



**Developing a
community model to
support family carers
of people with learning
disabilities within the
Southern Health and
Social Care Trust**

PLANNING FOR THE FUTURE



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Background

People with learning disabilities are now living longer and most are living with family carers.

Northern Ireland has a higher proportion of people with learning disabilities living in the family home and being cared for by family carers (i.e., mother, father, sibling) than elsewhere in UK and Ireland.

Most family carers are female (i.e., mothers/sisters), but there are also growing numbers of males taking on the role of carer, due to the death of a spouse/family member (Taggart *et al.*, 2012; Ryan *et al.*, 2014).

Despite 30 years of research into identifying the needs of family carers, the needs of family carers continue to remain unmet (Ryan *et al.*, 2014; NICE, 2018; Bigby *et al.*, 2019).

There is little planning undertaken to support family carers of people with disabilities within local communities as they age: the focus has been

on the person with the learning disability (Taggart, 2016).

Most current models for supporting family carers of people with learning disabilities are no longer fit for purpose, nor are they a viable or sustainable option to meet increased demand (Slevin *et al.*, 2011; Taggart *et al.*, 2012; Ryan *et al.*, 2014; NICE, 2018; Bigby *et al.*, 2019).

Traditional service models for people with learning disabilities (i.e., buildings-based day centres, residential provision, respite) are unable to meet the current and future demands of the changing demographics of this population (Slevin *et al.*, 2011; Taggart *et al.*, 2012; Ryan *et al.*, 2014; NICE, 2018; Bigby *et al.*, 2019).



Policy

The **'Equal Lives Report'** (2006) and **'The Winterbourne Report'** (2013) identified learning disability as an area that required specific planning within services based upon Human Rights, Citizenship, Inclusion and Being Valued.

The **'UN Convention on Rights of Persons with Disabilities'** (2006) promotes the rights of all persons with disabilities to 'live independently and be included in the community': freedom to make choices regarding their lives, including place of residence (access to range of in-home, residential, and other community supports) to prevent isolation/segregation from

community. The Convention also stresses the need to prevent age-related disabilities and promote the social inclusion of older persons.

The **'Caring for Carers'** Report (2006) advises that Health and Social Care Trusts (HSCTs) should pay particular attention to the needs of older people who are themselves providing substantial care to others.

Twelve years on from the implementation of **'Transforming Your Care'** (2011) and the development of population plans, which were to embody a joint commitment approach to improving the health and well-being of family

carers and people with learning disabilities, little change is evident.

The Northern Ireland Learning Disability Service Framework (2011a) recommended that all people with a learning disability should have:

- The impact of ageing taken into consideration when assessing and managing their and their family carers needs; and
- The option to remain in their own home, with their family carer, for as long as possible and should be provided with the appropriate care and support to do so.

The Commissioner for Older People for Northern Ireland (2013-15) Corporate Plan outlined several themes and priorities including that; **'older people feel safe in the community; and that they are recognised as individuals who have made and continue to make a contribution to our society'**.

What we set out to do?

Aim: To develop a community model to support family carers of people with learning disabilities within the Southern Health and Social Care Trust (SHSCT) for the future.

Objectives:

1. To explore the future needs of family carers of adults with learning disability (aged 16 years plus) living in the community in the SHSCT, as well as potential enablers/barriers, using in-depth focus groups.
2. To identify the future needs of family carers of adults with learning disabilities (aged 16 years plus) living in the community in the SHSCT using an online survey tool.
3. To co-produce a model of the future needs of family carers of adults with learning disability living in the community in the SHSCT.

The results of this study will help inform commissioners, policymakers, and service providers to plan and develop family services for people with learning disability for the future in the SHSCT.

What we did?

Design

We used a **community-based participatory research approach** involving four stages (see Figure 1). In Phase 1 seven focus groups were held with family carers. In Phase 2 we undertook a survey with 166 family carers. And in Phase 3 we held three co-production workshops with a range of stakeholders across the SHSCT, that informed the development of the community model and provided a series of operational and strategic recommendations.

Stage 1: Focus groups

Stage 1 involved holding seven focus groups with over 40 family carers from across the SHSCT. The focus groups were held virtually via Zoom and explored the needs of these family carers. We identified and recruited family carers who provided care to a relative with a learning disability (aged 16 years plus) and living in the community. A wide range of carers were represented in the groups, including: parents of young people in transition (16-18 years), carers of relatives with complex health needs, carers of relatives with behaviours that challenge, and older family carers of older adults with learning disabilities. Verbal consent was obtained from each participant before the focus groups commenced. The focus groups were digitally recorded, transcribed, and then analysed.



Stage 2: Survey

Stage 2 involved the completion of an anonymous postal/online questionnaire by family carers from across the SHSCT, to further document the future needs of family carers across the SHSCT. The online questionnaire was developed from a review of the international literature and informed by the results of the focus groups in Stage 1. For those family carers without an e-mail, the questionnaires were sent out by post. A total of 166 responses were returned.

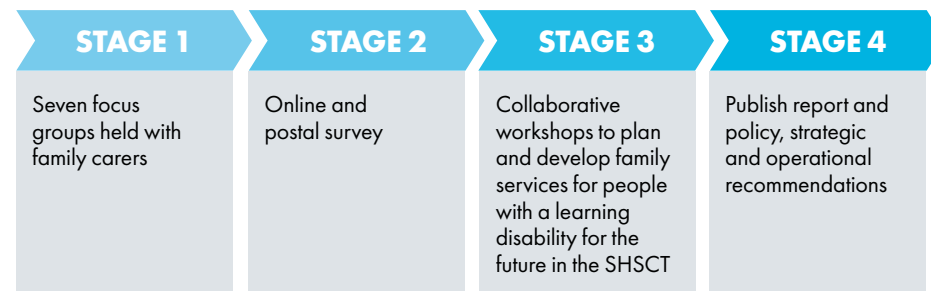
Stage 3: Co-production workshops

Stage 3 involved holding three co-production workshops across the SHSCT, where we invited a range of professional, statutory, family carer and service user organisations to maximise stakeholder representation. Participants included family carers; policy makers, commissioners, senior managers, and managers from the learning disability statutory and voluntary organisations; education; local council; and housing sectors; as well as mainstream older person's statutory and voluntary organizations and family carers.

Stage 4: Final report

Stage 4 is the publication of final report.

