



# The Challenging Behaviour Foundation

making a difference to the lives of people with severe learning disabilities

## Nottingham and Nottinghamshire Strategic External Workforce Planning: Enhancing our understanding of the local social care workforce within the independent and voluntary sectors

The Challenging Behaviour Foundation (2023). *What Matters to us: Families perspectives on workforce planning for people with a learning disability.*



### What matters to us: Families perspectives on workforce planning for people with a learning disability

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# Introduction

## The Challenging Behaviour Foundation

The Challenging Behaviour Foundation (CBF) is the only UK charity specifically focussed on challenging behaviour associated with severe learning disabilities. We aim to make a real difference to the lives of children, young people, and adults with severe learning disabilities and those who care for and support them. Our overarching objective is to ensure carers and people with a learning disability have access to the right support in the right place at the right time to enable them to live a full, healthy, and active life. We do this by combining the direct lived experience of the families we support with strategic influencing work by:

1. Providing Information and support to ensure family and professional carers are supported to feel confident in their role as carers, look after their own wellbeing and be strong advocates for the person they support
2. Representing and encouraging the voice of families at an individual, system-wide and national level through a strategic influencing approach to ensure policy and best practice reflect lived experience and provides robust and practical guidance
3. Working in partnership and engaging with professionals and other stakeholders to inform, develop, demonstrate and share best practice to ensure local areas & services are well informed and equipped to meet the needs of people with a severe learning disability

The CBF is based on core principles of partnership working to achieve shared outcomes and has a strong track record of bringing stakeholders from different backgrounds together. A small but efficient national organisation, started by a family carer, we provide support to over 4,500 families across the UK. Families are central to everything we do with carers represented at every level of the organisation across projects, trustees, staff, and volunteers.

The CBF has provided direct information, support, and casework to families of children, young people and adults with severe learning disabilities whose behaviour challenges for over 26 years. Family members are faced with a skilled, difficult and stressful role in supporting their loved ones with learning disabilities and/or are autistic, who display challenging behaviour. These families are a marginalised community facing numerous barriers, often isolated within their local community with little opportunity to connect with their peers.

The CBF has built up a strong reputation with families for providing practical, useful and relevant specialist information. We have also built up a network of family carers and professionals who input to all our work through co-development, co-production and co-delivery. We are in contact with over 10,000 families over a variety of platforms including direct support, networks and online. We already have an established email network of 300 families who provide peer-to-peer support and promote emotional and mental resilience. We believe that more can be achieved by working together and have always worked collaboratively. We have an established network of professionals through our Challenging Behaviour – National Strategy Group and Legal Panel. We also work with researchers and academics to ensure an evidence-based approach, and we work closely with other national charities (e.g. Mencap and NAS) as well as a network of smaller family-led organisations and groups.

The CBF helpline, casework and information service is a unique and established, valued and trusted support service for this group of individuals and their families. We deliver significant support with

limited resources and deliver good outcomes for families at an individual and strategic level. We have built a good reputation, acknowledged at very senior levels in a range of organisations and amongst a range of stakeholders for the significant advocacy role we play. As an independent charity, our sole motivation is to improve the lives of children, young people and adults with learning disabilities whose behaviour challenges and to ensure their human rights are met.

## Aims

The Challenging Behaviour Foundation have been commissioned by Skills for Care to carry out work looking at the social care workforce in the Nottinghamshire area. This focus was to hear from families about what the workforce that supports them and their relatives should be like, particularly what level of skills and experiences support staff should have. This will include frontline staff such as Personal Assistants (PA's) and support workers; in addition, the roles of leaders and social workers or commissioners of services.

## Key objectives:

- Develop an understanding of regional and national initiatives and good practice
- Conduct a desktop review of the needs of families and workforce development
- Engage with “What matters to me” focus groups and online survey
- Report on analysis of findings

This report is based on the findings of:

1. **Desktop research** - Research of keywords across various platforms including academic papers, journal articles, research reports, frameworks, national guidance and standards looking at workforce development for people with a learning disability from 2017 to present.
2. **‘What Matters To Us’ focus groups** - Two focus groups of family carers supporting a family member with a learning disability, who is considered to have complex needs and/or behaviour described as challenging, who live in Nottingham or Nottinghamshire. Discussion focused on 5 key themes (identified from the findings of the desktop research).
3. **‘What Matters To Us’ survey** - Shared with family carers supporting a family member with a learning disability, who is considered to have complex needs and/or behaviour described as challenging, who live in Nottingham or Nottinghamshire. The questions covered experiences of skilled support, access to support, ideas for improvement, and good practice.

This report outlines the findings of each of these approaches, including themes which emerged. All families have given permission for their quotes to be used by the CBF.

