

Growing Older Planning Ahead

Tees Valley Healthwatch Network: Darlington, Hartlepool,
Middlesbrough, Redcar & Cleveland, Stockton-on-Tees
January 2024

Contents

Contents.....	1
About Tees Valley Healthwatch Network	2
Executive summary.....	3
Introduction.....	4
Methodology	5
Survey findings: Summary	7
Integrated Care Board Position Statement	11
Survey responses: full details	12
Conclusion	13
Recommendations	14
Response from North East and North Cumbria Integrated Care Board	15
Next steps.....	15
Acknowledgements.....	16
Appendix one: Demographics	17
Appendix two: Case study	22

About Tees Valley Healthwatch Network

Healthwatch is the health and social care champion for those who use GPs and hospitals, dentists, pharmacies, care homes or other support services. As an independent statutory body, we have the power to make sure NHS leaders and other decision makers listen to your feedback and 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 5 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

The North East and North Cumbria Integrated Care Board (NENC ICB) is the statutory NHS organisation which is responsible for developing plans for arranging for the provision of health services in a geographical area – in this instance the Tees Valley.

The purpose of this report is to provide insight to the NENC ICB, to give them a greater understanding of the needs of people with a learning disability, aged 40+, so they can improve the planning process when families can no longer support their family member to stay at home.

We asked carers, those they care for, and professionals who support them, to tell us what is important to them, and what support they need to live a happy and healthy life.

All three groups of cared for, carers and professionals agreed the best outcomes occurred when appropriately trained support staff were available to help individuals live an independent life and there was help in maintaining a good social network of friends and family, including suitable transport and good community facilities to meet people with similar interests and needs.

To help NENC ICB achieve the best outcomes, we have offered seven recommendations based on our insight, in the following areas:

1. Adhering to NICE guidelines.
2. Good communication.
3. The importance of location.
4. Timely, clear, and phased transition planning.
5. Regular person-centred reviews.
6. Building on the good practice current services offer now.
7. Focused training and support packages.

We look forward to discussing this report with representatives of the NENC ICB and individual local authorities, to ensure the voice of those who are impacted by this service continues to be listened to.

On behalf of Healthwatch Darlington, Healthwatch Hartlepool, Healthwatch Middlesbrough, Healthwatch Redcar & Cleveland and Healthwatch Stockton on Tees

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) with the aim of delivering a local review in response to the national requirement to improve the planning process when families can no longer support their family member to stay at home.

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 families, 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

Tees Valley Healthwatch Network agreed a standard set of survey questions with the North East Commissioning Support team upon which this report is based. Our questions sought to discover:

- How people felt they were currently involved in the planning of their own future care needs as they grow older.
- If carers felt able to discuss how their child would 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 child, 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.

Three surveys were created to capture data from carers, workers and the cared for person. The intention being to capture data on what is and isn't currently working with existing services, find out what individuals and carers want to see and improve services for older people.

The surveys were available on the SmartSurvey platform and email invitations were issued to local groups, professionals, Local Authority teams, and the voluntary and community sector. Each local Healthwatch used their social media platforms to regularly promote the three surveys, distributed posters with QR codes, took part in radio promotional interviews, produced videos for our target audience, and Easy Read versions of the surveys were made available.

Each local Healthwatch also took the opportunity to use diverse engagement methods including discussions with supported living services and disability groups, support to help participants complete the survey, telephone interviews, attending drop-in groups and appropriate services, and ran focus groups based on the survey but with a smaller number of questions to enhance accessibility.

This report incorporates information within the individual reports created by the Tees Valley Healthwatch Network. The individual local Healthwatch reports can be found on their websites. Links to those websites are provided later in this report: Survey responses: full details section.

Demographics

Tees Valley Healthwatch Network worked with a variety of organisations to reach a diverse range of service users to gather insight which is reflective of the Tees Valley area.

A full demographic breakdown of survey participants is available in Appendix 1.