Figure 1: Four stages of the study



The first part of each workshop provided the participants with a summary of the findings of Stages 1 and 2 of this study. The second part focused on developing actionable outcomes or knowledge products using a round table methodology in order to create the environment in which the evidence can be clarified, interpreted and applied. Each round table session involved groups of between 10-15 people and was facilitated by a member of the Research Team. The facilitator briefly summarised the evidence presented thus far and provided opportunities for all the participants to explore and discuss the challenges services currently faced in each of the three target areas from the proposed model (**Supporting family carers; Redesigning services; and Transitions across the lifespan**).

Participants in each round table were then tasked to utilise the local evidence/knowledge to produce a community model and specific actionable outcomes that would then be used to inform a series of operational and strategic recommendations for the SHSCT in planning for the future. In total, there were 9 co-production round tables held over the three days (with a total of just under 100 participants), in three different locations to ensure a representation of urban and rural areas (see Figure 1).

It is these findings from the three stages of this study we present below, and the operational and strategic recommendations that we advise are considered for implementation by the SHSCT.



Data analysis

Through guided discussion within groups, specific recommendations and wording was agreed upon and recorded on flip charts. The flip charts from each group were then displayed and discussed with all the stakeholders at the end of workshop session to seek further clarity and agreement on the actionable outcomes. Field notes were used by several members of the research team to record alternate viewpoints, and further develop the community support model and refine the data collected from participating stakeholders.

Following the three workshops, the Research Team held a series of meetings to review all the written feedback and to agree on a set of actionable outcomes. These outcomes took the form of operational and strategic recommendations, and strategic drivers of change and innovation, that would help implement the community support model for family carers of adults with learning disabilities within the SHSCT.

NOTE: The Research Team would like to acknowledge that the focus groups and family carer's online survey were undertaken at a time when the SHSCT were rebuilding services which had been significantly reduced because of the COVID-19 pandemic. This will explain some of the feedback regarding the provision of day care and short-break services. At the time of writing this report, day care and short-breaks services have been returning to pre-COVID-19 provision levels.



What we found?

Family carers and caring

Information on family carers

- In total 166 family carers completed the online/postal anonymous questionnaire.
- Most family carers were female (86%), average age was 58 years (range 22-84 years).
- Mothers (70%), siblings (12%), fathers (8%) and other relatives such as brother/daughter-in-law, cousins, nieces, etc. (8%).
- Over half of family carers were married (71%), others were widowed/separated/divorced (20%) and a few carers were single (7%).
- Most family carers had been caring for over 20 years (75%) (minimum =1 year, maximum =58 years, average =26 years).

Living arrangements

- 87% of the adults with a learning disability in this sample lived with the family carer in their own home.
- 8% of the adults with a learning disability lived in some form of supported living/residential accommodation with other adults with a learning disability.
- 7 adults with a learning disability (4.2%) lived independently.

Additional caring responsibilities

- 34 family carers (21%) were also caring for a spouse/partner or mother/father with another disability such as dementia, stroke, etc.
- 14 family carers (8.4%) cared for another son/daughter with a learning disability within their own home.

Ageing profile of family carers and adults with a learning disability

- Figure 2 shows the ageing profile of the adults with a learning disability in this sample.
- Figure 3 shows the ageing profile of the family carers in this sample.



Figure 2: People with a learning disability average age (33 years)

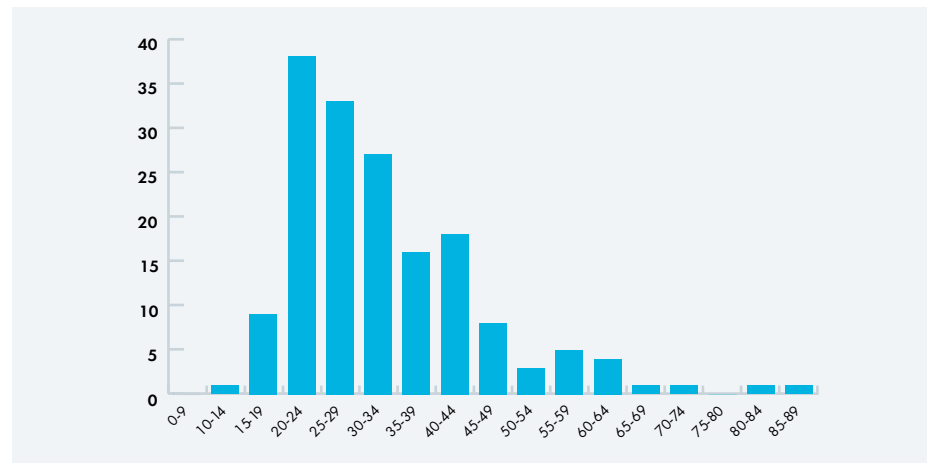
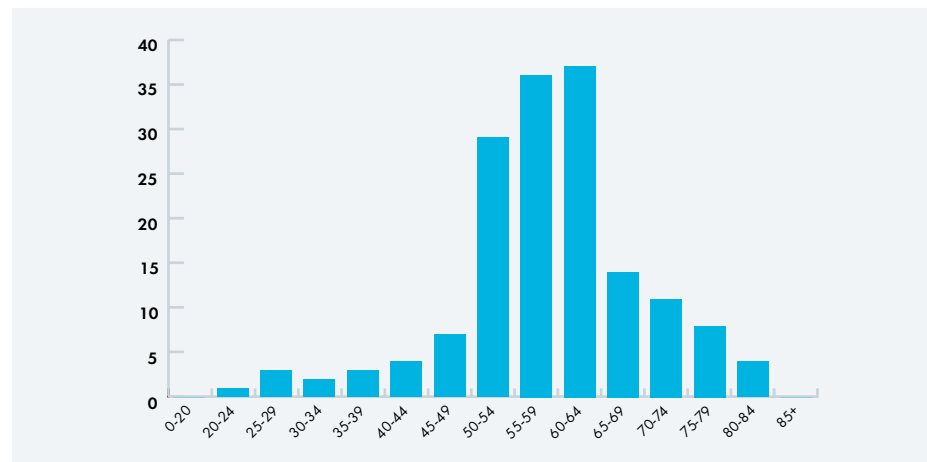


Figure 3: Family carers average age (58 years)