## Desktop Research

### Method

Desktop research was carried out across various platforms including academic papers, journal articles, research reports, frameworks, guidance and standards looking at national workforce development. This research provided information on what makes a good support worker, ways of recruiting staff, what the barriers are for support workers and employers recruiting support workers, and ideas for overcoming barriers. The findings also included examples of good practice and case studies. The research documents used are from 2017 onwards.

The key words used for the research included:

- Workforce Development
- Recruitment (in Learning Disability/Intellectual Disability) (of support workers) (through Direct Payments)
- Retention (as above)
- Learning Disability
- Social Care Workforce
- Support Workers
- Barriers to recruiting support workers
- Barriers to retaining support workers
- What makes a good support worker
- Key priorities in the job of a support worker
- Recruitment styles for support work
- Workforce development in learning disability industry
- Learning Disability Services and their staff
- Intellectual Disability Services and their staff
- Learning Disability staffing
- Workforce Development in working with PMLD

In addition, a request was made to core and associate members of the Challenging Behaviour – National Strategy Group (CB-NSG) asking to share any examples of local policies or good practice. The CB-NSG is made up of 94 core and 742 associate members, who are all experienced stakeholders in the care and support of people with a learning disability and behaviour described as challenging.

### Findings

The desktop research returned a range of national legislation, policy, guidance and standards applicable to workforce development. It ranged from a national scope covering all types of care staff (e.g., The Care Act 2014) to guidance specific to people with a learning disability and behaviour described as challenging (e.g., NICE guidelines). These are arranged by scope in table one below.

Table one: Scope of desktop research

Scope	Legislation, policy, standards and guidance
All carers and care staff	The Care Act 2014 The state of health care and adult social care in England 2021/22 Fair Care: A workforce strategy for social care, The Institute for Public Policy research (2018)
Carers and care staff of children, young people or adults with a learning disability and/or are autistic	Transforming Care: Building the Right Support (2015) People at the Heart of Care: Adult Social Care Reform White Paper (2021) NHS England Long Term Plan (2019) The learning disability improvement standards for NHS trusts (2018) Supporting people with profound and multiple learning disabilities: Core & essential service standards 1st edition (2017) Mental health problems in people with learning disabilities: prevention, assessment and management NICE guideline
Carers and care staff of children, young people or adults with a learning disability and/or are autistic who display behaviour described as challenging or have complex needs.	Learning Disability and Behaviours that Challenge: Service design and delivery NICE guidelines (2015;2018)

Desktop research returned a range of studies and reports about the care staff of people with learning disabilities and complex needs. These ranged from reporting on local services (e.g., Davies et al. 2016) to national research studies (e.g., Murray et al. 2020) as well as literature reviews (e.g., McKenzie et al 2021) and studies which focused on the voice of people with learning disabilities (e.g., Davies et al. 2018).

The request sent to members of the CB-NSG for local policies or good practice received limited responses, with especially few results for local case studies or examples or good practice of workforce development for staff of people with complex needs and behaviour described as challenging. One strong example of good practice for training for staff supporting people with a learning disability or autistic people is the How-to guide to training the workforce by Mencap and PMLD network as part of the 'Raising Our Sights' recommendations.

We identified 5 main core themes from our desktop research across the legislation, policies, research and case studies. These are outlined in table two below.

Table two: Summary of core themes (desktop research)

Key Themes	Details	Who/Where
Value-Based Recruitment	The right kind of staff recruited are more likely to stay in the post for longer.	Moriarty et al – General Review – Tizard Report
	Those who ‘fit’ well have better job satisfaction and are more likely to remain in the post.	Duffy et al – General Review – Tizard Report
	An important factor for support staff is for them to have a good relationship with the person they are supporting.	Questionnaire survey – British Journal of Learning Disability (BJLD)  Learning Disability Today Report
	Also mentioned in staff recruitment and retaining programme by Health Education England (HEE), LGA Report, PMLD Link Core Standards.	
Recruitment (general)	Include people with learning disabilities in the recruitment process. Repeated in PMLD Raising our sights and in NICE guidelines.	
	Involvement of clinical staff in recruitment process	Health Education England – Recruitment & Retaining Programme
Pay	Staff should be paid a real living wage.	Institute for Public Policy Research (IPPR) (Think Tank)
	There should be standards for pay terms and conditions.	IPPR
	Pay was the second most important factor for staff in survey.	Survey – BJLD
	Pay should be consistent with other employment opportunities	Nursing Times Peer-Reviewed Article (NT – PRA)
	Increased pay would help staff retention	Article Report on research – Journal of

		Intellectual Disabilities (J of ID)
	Repeated in LDE Report (re: pay and conditions), Paradigm Report, Disability Sheffield, LGA Report.	
<b>Training</b>	Staff should have training opportunities of good quality learning transferable skills.	NT - PRA
	Fair promotion and development opportunities	NT - PRA
	For staff to stay in post they need to have in-depth knowledge of LD and understanding of behaviours that challenge.	Royal College of Nursing
	Offering training shows staff are being valued.	J of ID
	Social Models for Disability Training is more effective. Safeguarding, Communication, Behaviour Support all vital.	HEE and Council for Disabled Children Report.
<b>Supervision &amp; Support</b>	Morale & Supportive team working are important factors	J of ID
	Also reference in the NICE guidelines.	