Demographics were not taken from those who took part in focus groups and workshops.

A total of 462 people from Tees Valley communities took part in this engagement exercise.

Local Healthwatch	Cared for survey	Carers survey	Focus groups	Total
Darlington	8	25	71	104
Hartlepool	26	23	0	49
Middlesbrough	62	25	81	168
Redcar & Cleveland	35	17	24	76
Stockton on Tees	33	12	20	65
	164	102	71	462

83 professionals took part in our survey, many of them covered more than one local authority area.

The project ran from June 2023 through to October 2023.



Survey findings: Summary

What matters most to people in the Tees Valley

The findings in this section are based on responses to the survey which was co designed with the North East Commissioning Support team, either through completion of the survey or taking part in focus groups and workshops centred around the survey questions.

This engagement exercise gave us the opportunity to have one-to-one conversations with a wide variety of people including carers, service users and professionals to gather information to support the future development and planning of services for those with a Learning Disability.

This report highlights the challenges facing those groups in being able to effectively plan and support individuals with their future care needs as they grow older. Some people we spoke with found this to be a particularly painful and difficult subject; some carers were apprehensive about sharing their concerns openly and honestly in case there were implications in the short term around their ability to care for their loved one. Our engagement teams reassured each participant of the purpose and need for this work, but it is worth noting this understandable concern of carers as this work is progressed.

The themes throughout each group were consistent, as were the responses from each of the three groups: carers, cared for, and professionals. They echo the NICE quality standards which provide advice about care and support for people with learning disabilities.



'My family helps with problems where I live. They are stepping in to help me find a better place to live in the future'. Participant, Middlesbrough

The **cared for** person told us what was important to them:

- Living in a nice house in a nice quiet area, with nice neighbours.
- Being nearby family, friends, shops, with good transport links.
- Independence with the freedom to make their own choices and be listened to and understood.
- Feeling safe.

What the **cared for** person told us they needed help with:

- Administrative tasks such as filling in forms, managing their money and benefits and making 'official' phone calls for administrative reasons.

- Transport to get to and from activities or appointments.
- Household tasks such as cleaning the house, washing clothes, making food and drinks and shopping.

The **cared for** person told us that to live a healthy and happy life as they get older, they need help and support in the areas listed above as well as:

- Support to manage their health.
- Emotional support when they feel anxious about life.
- Help in maintaining a good social network of friends and family.
- Good community facilities to meet people with similar interests and needs.



“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 to, 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.” Cared for, Stockton on

Tees.

Carers told us they worried about the person they cared for, as they get older, being able to:

- Manage their health needs.
- Live independently in a safe area.
- Manage financially.
- Have appropriate social opportunities and not be lonely.
- Have suitable access to appropriate support services.
- Suitable accommodation.
- Being understood and accepted (not getting in with the ‘wrong crowd’.)

In summary, carers told us they worried about the same areas that the cared for participants told us was important to them, and where they needed support to live a happy and healthy life.

Despite their worries, not all carers knew who to speak to about their concerns. Most did want to be included in future planning to ensure professional advice was obtained and understood, and generally support their cared for person in discussions and decision making.

There was a mixed response from **carers** regarding awareness of available services to support the cared for as they got older.

The support they would like to see was:

- Financial.
- Healthcare.
- Family support service / social care.
- Day care.

Improvements **carers** would like to see were strengthening social care support, more support for carers, more financial and legal support, improved medical resources, and more diverse accommodation options.

Included in this report as 'Appendix two' is a case study from two 70 year old carers for their daughter, illustrating the importance of involvement of carers in decision making for optimal outcomes.



“Older people with a learning disability living with family are frequently forgotten about unless there are problems or concerns with their health, behaviour, home situation etc. It's usually those who are well known to social services that get all the attention. Families just get on with it without a fuss until carer breakdown happens, or death / hospitalisation of a carer / family member / parent. Then it's crisis management. Lack of appropriate accommodation. Still in the Dark

Ages in Darlington. So much more can be done.” Carer, Darlington.