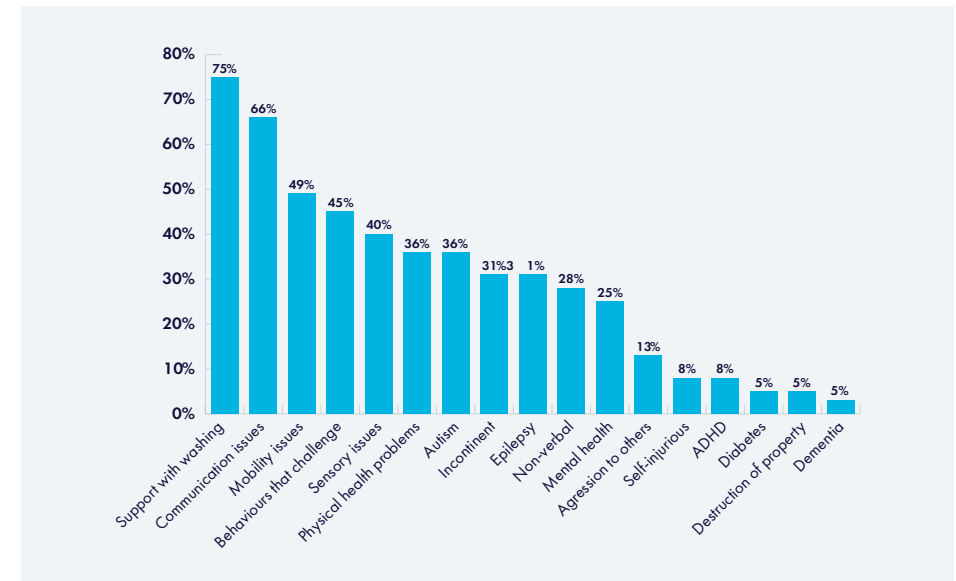


- It is clear from Figures 2 and 3 that there is an ageing population of people with learning disabilities in the SHSCT area, who are being cared for by an even older population of family carers, many of whom are over 60 years old, and who themselves may soon require caring support. This is the 'ticking time bomb' that MENCAP discussed in their report (MENCAP 2012).
- This must also be considered alongside the growing number of children with learning disabilities aged 3-19 years within the special schools in the SHSCT.

Complex needs of service users

- 73 family carers (44%) were caring for an adult with a learning disability aged 18 years plus.
- 39 (23%) family carers reported caring for an adult with a learning disability aged 18 years plus with severe challenging behaviours/ enduring mental health problems.
- 48 (29%) family carers reported caring for an adult with a learning disability aged 18 years plus with complex physical health needs.
- 9 family carers cared for a young person with a learning disability/ transition group aged 16-19 years.
- Figure 4 shows the range of complex needs of the adults with learning disabilities.

Figure 4: Complex needs of adults with learning disabilities



Family carer health conditions

- 62% family carers reported having a longstanding health related condition such as depression, anxiety, stress, bereavement/loneliness, arthritis, heart condition, mobility problems, high BP, chronic pain, diabetes, menopause, osteoarthritis, etc. with many carers reporting more than one health condition.
- Over two-thirds of family carers reported that their health condition disrupted their caring activities:
 - minor disruption (32%)
 - moderate disruption (35%) and
 - major disruption (6%)



The physical and emotional impact of caring (over the past 4 weeks)

Family carers reported:

- Feeling tired – 70%
- Disturbed sleep – 57%
- Stressed – 44%
- Feeling depressed – 28%
- Short temper/irritable – 30%
- Physical strain (e.g., back pain) – 27%
- Developed own health condition – 12%
- Made an existing condition worse – 12%
- Had to contact own GP – 11%
- Loss of appetite – 4%

The physical and emotional impact of caring (over the previous 2 weeks)

We asked carers how they had been feeling physically and emotionally over the past two weeks (response options were: None of the time, Rarely, Sometimes, Often, All of the Time)

- Feeling relaxed?
 - Only 10% of family carers reported Often, or All of the Time
- Feeling optimistic?
 - Only 19% of family carers reported Often, or All of the Time
- Feeling useful?
 - Only 24% of family carers reported Often, or All of the Time
- Feeling close to people?
 - Only 34% of family carers reported Often, or All of the Time
- Dealing with problems well?
 - Only 34% of family carers reported Often, or All of the Time
- Thinking clearly?
 - 40% of family carers reported Often, or All of the Time
- Able to make my own mind about things?
 - 50% of family carers reported Often, or All of the Time



“Looking after my son is getting harder because he’s getting older, he’s bigger and it is getting harder, it’s not getting easier.”

(Family carer, focus group 3)

“I think that’s another thing, they (SHSCT) need to consider what is actually going on in the family carer’s life... I don’t know what’s going on for you but it’s all about the person who has a disability which is fair enough but we’re the ones looking after them.”

(Family carer, focus group 1)

“Very stressful, yeah. It was very, very hard for a long time, yeah. Yeah their health wasn’t good and my husband is totally, his body is wrecked because of the amount of pressure he had managing her challenging behaviours.”

(Family carer, focus group 4)

“It’s physically and mentally exhausting. Forget about social life, forget about trying to work full-time and having your own career, you know, all those sorts of things, they’re more or less out the window because your life is centred around them now. I love my son. I’d do anything for him, but at the same time, you know, I don’t think people realise just how huge the impact can be on your life.”

(Family carer, focus group 2)



Main sources of informal support for family carers

Family carers reported receiving support from:

- Spouse/partner 65%
- Son daughter 33%
- Other relative 43%
- Neighbour 4%

Carer engagement in family and sibling support groups

We asked the family carers about their engagement with local support services.

Carer engagement:

- Few family carers (7%) engaged with a local community support group.
- 41% of family carers stated they would be interested in attending a local community support group if offered.
- 41% would not be interested in attending a local community support.

Sibling engagement:

- Family carers reported that most siblings did not attend a sibling support group.
- The main reason for non-attendance is that sibling support groups are not offered in their local area.
- Only one family carer indicated that her teenage son attended a sibling support group.

Engagement in training

- Few family carers (14%) had attended training in how to manage behaviours that challenge (managing behaviours that challenge/aggression/SIB, depression/anxiety, etc.).
- Just over half of family carers (51%) reported that if training was offered in this area, they would attend.

Rescue medication

- Over one quarter of the adults with a learning disability (30%) required rescue medication.
- Some of the family carers reported several issues regarding the usage of such medication:
 - SHSCT and voluntary staff are not allowed to administer the rescue medications in day care/respite facilities/social clubs.
 - Which means the family carers must be nearby to give the medication thereby further restricting their activities on these days.
- Representation of family carers within the SHSCT is needed.



“The SHSCT has this rule if your child is on emergency medication you must be there. The direct payment worker cannot administer the medication even though I have insurance as an employer for that person, they still have this rule that you can’t use, you can’t leave, you have to be within a five-minute distance to give the emergency medication.”