From this research we also identified a list of key qualities and values staff should have, and a list of skills, knowledge and training staff necessary to support staff. They are arranged below in order of frequency with which they were referenced.

Key qualities and values staff should have	Skills, knowledge and training staff should have
<ul style="list-style-type: none"> <li>✓ Respectful (3)</li> <li>✓ Understanding (3)</li> <li>✓ Reliable/Committed (3)</li> <li>✓ Good communicator (3)</li> <li>✓ Ability/Willingness to Listen (2)</li> <li>✓ Positive attitude/ friendly (2)</li> <li>✓ Person-centred</li> </ul>	<ul style="list-style-type: none"> <li>● Positive Behaviour Support (6+)</li> <li>● Understanding and knowledge of learning disability inc. Rights (4)</li> <li>● MCA knowledge and consent</li> <li>● Communication skills inc. Use of communicative aids</li> </ul>



<ul style="list-style-type: none"> <li>✓ Advocating</li> <li>✓ Supportive/Encouraging</li> <li>✓ Patience</li> <li>✓ Adventurous</li> <li>✓ Sense of Humour</li> <li>✓ Connective</li> <li>✓ Resourceful</li> <li>✓ Empathetic</li> </ul>	<ul style="list-style-type: none"> <li>• Safeguarding</li> <li>• Manual Handling</li> <li>• Advocacy training</li> <li>• Postural Care</li> <li>• Health – suctioning, medication etc.</li> </ul>
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## ‘What Matters To Us’ Focus Groups

### Method

Participants were recruited to attend the focus groups by distributing a digital flyer with session details which invited people to give their views on the social care workforce. Invitations to family carers were distributed via the CBF Parent Carer Email Network, targeted to Nottingham and Nottinghamshire based family carers. Flyers were also distributed to and shared with carers at two Nottinghamshire –based parent carer forums.

Recruitment efforts aimed to assemble 3 focus groups for different stakeholders, covering family carers, registered managers or service providers, and commissioners. Unfortunately, due to low levels of responses, only the focus groups with family carers occurred.

Two focus groups were held virtually on 20<sup>th</sup> July 2023 with a total of 3 participants. The attendees were all family carers of people with severe learning disabilities, some also being autistic, displaying behaviours described as challenging or complex needs. They had a range of experience of a supporting workforce including independent advocacy, being a registered manager, and managing direct payments.

The 5 key themes which emerged in desktop research informed how we approached focus groups discussion. We decided on an open approach, introducing the key themes which had emerged and asking the group which topics they felt were most important or wanted to comment on. We then guided discussion the following three questions (*Figure one*), chosen to incorporate each of the 5 key themes:

1. What does good support look like on a day-to-day basis? (*What makes a good support worker*)
2. How do you recruit a good support worker? (*Recruitment approaches*)
3. What's important to keep a good support worker? (*Pay, Training, Support & Supervision*)

Figure one: Focus group topic guide



## Findings

The focus group discussions touched on varied topics when exploring the above questions, led by the participants' personal experiences and priorities. The key points raised have been grouped and outlined under the following sections:

- Training and skills
- Personal skills and values
- Compatibility and matching of support workers.
- Recruitment and staffing
- Pay and conditions.
- Supervision and support
- Trusting relationships with support staff and management support

### Training and skills

The family carer focus groups reported that a support worker must have skills, training and experience specific to people with a learning disability or complex needs and behaviour described as challenging , and there may be other requirements specific to the person they are going to care for.

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*"Training is key"*

*“They are delivering that [person-centred planning] training to staff, but I don’t think they would understand a person-centred delivery”*

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In particular, when supporting children and adults who display behaviour described as challenging, it is vital they have a strong understanding of the person's communication needs and can effectively use strategies like Positive Behavioural Support (PBS). For instance, a person may use Makaton or social stories to communicate. Families also identified the importance of having a good understanding of mental capacity.

*“They just know how to communicate with [my child]. They’ve got the skill set to learn. I think the most important thing as a good support worker is they listen to you when you’re explaining what [your child] is like and how to communicate.”*

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Family carers also believed staff training should include how to teach an individual to develop and learn new skills.

*“A support worker who’s willing to see potential that they could do a little bit more, that’s what a good support worker is like. Somebody that’s willing to engage him, understand him. Somebody you can trust”.*

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Relatives highlighted that the skills required will be varied depending on the individual they are supporting/caring for. For instance, if supporting an adult, they may be required to support the person running their home, so they need to think about the practical ways to support activities such as shopping, cooking, or cleaning.