There was no universal clarity within the **professional** responses around the current process for moving older people (aged 40+) with a learning disability into a new home. Some were confident they were familiar with the process, and some were not.

There was consensus amongst **professionals** that involving the person and their families/carers in the planning, joint working between services and planning ahead worked well. This supports our insight that carers want to be involved in planning care. Professionals told us that more choice of appropriate accommodation, more resources in terms of trained staff with better communication between all parties concerned in the move were areas that needed improvement. Again, this supports the themes from carers and cared for groups.

The **professionals** told us what is working well:

- Person centred support.
- Social worker involvement in the process.

- Care assessments and Multi-Disciplinary Team (MDT) meetings.
- Visits to support transition.

The **professionals** told us gaps in services were:

- Lack of trained staff.
- Lack of choice / lack of availability of suitable housing.
- Lack of understanding of needs.
- Lack of available accessible information.
- Lengthy placement process.

In an ideal support service **professionals** told us they would like to see improved communication, more trained support staff, a better process, greater choice and more peer and community support.

In summary there was consistency across the 3 surveys which reveals a clear idea of what is important to the cared for, and what they need support with to live a happy and healthy life. This supports what carers tell us are their greatest concerns for their loved ones as they get older – that this level of support and care can be maintained when they are no longer able to provide that care. We also have clarity from professionals about what they know to work well and the improvements that can be made to minimise the gaps in care.



“The process **MUST ALWAYS** be ‘Person Centred’ and continuous. This ensures a person’s ‘best interest’ is not a one-off decision but a constant process as they live and grow. Those with severe learning difficulties have no less a right to recognition of life-long learning!”
Redcar and Cleveland participant.



Integrated Care Board

Position Statement

Each of the individual Healthwatch reports include position statements from their respective local authorities outlining the commitment of each local authority to the Care Act 2014, and NICE guidelines outlined below..

National Institute for Health and Care Excellence (NICE) guidelines

The latest NICE guidelines were published in April 2018 and provide advice about care and support for people with learning disabilities as they grow older. The guidelines are for providers and practitioners of social care, commissioners with a strategic role in planning local services as well as people with learning disabilities, their carers, families, and advocates.

The guidelines outline NICE's quality standard of 5 things that services could do to make the most difference to people's care. It advises people with learning disabilities of the standards they should expect from services:

1. You are always listened to when staff check about your care needs. You should always be able to say what you need, what things you like and what you want from your life
2. You have 1 person that you can contact if you have questions or need help from different services.
3. You are supported to talk about how your life and needs may change as you get older, and to make plans for those changes.
4. You have a detailed health check up every year.
5. If you need to go into hospital, you can meet the people who will look after you before you go so you can get to know each other.

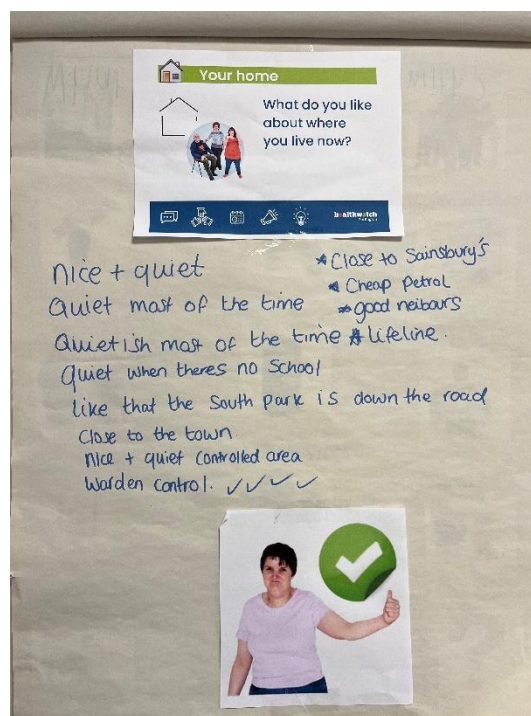
These guidelines were written with people who have learning disabilities, their families and carers, and staff who support them, and are based on the best research available.