(Family carer, focus group 4)



Service support

The impact of caring was further exacerbated by COVID-19. The total withdrawal of the formal supports offered by the SHSCT such as the closure of day centres and respite care, had a particularly negative impact. Carers reported that such services have still not returned to the pre-COVID-19 levels. This loss of vital daily and overnight respite was further adding to the negative impact upon the family carers health and well-being.

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“Well she was finishing her last year at special school and she’d been there since she was four and it wasn’t a great ending because it was so abrupt due to COVID-19. And her whole behaviours went really downhill from when she could no longer go to school anymore, she pulled out her hair, she punched out two of her own teeth, hitting herself.”

(Family carer, focus group 4)

“Everything had stopped because of COVID-19 from clubs to day care, everything stopped and I don’t think my son could handle that. He was punching walls. Lucky enough, his doctor had been in touch and she was able to up his medicine which calmed him down, so hopefully keep him calm.”

(Family carer, focus group 1)

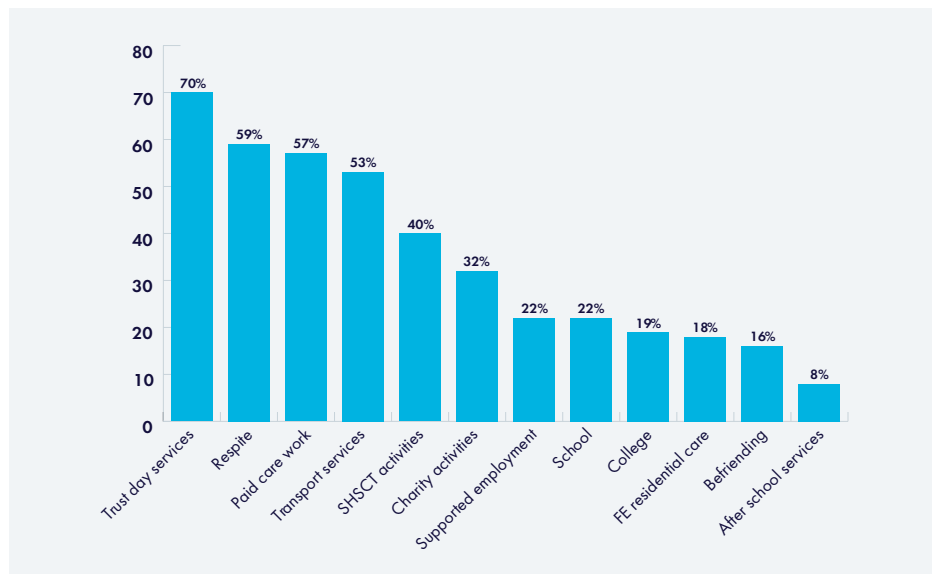
“The SHSCT told us they can only give us two days a week in the day centre now with her [daughter with a learning disability], now they’re hoping that come September that will improve but at the moment it’s only two days a week.”

(Family carer, focus group 4)

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- Some family carers reported ongoing issues with transport.
- Half of family carers use direct payments however there can be major challenges when doing so: Payments can be stopped when a child turns 18 years old and they move from children’s to adult services; not all carers are happy becoming employers, given the additional administrative burdens that this causes.
- Some family carers reported ongoing issues with transport.
- A few family carers reported long delays in getting home adaptations completed. These delays can impact on the carers’ physical health, emotional well-being, and their mental health.
- Only a small number of family carers were getting any support from older people services.
- Figure 5 shows how the family carers identified the key supports they need for them to continue caring into the future.

Figure 5: Formal Supports required to ensure carers’ ability to continue caring in the future (% who rated them to be important/very important)



“I did get direct payments, and my mum was doing them, and everything was grand, but in January of 2021 the social worker just told me that there were people more deserving of the direct payments and took them off me, and I went into that transition phase. And then in October last year, when he hit 18, a social worker came out and she told me, yeah, yeah, I’ll have a look, and nothing happened.”

(Family carer, focus group 1)

“So, I suppose in crisis point we did get the support, but we had to demand it. I’m going to very honest. We had to demand it. I mean, I wrote letters, and emails. I made phone calls. I literally had to say that if somebody didn’t do something this child was possibly going to kill himself because of the level of the behaviour that he engaged in. So, I suppose from that perspective we are getting a lot of support, but we had to hit rock bottom to get it, and we had to demand it, and we had to say, well, we weren’t telling any lies, we had to say we could not look after our child, and that’s a very difficult thing for anybody to say. So, it’s very difficult.”

(Family carer, focus group 1)

“I’m normally a confident person, like I can talk my way through anything. Hit social services and I feel totally inadequate because I don’t know enough. Everything is so sporadic about it. There is no consistency and trying to find a central point of communication, you cannot access this. You must search so many different areas, instead of just that one central point. This makes me feel frustrated, helpless and useless.”

(Family carer, focus group 1)



Transitions across the lifespan

Transitions from school to adult services

- Nine family carers who were caring for a young person (between the age of 16-19 years) completed the survey. Transition caused stress for both the young person and family carers. During the workshops, there were mixed reports of the transition support provided.
- Some family carers were linked with a Transition Worker and received early transition preparation within the school, involving other health professionals such as paediatrician, speech and language therapists, physiotherapists, psychologists, the Autism team, etc.
- Other family carers reported a poor transition experience for their son/daughter with a learning disability, when moving from school to adult services.
- No family carers reported receiving training on puberty in young people with learning disability and autism.

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“We did have a very good social worker in the children’s disability team, but like everything else that came to a very quick halt. Literally, he was 17 one day and he was a child, and he was 18 the next day and he was no longer a child. So, I suppose having to transition into adult services has been very difficult, because whereas now it’s more difficult navigating adult services now.”

(Family carer, focus group 4)

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“My son’s behaviour became very difficult when he reached puberty. Before that he was just a very hyperactive sort of lovely little boy, but when he hit puberty, his behaviour completely changed, and deteriorated, and he became very, very agitated, and severely self-injurious to the point that we could not manage him at home anymore full-time. So, I suppose we got the support because we literally were at crisis point, like literally.”

(Family carer, focus group 4)

“On the Thursday I was dealing with ID CAMHS, but on the Friday morning they could no longer deal with me. I had to go through the adult services. All of the relationships and the context I had made in children’s services just like literally overnight were gone. Then the next day you’re an adult, regardless of the level of your difficulties.”