#### **RELATED RESEARCH:**

- Davies et al. (2018) supports the focus group finding that different age groups require different skills and types of support from their staff, and how this may relate to what kind of home they are living in. Their findings have important implications for the range of skills needed within the learning disability care workforce.

#### Personal skills and values

Alongside having the right training and practical skills, relatives of people with severe learning disabilities and behaviour described as challenging focus group participants identified having the right values and personal qualities is an important part of providing good support. Good support workers must be confident, patient, resilient, compassionate, and empathetic.

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*“it feels like the recruitment doesn’t address things like empathy, compassion, being reflective, personality”*

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They should show dedication to providing good service. They should have excellent soft and personal skills, for example, being able to offer emotional support.

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*“I have had a few [support workers] who just really couldn’t care, they just wanted to get us off their backs. Then you’ve got ones who were so completely dedicated, and that knew what they were doing and were so insistent and made sure that they provided the service that we needed”.*

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Participants in the family carer focus groups described that staff caring for individuals with behaviours described as challenging must have the ability to be reflective. They must be able to review what has happened and their own actions to understand the reasons for challenging behaviour, and a willingness to work together and try innovative approaches. These kinds of principles underly Positive Behavioural Support practices.

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*“It’s hard to trust just anybody, to handover, especially if it’s a non-verbal child. You have no idea what to expect”*

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‘Value-based’ recruitment is a style of recruiting which is based on the principle that staff should not only have the necessary skills, but also have the right attitude and values needed provide care and support. Value-based recruitment processes can test if an applicant possesses values like respect, reflection, compassion, commitment to good quality care and other professional attributes.

#### **RELATED RESEARCH:**

McEwen et al. (2021) identified that respect and empathy for people with intellectual disabilities and their carers was one of the main categories perceived by staff to contribute to good quality service. This includes actions and beliefs such as valuing feedback from the person receiving care, and the contribution of family carers and viewing support as a ‘relationship’ rather than ‘service provision’.

## RELATED GUIDANCE:

*Supporting people with profound and multiple learning disabilities* (2017) identifies staff development as a core and essential service standard for organisations. It also includes the use of values-based recruitment within this standard.

Compatibility and matching of support workers.

Family carers in the focus groups described that there are a lot of distinct factors that affect compatibility when matching a support worker depending on the individual needs of the person with a learning disability and complex needs or behaviour described as challenging. For example, it may be important that a support worker has knowledge or experience of a specific medical condition that person has, such as epilepsy. It may be important that a person's carer is the same gender if they often do activities like swimming or have religious or cultural needs.

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*"I think there's been very little thought to the compatibility, the matching of people"*

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For people with severe learning disability and behaviour described as challenging, it is more likely a person has individual communication needs which a support worker would need to understand. For example, they may use Makaton or social stories. For people who require more than 1-to-1 support, it was important that the support workers 'get along' with each other, as well as the person they were supporting/caring for.

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*"If you're not interested in the detail [of matching staff] then it's a recipe for failure"*

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Family carers described that a 'proper induction' is often needed to work out if a support worker is compatible, rather than a decision made on paper or a 'tick-box' exercise. They want support workers to get to know the person, their environment and what their life is like.

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*"We said, look, he needs a consistent team, he needs a small team, people who know him well. They tried to send strangers in to do 11-hour shifts. People who have never met him"*

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This could be done informally, and it may be useful to have the presence of an existing support worker. This would enable prospective support workers to see whether they are able or would like to work there. It would also enable the individual to meet prospective carers and give them a say in who is supporting/caring for them.

#### RELATED RESEARCH:

Murray et al. (2020) explored factors which are most important for social care staff working in intellectual disability services to stay in their jobs, and they found the most important thing for them was getting on well with the person they supported.

#### RELATED GUIDANCE:

The NICE guideline *Learning Disability and Behaviours that Challenge: Service design and delivery (2018)* recommends involving young people and adults with a learning disability and behaviour that challenges in staff recruitment. It also recommends involving their family members and carers too if the person agrees unless there is a compelling reason not to.

#### Recruitment and staffing

Families found that recruiting staff using direct payments was very difficult. They described that they did not know, or it was not clear where to find support workers, and many services and catalogues had long waiting lists which resulted in long delays without any support.

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*“recruitment is horrendously difficult, I think, for parents”*

*“before he got shorts breaks, I couldn’t afford anybody to watch him, and now I could afford it there was just no one there. And it was just heartbreaking because we were so desperate to have a break from him and he was so desperate to have a break from us and we didn’t know where to turn”*

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Families preferred recruiting people they know via word-of-mouth personal recommendations or hiring support workers they have had previously rather than recruiting new people. They said it was harder to trust strangers, they were less likely to be able to understand specific or complex needs, and there is additional time and effort needed for the interview and induction process. Being able to trust a support worker and find someone who knew their relative well were very strong priorities for families when recruiting.