Survey responses: full details

Details of each of the survey responses across the five local authority areas can be found on the websites of each independent local Healthwatch that constitute the Tees Valley Healthwatch Network:

Healthwatch Darlington	https://www.healthwatchdarlington.co.uk/news-and-reports
Healthwatch Hartlepool	https://www.healthwatchhartlepool.co.uk/news-and-reports
Healthwatch Middlesbrough	https://www.healthwatchmiddlesbrough.co.uk/news-and-reports
Healthwatch Redcar & Cleveland	https://www.healthwatchredcarandcleveland.co.uk/news-and-reports
Healthwatch Stockton on Tees	https://www.healthwatchstocktonontees.co.uk/news-and-reports

Note: Healthwatch Middlesborough and Healthwatch Redcar & Cleveland are sometimes referred to jointly as Healthwatch South Tees and have developed a joint South Tees report available on both of their websites.



Conclusion

We wanted to understand the issues and aspirations around the planning process when families can no longer support their family member to stay at home from three different perspectives: the cared for, the carer and the professional viewpoint.

To establish that all three experiences had considerable consistencies throughout was reinforcement of the observational and anecdotal feedback we receive. In addition, the feedback reinforced the NICE quality standards, established in 2018 for health and social care services, which are still very much relevant to the needs of those with learning disabilities.

There was a mixed response to how people felt they were currently involved in the planning of their own future care needs as they grow older. There was agreement that the process worked well when trained staff with good interpersonal and communication skills helped individuals and carers navigate the service pathways.

Some carers were apprehensive about discussing how their loved one would be supported when they are no longer able to care for them. For some it was the inevitable sadness of knowing that they would no longer be around for them, and for others it was concern over short term responses if they indicated they were struggling to care for their loved ones and needed support – that is they were concerned about them being taken into care sooner than they would want.

Notwithstanding this natural concern, carers do want to be involved in planning for when they can no longer provide care for a loved one. There was no definitive agreement to when this should start, it was considered very much dependent upon the capacity of the individual concerned.

Carers expectations and knowledge of health and social care services were mixed depending upon experience. The consensus opinion was good communication and targeted promotion of services available was needed to raise awareness.

All three groups of cared for, carers and professionals agreed 'good' looked like:

Trained support to help individuals live an independent life: To help manage health, and emotional support for when they feel anxious about life. To help with household tasks and administrative tasks such as filling in forms, making appointments and managing finances.

Social network: help in maintaining a good social network of friends and family, including suitable transport and good community facilities to meet people with similar interests and needs.

Recommendations

Our engagement has highlighted areas that could help to improve transition pathways. Valuable feedback received has informed the following recommendations:

1. **NICE guidelines:** Published in 2018 and still current, these five quality standards of care should be used as the basis of any service pathway. They resonate with the aspirations of all three groups included in our survey, requiring that those with learning disabilities be listened to, feel free to say what they need and want from life, have a dedicated contact to help with questions or provide support in interactions with services, help make plans for changes, have an annual health check, and specific support for hospital stays.
2. **Communication:** A clear service pathway, with timely and appropriately communicated information in the planning process is key to supporting carers, service users and professionals in approaching difficult conversations confidently, with awareness of the options available.
3. **Location.** The ability to stay within the locality, access local services, and have regular contact with family and friends was seen as one of the most important aspects in the planning process. Consideration must be given to ensuring local housing strategies are developed to address the shortfall in appropriate housing options for adults with learning disabilities, to maximise opportunities for supported independent living.
4. **Clear and phased transition plans.** 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. Documentation needs to be consistent and easy to read to ensure ongoing support is appropriate to the needs and wants of the service user. Conversations and preparation for independent living should not be left until a time when current living arrangements are no longer tenable, thus reducing the potential for difficult transitions which may lead to personal crisis. For example, this could include planned visits to established residential facilities to help gain insight and understanding into future options.
5. **Review.** It is important that regular person-centred planned reviews take place to ensure that service users feel happy, safe and have choice and control in their lives.
6. **Good practice.** There is current good practice which is working well for all parties. Each local Healthwatch will be happy to work with the ICB to highlight the good practice we are aware of, to help inform the future planning and delivery of services.