(Family carer, focus group 1)

“I got off the phone and I cried. I literally burst out crying because I had spent a year and a half chasing people to support my son in school to transition, something that should have happened automatically, I shouldn’t have had to chase this up, it shouldn’t have been this complicated.”

(Family carer, focus group 3)

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Adult to older adult services

- Of the 166 family carers who took part in the survey, half (51%) had talked about who would care for their relative with a learning disability, if they themselves were no longer able to provide care.
- A few family carers had talked to their social worker/key worker, consultant, or a solicitor. For only a third (34%), such conversations about future planning ended in a future plan, or a will being written.
- Some of these plans were aspirational with nothing clearly agreed, in other cases family carers had agreed for the person with the learning disability to live with another family relative, or in supported living scheme.
- Other family carers reported that they did not want another son/daughter caring for the person with the learning disability, due to the stress that this may cause.



“I’m just assuming one of my other sons, probably the oldest boy will look after his brother [with learning disabilities], but I have never talked about it with him. That is something that needs to be talked about and prepared for; I always think who is gonna care or look after my son with learning disabilities when I die.”

(Family carer, focus group 4)

“Who prepares the young person about where they’re gonna go, who are you gonna live with? That is something that probably does need to be talked about and prepared for the day that it happens.”

(Family carer, focus group 1)

“I don’t know who will care for my daughter with learning disabilities when I die, but I don’t expect my daughter to do that because she has her own life to live. And I wouldn’t want to put that on her, you know. It would be a big worry.”

(Family carer, focus group 3)



Key messages

The numbers of people with learning disabilities across Northern Ireland are continuing to rise, which will increase the demand for services in the future for the person with the disability and the family carers: both need to be seen together.

Family carers are the cornerstone of caring, and they are free, however they are providing caring services at a cost to their physical, mental, and social health. The needs of family carers need to be recognised.

It is imperative that family carers are given the support that they need, to enable them to continue to care for their loved ones.

Different populations have different needs (those children in school, those who will transition from children to adult services, complex physical health needs, behaviours that challenge, mental health, and older people).

Day services and overnight respite provision are crucial for families to continue caring, but levels of respite provision have not returned to the pre-COVID-19 rates. Family carers are strongly calling for this situation to be urgently addressed.

There is a lack of family carers support groups and sibling support groups.

There is a lack of training offered to family carers and siblings.

Direct payments are helpful but they are not being fully utilised.

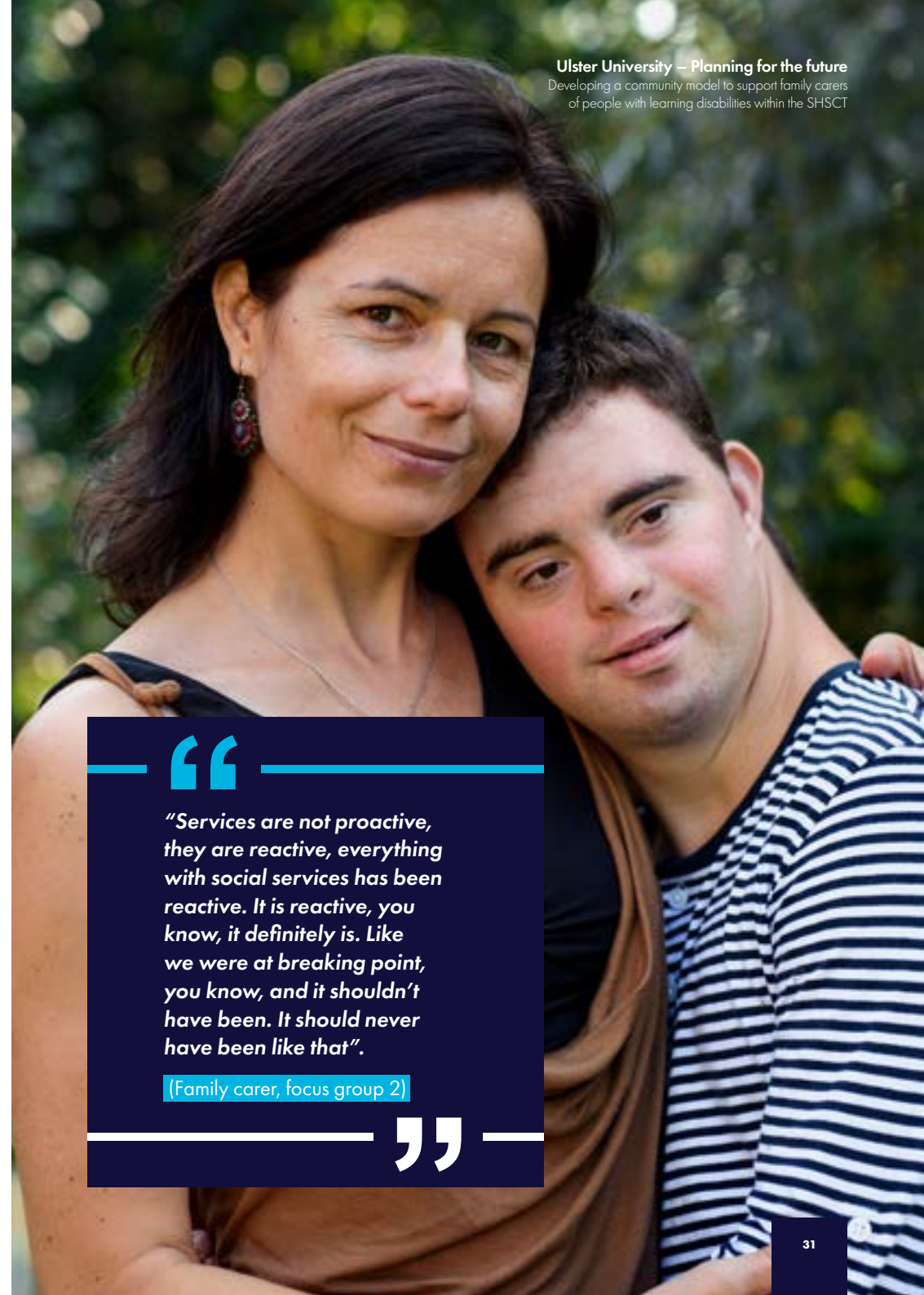
Different housing options are needed to support adults with a learning disability: a multi-agency approach is needed that maximises working with different housing organisations.

Caring needs to be pro actively planned across the lifespan, and not just when a crisis occurs.

Commissioners, policymakers, and service providers must urgently, and radically, rethink current models of family support and service provision.