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*“I feel a bit bad saying my experience [with direct payments] so far has been good, but that’s because it’s two people I know. What would happen if I had to recruit again? I don’t think I would. I would go back to my source at school and say is anybody else looking for a job?”*

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*It's a lot to ask for parents and then you've got to entrust your child over"*

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When recruiting support workers via direct payments, family carers had concerns about being an employer. They were worried about managing budgets, being responsible for payrolls, and feeling vulnerable in case something goes wrong.

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*"[recruitment with a personal budget] is quite nerve-wracking, and that's why I've kept it very small and with people I know. Because then you're managing and you're responsible for HR, you are the employer"*

*"I'm still nervous [about direct payments] because I know I'm vulnerable if I get it wrong"*

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#### **RELATED RESEARCH:**

Turnpenny et al. (2020) supports these concerns, finding that people managing personal budgets did not always get choice and control, and there could be a lack of suitable services available to purchase in the local area. It also found that managing a personal budget required substantial skills, resources, tenacity and resilience. Family carers need adequate support to ensure personal budgets deliver personalised support and are sustainable. They also note advantages of budgets over traditional services, including increased choice, more person-centred care and flexibility in how they use the budget.

In their research, Disability Sheffield surveyed and interviewed a group of direct payment recipients, producing a list of five key areas where improvements could be made:

- Creating a clear information map of the rules and processes.
- Establishing an ongoing user-led review to ensure quality and satisfaction in direct payment use.
- Facilitating a problem-solving supportive hub, so that when people encounter difficulties, they can connect with a range of experienced others to develop personal and enabling solutions.
- Prioritising the development and infrastructure of the Personal Assistant workforce, including increasing pay rates, ensuring development opportunities, offering peer support and supervision.
- Profiling direct payment successes and how it can be flexibly used in a person-centred way.

#### **RELATED GUIDANCE:**

*The learning disability improvement standards for NHS Trusts (2018)* identifies workforce as one of the four main standards of concern for local health care systems. The standard requires all trusts to have both the skills and capacity to meet the needs of people with learning disabilities, autism or both within local strategies to ensure safe and sustainable staffing.

Pay and conditions.

Participants in the family carer focus groups discussed that some direct payments are at low rates per hour, and believed this failed to reflect the skills, commitment and importance of the job.

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*“I’m thinking that with low pay, for anybody who’s took it, as horrible as it may sound, they think we’ll take it because it’s an income but I’m not going to do a proper job”*

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*“I think pay and conditions is the way to recruit. I think it has to be more valued”*

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Some family carers were aware that there are higher rates of pay in direct payments for individuals with more complex needs, and they expressed this increase in pay was much more acceptable. Another concern was raised that, unlike other professions, pay rates for support workers are not supplemented when they work anti-social working hours.

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*“The set amount that was given to be able to pay someone per hour [on direct payments] was quite low, especially with someone like my son. I wouldn’t even accept that watching my son”*

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They also highlighted that consistency in the working patterns of support staff is helpful because people with severe learning disabilities often benefit from a reliable routine. Family carers reported that consistency has benefited staff too, for instance, in arranging their own caring responsibilities.

One family carer expressed strong concerns about ‘hub’ models which rotate who a support worker is assigned to, meaning they often have a new support worker. They described that it is difficult to have confidence or trust a stranger who has not been matched specifically to their relative’s needs or had a thorough induction to the person and their environment. It appeared the change to a hub model did not suit the family or the support worker, and they were not consulted before these changes were made. This results in frustration at having to start all over again when the previous arrangement was working well.

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*“I don’t want my son to have four lives depending on which of the four staff are on. I want him to have one life and they know what his life looks like”*

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As well as pay, family carers reported that job advertisements did not do justice to support worker roles. They failed to recognise the high levels and skill and expertise needed to provide good quality care for people with learning disabilities and complex needs.



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*“Those adverts demean the job. They make it sound like anybody could do it. You could walk off the street and look after my son. And you couldn’t”*

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#### RELATED RESEARCH:

Murray et al. (2020) explored factors which are most important for social care staff working in intellectual disability services to stay in their jobs, and they found pay was the second most important factor.

McKenzie K et al. (2021) suggest improving the pay and conditions of staff as a potential way to increase the recruitment and retention of staff in social care settings in the UK. This may include flexible working arrangements that can be adapted to the needs of staff.

The Institute for Policy Research’s report *Fair Care* describes the adult social care sector as characterised by endemic low pay and recommend that the Government should introduce the real living wage and establish minimum employment standard in order to fairly reward the workforce.

Warren (2022) describes how the social care sector is failing to pay at a level which attracts new staff or rewards experienced staff appropriately, contributing to the risk that experience and skills leave the sector. It also highlights other working conditions that are factor into attractiveness of a job, including current tax laws on NHS pensions, wider benefits, progression opportunities and flexible working.

Paradigm’s report *Don't ever call us unskilled again! Learning from the experience of Support Workers during Covid-19* explores how the social care workforce is overlooked, underpaid, unappreciated and often perceived as unskilled.