7. **Training and support packages:** To increase awareness and skills in areas such as budgeting, benefits, employability, food preparation and healthy living, training and support should be made widely available and promoted via social workers, care providers and health professionals. This will support key skills development and confidence building need for successful and supported transitions.

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

The insight gained from this engagement will be shared with the North East and North Cumbria Integrated Care Board, local commissioners and service providers, community and voluntary sector partners, local Health and Wellbeing Boards, and Healthwatch England 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

The Tees Valley Healthwatch Network thanks all service users, carers and professionals who have helped us to gather this valuable information, either by completing a survey or taking part in focus groups, workshops, and discussions to tell us about their experiences.

The information you have provided has been vital in helping us to ensure the voice of service users influence the improved delivery of health and care services and is greatly appreciated.

Appendix one: Demographics

Age category	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
17 or younger	1	<1%	-	-	12	12%
18 – 20 years	4	2%	2	2%	5	5%
21 – 29 years	27	16%	12	12%	20	20%
30 – 39 years	36	22%	16	16%	17	17%
40 – 49 years	27	16%	14	14%	14	14%
50-59 years	38	23%	21	21%	9	9%
60 or older	28	17%	34	33%	25	25%
Did not respond / prefer not to say	3	2%	3	3%	-	-

Gender	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
Male	79	48%	32	31%	55	54%
Female	67	41%	67	66%	44	43%
Prefer not to say	1	<1%	3	3%	1	1%
Prefer to self-describe	-	-	-	-	-	-
Did not respond	17	10%	-	-	2	2%

Are you currently...	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
Single, never married	137	84%	11	11%	65	64%
Married or domestic partnership	7	4%	69	68%	28	27%
Divorced	1	<1%	6	6%	2	2%
Separated	1	<1%	3	3%	-	-
Widowed	3	2%	8	8%	4	4%
I don't want to say	3	2%	5	5%	3	3%
I don't know	2	1%	-	-	-	-
Did not answer	10	6%	-	-	-	-

Can you tell us if you have any physical or mental health conditions? (Please tick as many as you like)	Cared for person completing the survey themselves	%	Carers who completed the survey	%	The person they care for	%
Long-term standing illness or health condition such as: cancer, HIV, diabetes, chronic heart disease / circulatory conditions, high blood pressure, respiratory conditions (asthma), epilepsy, digestive conditions (e.g., irritable bowel syndrome (IBS) and Crohn's disease)	42	25%	30	29%	37	36%
Physical impairment or mobility issue such as: difficulty using your arms or using a wheelchair or crutches	31	19%	13	13%	39	38%
Sensory loss such as: sight and hearing loss	31	19%	20	20%	23	23%
Mental health conditions or illnesses such as: anxiety, depression, and eating disorders	50	30%	22	22%	37	36%
Developmental conditions such as: Autism Spectrum Disorder (ASD), which includes Asperger syndrome, and Attention Deficit Hyperactivity Disorder (ADHD), Learning impairments e.g., dyslexia and processing issues	89	53%	5	5%	50	49%
Genetic conditions such as: Down syndrome and cystic fibrosis	31	19%	2	2%	11	11%
Prefer not to say	6	4%	3	3%	4	4%
None	0	-	32	31%	7	7%
Other	6	4%	17	17%	5	5%