There is a need to pool existing resources, place greater emphasis on “family-centred care and support” and create new community-based initiatives:

- Supporting family carers
- Redesigning services
- Transition planning across the lifespan



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“Services are not proactive, they are reactive, everything with social services has been reactive. It is reactive, you know, it definitely is. Like we were at breaking point, you know, and it shouldn't have been. It should never have been like that”.

(Family carer, focus group 2)

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Operational recommendations: Family carers and caring

Greater partnership working with family carers

The **rights of family carers** of people with a learning disability across the lifespan should be more clearly recognised as a priority within the SHSCT policies (including but not limited to, full recognition of the valuable role they provide, and access to appropriate support services to enable them to continue caring).

Engaging with family carers

The Trust should review how it currently engages with family carers and explore new and effective ways to work collaboratively with these carers, to develop and improve services delivered to the SHSCT learning disability population.

Single point of contact for family carers

We are aware that there are existing information sources (case managers, carer consultants and SHSCT website),

however based on the views of the family carers and stakeholders who participated in the co-production workshops, it is recommended that their needs to be a **single point of contact** where families can access practical information and signposting about all services/support opportunities within their area/community.

Family carer and sibling support groups

The Trust needs to develop and appropriately resource **family carer support groups, and sibling support groups**, in local areas providing carers and siblings with practical information, emotional support, signposting on statutory/voluntary learning disability and older peoples' services, empowerment, and the opportunity to engage with other family carers (i.e., face to face groups, online format, message board and lists of resources). (see the **Better Futures Project** below as an exemplar of a low-cost community intervention for family carers).

Sibling support interventions include conferences, support groups (in-person and on-line) and information provision. International examples include 'Working for adult siblings of disabled people' (<https://www.sibs.org.uk>) and the National Sibling Leadership Conference, USA (<https://siblingleadership.org/media-library/past-conferences/2021-sln-conference/>). These gatherings provide opportunities for siblings to increase their involvement in disability advocacy, policy making and services, and can support siblings to become carers for the future.

Training of family carers and siblings

Parent carers and siblings should have access to **evidenced-based education and training programmes**, designed to provide support and optimise their ability to provide care for people with a learning disability. Topics to included, but are not limited to: behaviours that challenge, enduring mental health problems, complex physical health needs, and support for those in the process of transitioning from children to adult services, and adult to older persons services. An example is the **Early – Positive Approaches to Support (E-PATs)** project which is an 8-week parenting programme for young children with learning disability and/or autism currently taking place across the

UK (delivered by MENCAP in Belfast and Derry/Londonderry (<https://research.kent.ac.uk/tizard/e-pats/>)).

An online support and counselling service for carers should be established, piloted, and evaluated.

Family support programmes should be individualised, multi-faceted, focused on early intervention and delivered over multiple sessions.

Training of Health and Social Care Staff

Health and Social Care staff should have access to **evidence-based education and training programmes**, designed to provide support and optimise their ability to provide care for people with a learning disability with behaviours that challenge, enduring mental health problems or complex physical health needs, and those in the process of transitioning from children to adult services and adult to older persons services (NICE Guidelines on Challenge Behaviour and Learning Disability (2015): <https://www.nice.org.uk/guidance/ng11>); (NICE Guidelines on Mental Health and Learning Disability (2016): <https://www.nice.org.uk/guidance/ng54>); and NICE Guidelines on Older People and Learning Disability (2018): <https://www.nice.org.uk/guidance/ng96>).

Training should focus on the needs of young people, adults and older adults with learning disabilities with topics included, but not limited to: health screening through annual health checks, physical and mental health promotion, autism, sexuality/puberty, reduction in sedentary lifestyles, obesity, greater engagement in the community, etc. (an example is a current research project being conducted at Queens University Belfast developing Best Practice Guidelines on Relationships and Sexual Education for Children and Young People with Learning Disabilities).

Self-directed support and direct payments

Families should be encouraged and supported to **use self-directed support and direct payments** to ensure that their family member with a learning disability continues to have a meaningful day and that they have access to the support they need to remain within the family home.

Training and support needs to be offered to both family carers and staff on what are Direct Payments and how to use/manage Direct Payments (<https://cilni.org>).

Direct Payments are provided by the Trust to meet social care needs identified through assessment. Families remain frustrated that direct payments cannot be used to meet health care needs.

Review of carers assessment and carers grant

All family carers should be offered a **carers assessment** that includes an assessment of the needs of the family unit (a 'family centred assessment') and be reviewed yearly.

Family carers should be informed about the **Carer's Cash Grant**, in light of the recommendations reviewed in this study the **Carer's Cash Grant should be reviewed** in terms of its financial range and utility scope.

Recognising adults with a learning disability who become reciprocal carers

The SHSCT should pro actively and pre-emptively identify those adults with a learning disability who will likely become carers for their ageing parents, assess their needs and support them, offering short breaks/respite in the same way as it is made available to other family carers

(see Truesdale et al 2021 who undertook a number of interviews with adults with learning disabilities in Northern Ireland about caring for an older parent).

Use of technology

Identify assistive technology solutions that can promote continued independence and monitor and support family carers' health, in order to enable them to maintain their caring role within their own home (i.e., tele-health, home-adaptations) (see Tasse et al 2020 for a discussion on the benefits of technology for people with learning disabilities and their family carers).



Operational recommendations: Service support

Housing options

The SHSCT should work with the NIHE, and other housing providers, to identify and develop additional family placement schemes beyond traditional statutory learning disability residential and supported living schemes, such as home ownership, co-ownership, and shared lives options.

Day care

This report recommends that the SHSCT should return day-care placements for adults with a learning disability to pre-COVID-19 levels thereby providing the vital respite that so many family carers need to continue caring.

To review existing statutory learning disability day opportunity provision to ensure that it is fit for purpose and meets the changing needs and choices of people with a learning disability. Examine the opening times of these day-centres from beyond Mon-Fri to Mon-Sun, and from 9.30am-3.30pm

to 9am to 9pm, thus offering adults with learning disability and their family carers greater choice and flexibility.

Learning disability day-centres to engage with older person day-centres in order to scope the enablers and barriers to such integration. This would be in keeping with the DHSSPSNI (2005) paper on 'Ageing in an Inclusive Society' that endorsed delivering integrated services that would improve the health and quality of life of older people with a learning disability and have access to services and facilities that meet their needs and priorities.

Respite

We recommend the SHSCT undertake a review of the demand for, and availability of, day and overnight short break/respite options including shared lives, adult family placements and short breaks that bring added value to people with a disability and their family carers.