#### RELATED GUIDANCE:

The white paper *People at the Heart of Care* (2021) recognises that prioritising the health and wellbeing of staff is a key challenge within adult social care, pledging new initiatives to provide support and access to occupational health and create a healthy and supported workforce. It does not address the issue of pay.

#### Supervision and support

Family carers in the focus groups suggested that it is important that managers of services routinely support staff who work with people with learning disabilities and behaviour described as challenging. They should support by debriefs or reflective meetings where staff can review what has happened, understand it, and formulate a new approach or strategy for more proactive supports going forward.

Family carers also shared that they believed recognising and valuing staff by their management teams, senior leadership or commissioners would help with retention and job satisfaction. They believe it is important to recognise when they deliver good service to boost their morale and to appreciate that it is a skilled job that not one just anybody could do.

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*“It’s the recognition by management that they’re doing a good job [that helps retain staff]”*

*“The other thing is to encourage staff to take on extra training, develop qualifications and skills they can take with them. I think that’s also important, that we value you enough to train you”*

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#### **RELATED RESEARCH:**

Lokman et al. (2023) found that for staff of people with intellectual disabilities and severe challenging behaviour, well-being was associated with receiving support from team leaders, psychologists and other staff members in the team. They also found that staff support and team climate are negatively linked to the turnover of staff.

McEwen et al. (2021) found that staff value strong relationships between frontline staff and management. They also found that staff believed managers did not perceive frontline support work required specialist skills and knowledge but rather as ‘straightforward’, and as a result were offered little direction or training.

Warren (2022) describes the importance of collective, compassionate and inclusive leadership in the care sector.

#### **RELATED GUIDANCE:**

The NICE guideline *Learning Disability and Behaviours that Challenge: Service design and delivery* recommends that service providers are able to give staff providing direct support access to advice from behaviour support specialists with 'consultant' level competencies of the Positive Behavioural Support Academy's Positive behaviour support competence framework.

*Supporting people with profound and multiple learning disabilities* (2017) identifies quality as a core and essential service standards for organisations, which includes auditing tools that create a learning environment for all staff. They should show commitment to an honest and open culture of practice where staff are listened to, empowered, and their knowledge is recognised.

#### **Trusting relationships with support staff and management**

Participants in the family carer focus group identified consistency as a particularly important aspect of care because it enabled support workers to form relationships with them and the person they are supporting/caring for. Family carers appreciated having the same support workers come regularly because they could get to know a person well. They emphasized the ability to trust a support worker was incredibly important. They expressed concerns about the high turnover of staff, as they wanted support workers who knew their needs and history well.

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*“case gets opened, case gets closed, case gets opened, case closed, so there’s no consistency”*

*“So it’s repeating the cycle, someone else got to know [my child], someone else had got to find out what he wants, someone else has got to listen to that provider. So it’s a barrier, but that is the culture”*

*“They do need to sort staffing out, the high turnover because that is a problem. I know a lot of people whose children are bothered with all that change. They can’t develop a relationship”*

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Family carers also suggested that they would like to be able to give feedback and raise concerns and work closely with the support workers and leadership to address them. They reported that they were rarely, if ever, asked about what they thought of the services their relative received.

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*“Since [a provider] took over about four years ago, I’ve not as a family ever had any feedback forms, I’ve not had any surveys, I’ve not had anyone come to me and say how are things going? I’ve had a good relationship with the frontline staff, but no relationship with the people making the decisions”*

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They expressed fear that if they reported any issues they would be seen as a troublemaker by providers, and the provision of support may be put at risk. Support workers and providers should be responsive when a concern is raised and demonstrate a willingness to resolve any issues and provide a high standard of care.

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*“I’m hearing stories from staff that are quite worrying about the way the service is managed, and I think it’s a question of how do parents share that without seeming like a troublemaker?”*

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#### **RELATED RESEARCH:**

McEwen et al. (2021) found that staff caring for people with intellectual disabilities perceived that good quality service should include a culture of continuous improvement and critical reflection to evaluate practices. For instance, engagement with the people they supported to find out how satisfied they were with the services. They also found that staff value strong relationships between frontline staff and management.

## RELATED GUIDANCE:

*Supporting people with profound and multiple learning disabilities* (2017) identifies that effective partnership working with the people most important to the person being supported an important part of the standards organizations should follow.

## ‘What Matters To Us’ Survey and Phone Call

### Method

Participants in the focus groups had some particularly good links in the local Nottingham and Nottinghamshire area we wanted to explore. There was not an opportunity to run further focus groups, so we invited additional family carers to share their experiences via phone call, and later through a survey.

