to people in Stockton-on-Tees

This engagement gave us the opportunity to have one-to-one conversations with a wide variety of people with a specific focus. We were able to speak with Carers, Service Users and Professionals to gather information that will be used to support the future development and planning of services for those with a Learning Disability.

This extensive focused collaboration with services identified the challenges facing those people with a learning disability, their carers and professionals in being able to effectively plan and support individuals with the planning of their own future care needs as they grow older.

The people we spoke with found this to be a particularly painful and difficult subject that echoed throughout our conversations, people felt unsure what to expect or how care would be delivered in the future. The theme that ran throughout all our feedback, particularly from carers was the concern of who would care for their loved one if they were no longer able to. These concerns focused around:

- Health Deterioration.
- Emotional Wellbeing – individuals being unhappy.
- Financial struggles.
- Living Independently.
- Who will take care and responsibility of their loved one when they are no longer able to.

For those living with a Learning Disability most people said they would prefer to live in sheltered or supported accommodation as opposed to living on their own, however there were five individuals who expressed that living in their own place would be a preferred option, while also having access to 24-hour care and support.

We asked people what they liked about where they currently live and what was important to them feedback gathered included:

- Having their own space and independence, allowing for privacy.
- Being able to see family and friends.
- Feeling safe, secure and supported with familiar surroundings.

- Communal activities – such as TV, pool table, dancing, wordsearch and colouring.
- Being able to access shops and days out when they wanted to.
- The ability to plan and make own meals and complete other household chores with support if needed.
- Location was very important to individuals to ensure ease of access to family, friends and local facilities such as shops, pubs and clubs.

The individual care needs of people were wide ranging with some needing support with personal hygiene and others requiring more low-level intervention. This highlights the continued need for services to ensure a person-centred approach that can be adapted easily as needed, allowing for continued care in the same location while maintaining safety and familiarity for the individual.

When asked what three things made them happy the responses were as follows:

1. Spending time out and about with family and friends, holidays, dancing and day services
2. Being able to watch TV, play music or use of a games console.
3. Going on trips to Bingo, football, shopping, bowling, cinema and keeping active
4. Doing puzzles, arts and crafts, and being able to help others in a social environment.
5. Having a routine was seen as important.

We asked individuals if they had their own place to live would they like someone to live there with you. This was a mixed response with some people saying yes, they would while others were unsure and some saying no. This highlights the need for services to be adaptable to individual requirements.

When asked if people would like to live close to where they live now, most people answered yes, highlighting that planning for future service delivery needs to be maintained within local areas, supporting familiarity and ease of access to friends and family.

Of the people we spoke to there was an equal split of those who had been spoken to about where they would be living in the future and options available to them. Consistent, clear communication needs to be embedded within the future planning

needs. Although some people felt they did not want to be included in choosing where to live, some individuals would like to be part of that process. Likewise, some of the respondents said they would like to be involved with tasks such as:

- Helping to pack and move.
- Helping to buy things for the new place.

They also expressed that they would like support to:

- Understand how to use things in the new place.
- Help to get to know their surroundings and new neighbours.
- Access a specific contact or support when needed.
- Have regular visitors.
- Take part in activities.
- Make new friends.

While carrying out this piece of engagement we used the opportunity to find out if individuals had been offered their Annual Health checks. Most people we spoke to had been offered their Annual Health check and had attended, with a few individuals feeling unsure if they had been offered their health check or attended. However, of those who had attended their Annual Health check there were some who did not know if they had a Health Action Plan in place.

For those who had attended and were aware of their Health Action Plan we asked people to list three things the Health Action Plan helps them to do.

These were:

- To keep fit and active and the importance of exercise, movement, and dance.
- To get blood tests and to have blood pressure checked.
- To eat healthy and how to prepare food and drinks safely.

We asked individuals if they wanted to tell us anything else, it was clear from the responses that the correct support was important to ensure health and wellbeing.

Gathering responses from professionals was difficult, we found that a lot of staff that we spoke to did not see themselves as professionals. We identified this early in the intelligence gathering process and amended the title of the survey to include 'Support

Worker' however, this still did not gather the feedback we were hoping to achieve. Staff did tell us they did not feel equipped to provide this feedback.

Of those who did complete the survey we were told that families were part of the process for planning for individuals and moving, with most responders reporting that they felt this was done quite well. Areas that they felt were good were:

- The sharing of information.
- Advocating on behalf of the service user – ensuring a person-centred approach.
- Supporting families to make choices to transition to a new home.