Implementing evidence-based intervention to support family carers

There have been a number of funded projects that regional charities across Northern Ireland have developed and delivered, including family carer interventions targeting children and adults with learning disabilities. Such successful projects have been time and financially bound and have therefore subsequently ended. The Trusts have failed to implement these low-cost community-based interventions. We recommend the SHSCT to engage with these local charities to continue to fund such evidence-based community initiatives, given their success stories.

An example of this is the Better Futures Project developed and delivered by Positive Futures, funded by the Big Lottery. This programme focused on supporting older family carers of older adults with a learning disability. The Better Futures project developed a bespoke array of family services (i.e., respite/short break, family carer support

groups, practical information, emotional support, knowledge information sharing, signposting, emergency, and future plans) that clearly met the specific needs of each of these families. The Better Futures project clearly addressed the needs of the adults with a learning disability and their family carers, and was found to be a low-cost community project compared to the high-cost services provided by the Trust (https://www.positive-futures.net/cmsfiles/downloads/other/UUBetterFutures_Report-13June16.pdf).

Operational recommendations: Transitions across the lifespan

Children to adult transition

An **urgent review** is required of the support offered to children with a learning disability transitioning from children services to adult services, that should focus on: early initiation and preparation for transition, identifying a lead agency, outlining responsibilities, parent-provider relationships, improved joined and multi-agency working, effective information sharing, adequate follow-up, a transition coordinator, and multi-professional involvement (see Brown et al 2019 for a systematic review of the literature on this topic, and Brown et al 2022 for an on-line learning resource that offers the potential for health and social care staff to undertake evidence-based, structured further education regarding the effective transitions for young adults with learning disabilities and their families).

Clearer communication and co-ordination is needed between the different multi-agencies and professionals involved in a young person's life, family carers, school and health professionals.

We recommend that the SHSCT engage with the SPPG in their review of transition provision and develop a Transition Team in each area that offers a smoother transition for the young person with a learning disability and family carer, that does not stop automatically at 18/19 years of age, but the Transition Team continue to support the family into early adulthood.

The Transition Team should be the **one point of contact** that the family and schools can approach, providing accessible information of the different stages of the process, regarding the different opportunities available, and can act as a conduit for sharing good practice.

Parent carers and paid staff should have access to **evidenced-based education and training programmes**, designed to provide support and optimise their ability to provide care for the young person with a learning disability with communication, sleep, toileting, autism, behaviours that challenge, promoting emotional well-being, complex physical health needs, sexuality/puberty,

preparing for adulthood, etc. (see Schmidt et al (2020) for a review of sexual health education programmes for adolescents with learning disability).

Family support programmes should be individualised, multi-faceted, focused on early intervention and delivered over multiple sessions.

Adult to older person transition

All parents of adults with a learning disability should be offered the opportunity to **develop a future plan**, including an emergency plan, housing options, financial planning, making a will. These plans should take into account the contribution of siblings (a family-centred approach) and should establish a circle of support for the older person with a learning disability and their ageing family carers. A training resource that addresses these needs already exists (see Taggart & Thompson 2015: <https://pure.ulster.ac.uk/ws/portalfiles/portal/11622262/FuturePlanningReport%28WEB%29->



12June15.pdf).

Adults without a learning disability should be recruited to mentor and support older people with a learning disability to access and engage in mainstream community older people’s activities (e.g., Volunteering, Men Utd, Men’s Sheds, Gardening Clubs, Photography Groups, University of the Third Age). At the time of this report’s production, a new programme is being piloted within the NHSCCT called the Matilda Project that is supporting older adults with a learning disability to engage in their local community group (<https://www.ulster.ac.uk/research/topic/nursing-and-health/caring-for-people-with-complex-needs/research-themes/neurodevelopmental/matilda>).

The statutory and voluntary sector should **promote the health and well-being of older people with a learning disability and their ageing family carers via the Public Health Agency**, which has a responsibility to reach out and support people to access these services, by making

necessary ‘**reasonable adjustments**’¹ to all their mainstream community health programmes to ensure that they are accessible to this population (i.e. healthy living, health promotion, health education, vaccinations, health issues, men’s health, women’s health, mental health).

Training should be offered to all staff within both learning disability services and the older persons programme of care, and across the voluntary and community sector to improve their attitudes, knowledge and skills development to focus on the health needs of older people with a learning disability and their ageing family carers.

Local Councils also have a responsibility to reach out to support people to ensure that all mainstream community health programmes operate within their localities by making the necessary ‘reasonable adjustments’ for this population, (i.e., learning and education, employment support, sports, leisure and recreation, the arts, travel and access to transportation, home safety, benefits, planning

your retirement and well-being.

Dementia and people with learning disability

The international literature recognises that as the occurrence of dementia is expected to rise proportionately with the increase of longevity among adults with learning disability, **health and social care systems will have to become dementia ready** by improving their diagnostic and technical resources, as well as their care management supports (McCarron *et al* 2017).

Although screening and managing those adults with a learning disability who develop dementia was not identified within this study, we recommend:

- The **routine gathering of baseline data** so as to monitor suspected cognitive deterioration, from all adults with a learning disability over the age of 45;
- **Early screening for dementia** particularly for those adults with down syndrome from the age of 35 years as recommended by the NICE (2018) Guidelines On Older Adults with Learning Disabilities (<https://www.nice.org.uk/guidance/population-groups/people-with-learning-disabilities>); and

- **Proactive strategies to manage the person who has developed dementia** such as use of accessible information, use of early dementia medication to delay symptoms, reminiscence, memory and orientation work using visual reinforcement and personnel support, the development of memory clinics such as those delivered by the Sisters of Charity, Dublin for older adults with down syndrome and dementia (<https://www.tcd.ie/tcaid/research/NIDMS.php>); and palliative care and end of life services for this population.

We recommend **training for family carers, and health and social care staff**, on how to recognise the early signs of dementia and the management of dementia in adults with learning disability (see *Acton et al 2023* for a review of the literature that identify’s the value of and need for continued development in dementia education and training to improve person-centred dementia care).

¹Under section 49a of Disability Discrimination Act 1995 (as amended by the disability discrimination (Northern Ireland) Order 2006), public authorities when carrying out their functions must have due regard to the need to 1. Promote positive attitudes towards disabled people. 2. Encourage participation by disabled people in public life.