The survey ran from 22<sup>nd</sup> August to 8<sup>th</sup> September 2023 on SurveyMonkey. It was shared with three organisations to circulate with their family carer contacts: Carers Space Notts, Nottingham Carers Hub and Carers Matter at Reach. The call for participants invited family carers of a person with a learning disability who is considered to have complex needs and/or behaviour described as challenging to share their views. The survey questions were made up of the same questions as used in the focus groups. See Appendix 2 for a full list of survey questions.

### Follow up Phone Call Findings

One response was provided via phone call. The key points raised by the respondent about their experiences of support workers for their relative with severe learning disabilities and behaviour described as challenging behaviour:

**Communication** – they reported having experienced poor communication at all levels. This includes staff communication with their relatives, staff communication with family, communication between staff, and management’s communication with families.

- 4 of the 6 people who live in the shared house where their relative lived used Makaton, but none of the staff use it.
- Staff do not understand their relative’s needs, which can escalate their relative’s anxiety and in-as a result their self-injurious behaviours
- The family were not informed about an incident which led to a safeguarding referral until a week after it occurred.
- Staff did not handover important information such as activity start times, and a request from a parent for a photo to be taken for a medical appointment.

**High turnover of staff** – Family are not updated with staffing changes, and neither family nor the service user are involved in the recruitment processes.

- Since the provider was last rated by CQC in 2019, all the staff have left except 1, so the relative feels the current ‘Outstanding’ rating does not reflect the current provider level.

- They used to get sent photos and information about new staff, but since a change of provider this does not happen. There are times during pick up and drop off when family have never met or seen the new staff working there.
- They are allocated a new social worker for each issue and work with them until the case gets closed, which feels like box ticking.

**General lack of needs being met** – the support workers have not properly supported their relative to meet their basic needs.

- Relative has had 3 new pairs of glasses in less than a year because staff don't support with cleaning them properly.
- Parent has not been able to visit their relative's room and been banned from communicating with staff except in writing after complaining about a member of staff working with their relative despite a previous safeguarding incident.

### Survey Findings

The survey received 4 responses. All participants confirmed they lived in the Nottingham or Nottinghamshire area and are a family carer or relative of a person with a learning disability who has complex needs. Of these, 1 had a relative who was over 18 years old and the other 3 were all under 18 years. Two reported that they were currently receiving no support, one reported using a day service and one reporting currently using a key working service, autism support and CAMHS.

When asked about their experiences of skilled support, participants said:

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*“Not enough skilled staff. Most learn on the job”*

*“Autism Support and Keyworking service are both wonderful”*

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When asked what core skills support staff need to have, respondents suggested:

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*“patience” (x3), “empathy”, “autism/LD training”, “experience of challenging behaviour”, “sympathetic to parents”, “listening and not judging or saying it’s the parents’ fault”, “kindness”, “curiosity”, “trustworthiness”, “confidentiality”*

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The survey asked respondents how they have been, or how they could be supported to access skilled support. One reported being unsure, and another named a local school which supported them. Other responses included:

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*“The services to be made widely known and contact details given by other professionals”*

*“We had to go through social care to get a referral to both services, despite not needing their involvement”*

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Respondents’ ideas for improving how individuals are supported were:

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*“Wider access”      “More training needed”*

*“Support for parents to handle the behaviour, for parents to be given a break even if they don’t receive benefits. Those who work miss out on so much support”*

*“We are supported well with weekly/fortnightly visits”*

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Next, they were asked what support and information is needed to showcase good practice models of support. They answered:

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*“Training modules should be compulsory”*

*“Knowledge and experience of challenging behaviour”*

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Other comments and experiences regarding social care workforce development in the Nottingham and Nottinghamshire areas included:

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*“Access - we seem to slip through the gaps”*

*“You often get passed from pillar to post, end up going round in circles and denied support. Parents have to fight to receive any support”*

*“I think the service should be more accessible to parents, without social care assessment. We can, as adults, refer ourselves into mental health treatment, but we can’t ask directly for support for a disabled child”*

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These survey responses mirror several the key words returned by the desktop research regarding the qualities, values, skills and training that staff should have.

### Links to ICS people functions

*Building strong integrated care systems everywhere* (2021) sets out a vision for the workforce which identifies 10 outcome-based functions that are expected to be delivered by Integrated Care Systems (ICSs) from April 2022. See Appendix 3 for a full list of ICS people functions.

Three of the ICS people functions were recognised in the findings of this report:

- The 4th ICS people function “**valuing and supporting leadership at all levels, and lifelong learning**” about establishing a learning culture and continuous development relates to the theme of supporting and offering supervision to staff.
- The 5th ICS people function of “**leading workforce transformation and new ways of working**” may include “enabling staff to learn and work across different settings and locations”, “workforce-sharing arrangements” and “rotational roles”. This function relates to concerns about rotational models of working that were raised by family carers in focus groups.
- The 10th ICS people function of “**supporting system design and development**” including building up of skills and expertise relates to the theme of skills and training.