We then asked which areas needed improvement, the findings were:

- Facilities and homes that meet the needs of the clients in the local area.
- More involvement with carers early, to make transitions easier.
- More time and finances to help with the planning.

We wanted to determine the support received by older carers when they are unable to support those they care for; we were told that this forms a wide variety of support including:

- Extra care going into the home to support areas such as helping with their relative's personal care.
- Taking them into the community.
- Sitting with the person while the carer goes out and offering respite care.
- Providing reassurance from the staff team and liaising with professionals to highlight any concerns.
- Working closely with Social Services and STEPS to look at ongoing needs and make adjustments.

We asked what current services support a carer of an older person (40+) with a learning disability as they age. Professionals/Support Workers informed these were:

- Day Services
- Advocacy Services
- Social Care Respite Service
- Direct Payments
- Care Companies
- Carers Support Services provided by Stockton-on-Tees Borough Council
- STEPS

We asked if any gaps in services could be identified in current service provision for older people age (40+) with a learning disability when leaving home for the first time. We were told these were:

- Availability of housing provision.
- People not having independent living skills to cope with living alone, such as cooking and budgeting.
- Mental Health Support.
- Support with transition.

From the perspective of a professional we wanted to determine what elements of care would be included in an ideal support service for older people (40+) with a learning disability to move out of their current home. Feedback included.

- Person Centred Care – with a clear, detailed transition plan that includes what the person wants and where/how they want to live i.e., Residential, supported or independent.
- Detailed information to be passed through assessment, including discussions with social Workers, carers and the individual to ensure needs are met.
- Communication to be seen as key in explaining a person's journey, wants and needs.
- Individuals and Carers to be involved in all aspects of the decision making with regular reviews initially to ensure the new home is working effectively, maintaining regular contact with Carers.

As part of this process, we wanted to determine from the perspective of professionals how they support individuals to access their Annual Health Checks. We found that this was usually through discussions with Carers at Preadmission and at that point professionals would be able to recommend attending. However, they did not gather feedback as to whether the individual had attended and felt unable to pursue this further. Professionals were aware of Health Action Plans and told us the individual or Carer would have these.

We asked for any examples of good practice in residential, supported living and family support services that support interventions for older people with learning disabilities (and their family/carers) with behaviours that challenge others. We were told these could include:

- 'At a glance' – quick access information

- Supported living – Community Campus which would support the individual to help build a routine as well as developing better hygiene/self-care.

When asked if there was anything else they would like to tell us we were told:

*“I personally feel that people with a Learning Disability should be encouraged when they turn to a young adult to start thinking about and exploring the idea of living away from their parents/carers to promote their own independence more and I don't feel like they always get the opportunity too and then it comes to a crisis point of the parents becoming elderly and unable to look after them anymore or worse and then the process is harrowing for all involved.”*

# Argyl House Residential Provision

A view of what 'good' looks like in a residential service provision from the eyes of service users.

As well as using surveys to promote our work we took part in focus groups and one-to-one meetings to provide additional opportunities to gather feedback.

We attended a meeting held with residents and the Service Manager of Argyl House where we were able to speak with 13 residents.

The centre has 34 self-contained flats and allows independent living for residents with a large communal room and a large communal garden. A further 20 properties are on the surrounding road. Residents have a range of Learning and Physical disabilities. The needs of the service user are used in determining the accommodation that is provided and is supported by the Service Manager. The role of the Service Manager is to provide a wide range of support to help residents to live independently.

We received very positive responses from residents who wanted to make it clear that this way of living offered them independence, choice and control, while making them feel safe and supported.

Many reporting 'they wouldn't be here' if it wasn't for the service manager, telling us 'they feel she goes above and beyond to make sure they are included in making choices as the residents.'

They told us they feel cared for, listened to and more confident in trying to do things for themselves, and said that loneliness and isolation had reduced as they have the opportunity to meet and speak to someone every day.

They spoke with enthusiasm about a regular coffee mornings including a bacon bun cooked by the residents who are more able. They share this cost as it allows them to socialise with each other and to check in on those who have not attended to make sure they are ok. This provided individuals with additional reassurance that they would also be checked on if they did not attend and that people were 'looking out for them.'

People were keen to inform us of the work undertaken by the manager in setting up regular activities including a community centre lunch, arts and crafts, sing along



sessions and chair-based exercises. We were told that they feel motivation and enthusiasm and are encouraged to meet up to go out for walks.