Ethnic background:	Cared for person completing the survey themselves	%	Carers who completed the survey	Carer %	The person they care for	%
White						
White British	136	83%	85	83%	84	83%
Irish	-	-	-	-	1	1%
Other	-	-	-	-	-	-
Asian / Asian British						
Indian	2	1%	-	-	-	-
Pakistani	2	1%	2	2%	2	2%
Bangladeshi	-	-	-	-	-	-
Any other Asian background	-	-	1	1%	1	1%
Mixed						
White and Black Caribbean	-	-	-	-	-	-
White and Black African	-	-	-	-	-	-
White and Asian	1	<1%	9	9%	7	7%
Any other mixed background	-	-	-	-	1	1%
Black or Black British						
Caribbean	-	-	-	-	1	1%
African	-	-	1	1%	1	1%
Any other Black background	-	-	-	-	1	1%
Other ethnic group						
Chinese	1	<1%	1	1%	-	-

I do not wish to disclose my ethnic origin	5	3%	2	2%	1	1%
Other, please specify	-	-	1	1%	-	-
Did not respond	17	10%	-	-	2	2%

What do you consider your religion to be?	Cared for person who completed the survey themselves	%	Carers who completed the survey	%	The person they care for	%
No religion	46	28%	26	26%	31	30%
Christianity	42	26%	52	51%	48	47%
Buddhist	-	-	3	3%	-	-
Hindu	1	<1%	3	3%	1	1%
Jewish	-	-	3	3%	3	3%
Muslim	4	2%	2	2%	4	4%
Sikh	-	-	-	-	-	-
Other	4	2%	4	4%	-	-
Prefer not to say	10	6%	6	6%	6	6%
I don't know	24	15%	-	-	-	-
Did not respond	33	20%	3	3%	9	9%

Appendix two: Case study

We are two 70-year-old parents of a 42 year old daughter with a rare genetic disorder which manifests itself in severe learning disabilities, autism, and poor physical mobility. We live in Redcar & Cleveland and are both now retired.

Our daughter lives close by but independently of us, in supported living with 24-hour care.

These are the things we now oversee:

- General oversight and continuing support.
- Her property and Finances as Deputies Jointly and Severally.
- Continued emotional support.
- When the level of care breaks down for any reason, we step in to cover any inconsistencies and respond to the situation.
- Support to access all medical services.
- Ensure she has a holiday and regular contact with siblings and extended family.
- Communication e.g., WhatsApp, to communicate with her support workers, and family and friends using her 'voice'.
- Promote person centered planning, review and updating where necessary.
- Access to community activities by highlighting events and facilitating her engagement.

We realised that as our daughter got older, she needed her independence and that we needed to retain our role as parents, whilst ensuring her care and development. Doing something about this took us through a plethora of emotions and concerns, taking us through a journey beginning with residential college, community residential care and eventually supported living. Our daughter was always at the fore front and centre of these developments. The whole family, geneticists and social services were also involved. We had a feeling that, as parents, our proactivity drove the process and was a continuous necessity.

The outcome of this process was long term supported living tenancy in her own flat with 24/7, one-to-one care.

We are happy with the outcome and do feel that it has improved things for our daughter, ourselves and family. We feel that she is in a good place, fulfilling her potential and happy that we have contributed to her enjoying a life of her own with a positive outlook for the future.

It was great to encounter professionals who were prepared to keep our daughter at the heart of decision making. However, it was challenging when some professionals let us down through poor decision making and by being driven by factors other than our daughters' best interests in addition to poor communication and co-ordination between interested parties.

Parents need to be confident in the unique insight you have on your daughter/son. Acknowledge the contribution of 'professionals', whilst not minimizing the validity of yours as this is paramount to the outcome.

We feel that there should exist an independent and dedicated advocacy service other than statutory authorities which could be a present, personal and continuous service which could be alongside our daughter, speaking for her when family are no longer able to do so."

You need to be acknowledged and included as an equal stakeholder in the process and decision making.



healthwatch