### Limitations & Lessons learned.

In conducting the research, focus groups and survey we encountered limitations which have impacted the quality and quantity of information in the report. It is important to reflect on the lessons learned in this process:

- How call for participants were distributed – in distributing the invitations to take part in the focus groups and survey we were reliant on organisations passing on the information to family carers local to the area. This impacted the attendance of focus groups and the response rates to the survey.
- Gaps in local good practice examples – the desktop research did not return any examples of good practice local to the Nottingham or Nottinghamshire areas, and few at a national level. Without local insight, and with few case studies of good practice, it is more difficult to showcase exemplars of developing the workforce.

## Recommendations

In addition to the three ICS People functions listed above the following areas need to be considered as part of workforce development from the perspectives of family carers who support people with a learning disability and behaviours described as challenging.

- Training and skills
  - Are specific to the needs of the individual being support.
- Personal skills and values
  - The areas are considered as part of the recruitment process and are identified as essential criteria which is assessed as part of recruitment.
- Compatibility and matching of support workers
  - Recognition of the importance of building trusting relationships and working environments as a key factor of good support
- Recruitment and staffing
  - Focus on values led recruitment.
  - More focused support for families in support of their role as employers (direct payments)
- Pay and conditions
  - These areas need to reflect the role as being a professional skilled role with a focus on pay and working conditions which recruit and retain staff.
- Supervision and support
  - Robust systems in place to support and supervise staff in the specifics of their role.
- Trusting relationships with support staff and management teams
  - Creating open cultures of dialogue with leaders of services to focus on the key outcomes of support.



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## Appendix 1 - Focus Group Prompt Questions

- What are your experiences of skilled support?
- What are the core skills support staff need to have?
- How you have or could have been supported to access skilled support
- Your ideas about how individuals are supported and what can be improved?
- What support and information is needed to showcase good practice models of support?

## Appendix 2 - Survey Questions

1. I understand that my responses will remain anonymous and the CBF will not use any identifying information such as names, ages, locations, service providers in their final report.
2. Do you live in the Nottingham or Nottinghamshire area and are a family carer or relative of a person with a learning disability who has complex needs?
3. Is your relative a child or adult?
4. What model of support do you currently use? (e.g. Direct Payments - PA - employed by yourself/agency, day centre, supported living etc. How do you find this works?)
5. What are your experiences of skilled support?
6. What are the core skills support staff need to have?
7. How have you or could you be supported to access skilled support?
8. Your ideas about how individuals are supported and what could be improved?
9. What support and information is needed to showcase good practice models of support?
10. Do you have any other comments or experiences you wish to share regarding social care workforce development in your area?

## Appendix 3 - ICS people functions

The 10 ICS People Functions are:

1. **Supporting the health and wellbeing of all staff:** people working and learning in the ICS feel safe and supported in their physical and mental health and wellbeing, and are therefore better able to provide high-quality, compassionate care to patients.
2. **Growing the workforce for the future and enabling adequate workforce supply:** the system is retaining, recruiting and, where required, growing its workforce to meet future need. The 'one workforce' across the ICS is representative of the local communities served.
3. **Supporting inclusion and belonging for all, and creating a great experience for staff:** people working and learning in the ICS can develop and thrive in a compassionate and inclusive environment. Issues of inequality and inequity are identified and addressed for all people working in the system. The workforce and leaders in the ICS are representative of the diverse population they serve.
4. **Valuing and supporting leadership at all levels, and lifelong learning:** leaders at every level live the behaviours and values set out in the People Promise, and make strides so that this is the experience of work for all of their 'one workforce'.
5. **Leading workforce transformation and new ways of working:** service redesign is enabled through new ways of working, which make the most of staff skills, use of technology and wider innovation to meet population health needs and drive efficiency and value for money.
6. **Educating, training and developing people, and managing talent:** education and training plans and opportunities are aligned and fit the needs of staff, patients and citizens, including to enable new ways of working and support meaningful and personalised career journeys.
7. **Driving and supporting broader social and economic development:** leaders ensure that their organisations leverage their role as anchor institutions and networks to create a vibrant local labour market, promote local social and economic growth in the wider community, support all ICS partners to 'level up', address wider health determinants and inequalities at the heart of poor health.
8. **Transforming people services and supporting the people profession:** high quality people services are delivered by a highly skilled people profession to meet the future needs of the 'one workforce', enabled by technology infrastructure and digital tools.
9. **Leading coordinated workforce planning using analysis and intelligence:** integrated and dynamic workforce, activity and finance planning meets current and future population, service and workforce needs, across programme, pathway and place.
10. **Supporting system design and development:** the system uses organisational and cultural system design and development principles to support the establishment and development of the integrated care board (ICB), and the integrated care partnership (ICP). The organisational development approach creates a system-wide culture that is driven by purpose; enables people, places and the system to fulfil their potential; is connected to the people served by the system and delivering those services; harnesses the best of behavioural, relational and structural approaches; and nurtures collaboration.