While we were there, we asked what it was like before coming to Argyl House? We were told how people felt lonely, isolated, unable to leave the house, depressed, unable to communicate with strangers, no friends, nothing to look forward to, not eating properly, some individuals said that they didn't bother to get dressed and sat watching tv all day, neglecting themselves and their home.

We asked what had changed since coming to Argyl House? We were told they made new friends, were able to meet up every day and speak to likeminded people, that they felt listened to, and had instant help and support when needed. They liked being able to join activities and have a reason to get up and dressed, but still felt that they maintained their independence if they needed their own space. They described feeling part of something and feeling safe.

They were asked what made supported housing with Accent Housing so different, the reasons given were:

- That the Service Manager joins in and is part of it with them.
- They feel encouraged to take part even when they say 'we're not interested.'
- They said they feel motivated to give back as they always get support with their problems.
- They feel safe, reassured, and comfortable in their surroundings.
- They are supported to be independent, and there is always someone to help with problems.

# Local Authority Position Statement

Stockton Local Authority

*“Thank you for sharing this report with us. It is very positive to see how many people and services have contributed to the content. It is pleasing to see the good practice evidenced in the report. We welcome the recommendations and will take forward within our planning processes.”*

**Emma Champley**

Assistant Director, Adult Strategy and Transformation  
Stockton-on-Tees Borough Council

# Conclusion

This work has highlighted the challenges facing family, friends, carers and service users when looking to plan for future needs. This delicate and difficult conversation could feel better supported if clear transition pathways were communicated in a timely manner.

There are areas of good practice that would be beneficial to learn from for the future planning and commissioning of service delivery. People told us how important it was to be able to remain within the local area, future commissioning should ensure that provision, wherever possible remains within the locality.

Clear communication needs to be embedded within the transition process. This should form part of early discussions and continue with regular reviews to ensure that service users feel safe and happy and are able to access support while maintaining choice and control.

From the intelligence gathered professionals told us that service users may not feel prepared for the transition into supported living – it may be useful if day services could support service user in development in this area to further aid the ability of service users.

Although this work will form part of a wider Tees Valley Report, it is clear that service users want to remain within their local area. Provision, wherever possible, needs to remain within the Stockton-on-Tees area.

# Recommendations

This focused engagement work has highlighted areas that could help to improve transition pathways for those with a learning disability, carers and professionals.

Valuable feedback received has informed the following recommendations:

- **Communication** – Clear, timely and appropriate information to form part of the future planning process, this information should detail options that will be available in the future. This would support carers; service users and professionals in approaching difficult conversations confidently in a supported way, with awareness of the options available to them.

- **Introductory Visits/Open Days** – Lack of awareness of facilities was evident from the intelligence we gathered. Planned visits to established residential facilities would help to gain insight and understanding into future options, this could provide reassurance of how services could support future needs and ensure a person-centred approach. This could also give residents the opportunity to feel empowered and showcase their communities.
- **Location** – It was clear throughout our engagement that location is of great importance to individuals and their carers. The ability to access local services, stay within the locality and have regular contact with family and friends was seen as one of the most important aspects in the planning process. Most individuals said it was important for them to stay within Stockton-on-Tees.
- **Continuous Reflection and Review** – It is important that planned reviews take place to ensure that service users feel happy and safe within the environments that best caters for their individual needs. It was clear that a main concern for carers and service users when planning for the future, was that they felt happy, safe and had choice and control of their lives.
- **Clear Transition Plans** – The input from service users, carers and professionals during the transition is vital to ensure a co-ordinated approach that clearly identifies the needs and wants of the individual. This documentation needs to be consistent and easy to read to enable ongoing support is appropriate to the needs and wants of the service user.
- **Best Practice** – It was clear from our visit to Argyl House that service users felt happy and supported in this provision. There was great emphasis on the managerial style of a staff member, with an inclusive approach to building a community that encouraged participation. It would be useful to look at what works well to help inform the future planning and delivery of services.

# Response from North East and North Cumbria Integrated Care Board

*“The North East and North Cumbria ICB would like to thank Healthwatch for producing the Growing Older Planning Ahead report and everyone who took the time to provide feedback. The report gives a valuable insight into what is important to people and their carers as they plan for their future and helps highlight the journey we need to continue in partnership with those people at the heart of our work.*

*“The ICB is committed to improving lives for everyone with a learning disability and their carers and we welcome the report, with its recommendations when planning for people and their future needs. The report will help steer decision making and we will continue to reflect on the recommendations when developing plans with stakeholders. The case studies also resonate with us with continued listening, hearing people’s views and their experiences will support in our learning, to achieve better outcomes for people and their families”.*

Liz Whitehead

Commissioning Delivery Manager

County Durham and Tees Valley Mental Health and Learning Disability Partnership

## Next steps

This work will form part of a wider piece of work with the Tees Valley Healthwatch Network, in partnership with North East Commissioning Support on behalf of the North East and North Cumbria Integrated Care Board (NENC ICB).

This report will be circulated to Stockton-on-Tees Borough Council, Public Health, Healthwatch England and the Integrated Care Board to inform the future planning and delivery of services, which will help to improve support for family, carers and older people with a learning disability.

# Acknowledgements

We would like to express our thanks to all service users, carers and professionals who have helped us to gather this valuable information. We would like to thank our partners for their support in disseminating and promoting this workplan item, helping us to ensure the voice of service users influence the improved delivery of health and care services.

- Catalyst (VCSE)
- Stockton-on-Tees Borough Council Adult Learning Disability Service
- Pharmacy Express Eaglescliffe
- Stockton Adult Carers Support Service
- Tees Healthy Living Pharmacy
- Stockton Social Prescribing Link Workers
- Woodbridge PPG
- Cohen Court, Norton
- Billingham Environmental Link Programme (BELP)
- SBC Learning Disability and Mental Health manager
- Saint John of God (SJOG) - Head of Operations Complex Care
- Fairer Stockton
- Creative Village
- Department of Work Pensions (DWP) Stockton-on-Tees Locality
- Public Health Stockton-on-Tees
- Adult Social Care Stockton-on-Tees
- Carers Group Stockton Borough Council
- STEPS
- Project Choice
- TEWV Adult Learning & Disability Service
- NHS North Tees & Hartlepool Foundation Trust
- Groundwork North East
- Community Based Options - Billingham, Thornaby & Ragworth
- Starfish Health and Wellbeing
- Accent Group – Argyl House Residential Provision
-

# Appendix one: Survey questions and demographic data


A list of survey questions, responses from the surveys and demographics data can be supplied on request.

Please contact Kathryn Clapham, Healthwatch Stockton Projects Administrator at [kathryn.clapham@pcp.uk.net](mailto:kathryn.clapham@pcp.uk.net) for details.

# Appendix two:

## Public Health: Learning Disability Profiles

https://fingertips.phe.org.uk/profile/learning-disabilities/data#page/1/gid/1938132702/pat/6/ati/302/are/E06000004/iid/92127/age/217/sex/4/cat/-1/ctf/-1/yr/1/cid...

 **Office for Health Improvement & Disparities**

**Fingertips | Public health data**  
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[Home](#) > [Profile home](#) > [Data](#)
Select profile content ▼

### Learning Disability Profiles ▼

**Data view** ▼  
Area profiles

**Geography** ▼  
Stockton-on-Tees  
Counties & UAs in North East region

**Topic** ▼  
Population

[Legend](#) | [Benchmark](#) | [More options](#)

 Geography version Counties & UAs (2020/21)

CIPFA nearest neighbours to Stockton-on-Tees

Indicator	Period	Stockton		Region England			England		Highest
		Recent Trend	Count	Value	Value	Value	Lowest	Range	
Children with Moderate Learning Difficulties known to schools	2020	↓	856	26.8	33.8	29.1	7.9		67.4
Children with Severe Learning Difficulties known to schools	2020	→	192	6.0	5.2	4.0	0.7		12.5
Children with Profound & Multiple Learning Difficulty known to schools	2020	→	40	1.25	1.32	1.29	0.00		4.23
Children with Autism known to schools	2020	↑	456	14.3	19.3	18.0	5.8		34.4
Children with learning difficulties known to schools	2020	↓	1,088	34.0	40.3	34.4	11.3		75.1
Adults (18+ yrs) with learning disability receiving long-term support from local authorities (per 1,000 population)	2019/20	→	540	3.52	4.24	3.46	2.00		6.32
Learning disability: QOF prevalence (all ages)	2019/20	–	1,032	0.5%	0.7%	0.5%	0.2%		0.9%





# healthwatch

## Stockton-on-Tees

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