Strategic recommendations

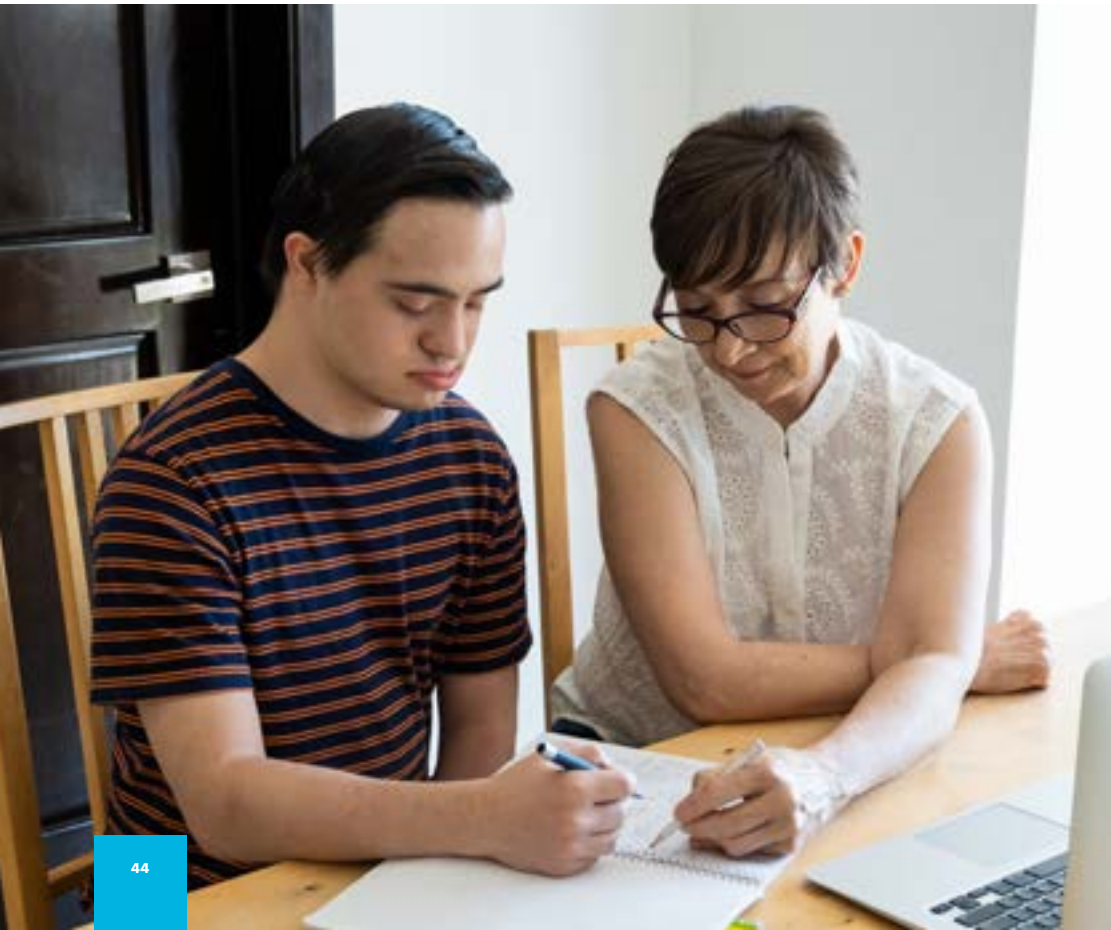
The SHSCT commissioned this report, and we have highlighted a number of recommendations for the Trust to consider to implement but recognise some of these recommendations will require partnership working, planning and funding with other statutory, voluntary and community agencies (such as PHA, SPPG, NIHE, Councils).

- To develop a regional **electronic register/database** in line with UNCRPD, Article 31, to help identify the numbers and needs of all people with a learning disability and their family carers across Northern Ireland. This would predict the likely rise in numbers over the coming 10-20 years, as well as the potential for measuring community participation, health inequalities, access to services and morbidity levels. Data could be obtained from the 2021 Northern Ireland Census (<https://www.nisra.gov.uk/publications/census-2021-main-statistics-health-disability-and-unpaid-care-tables>).

- Establishment of a **Family Manifesto/Charter** to protect the rights of people with a learning disability and their family carers, overseeing and guiding on issues such as a Carer's Bill; Direct Payments; Entitlement Legislation (Make the Call Campaign, COPNI, 2015).
- To develop a **Family Carers Bill for Northern Ireland** aimed at promoting the rights and requirements of all family carers of children and adults with a learning disability.
- A cross-departmental working group should be put in place to oversee the establishment and operational management of an **'Expert Committee'** to advise on how services can be developed to meet the needs of family carers and people with a learning disability given the recommendations listed above. This committee should have the authority to hold these organisations (i.e., HSCT's, Councils, Public Health Agency) and the Trust's Carers Champions accountable.
- The Department of Health should ensure that the proposed **New Service Model for Learning Disability Services** is validated with persons with learning disabilities and their family carers.
- Northern Ireland should appoint a **Champion for Learning Disability and Family Carers** to bring a co-ordinating function to the HSCT services, and an advocating role for people with learning disabilities and their family carers at both public and governmental levels. This should be modelled on roles such as that held by Prof Siobhan O'Neill, who is the current Mental Health Champion for Northern Ireland.
- All family carers and people with a learning disability should be supported to access the **Equality Commission** and the **Law Centre** if their needs are not being met.
- All service providers (statutory and voluntary) **need to evidence leadership and share responsibility** to build the relationships required to ensure that existing service models are **reshaped and co-designed with people with a learning disability** to create new cost-effective solutions.
- New solutions ('best practice') must be proactive and require a **change of mind-set** on the behalf of all stakeholders, to enable people with a learning disability to become actively involved within their communities ('positive risk-taking').
- **Everyone has a responsibility to ensure that our communities are welcoming and inclusive** of all, and that people with a learning disability are provided with opportunities to have their contribution valued and have a real role within their individual communities.

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References

Acton, D.J., Jaydeokar, S. and Jones, S. (2023), "Dementia education and training for caregivers supporting older people with intellectual disability: a scoping review of the literature", *Advances in Mental Health and Intellectual Disabilities*, <https://doi.org/10.1108/AMHID-02-2023-0006>.

Bamford Review (2006) *The Bamford Review of Mental Health and Learning Disability (NI): Equal Lives: Review of Policy and Services for People with a Learning Disability in NI*. Belfast: DHSSPSNI.

Bigby C, Whiteside M, Douglas J. Supporting decision-making of adults with intellectual disabilities: perspectives of family members and workers in disability support services. *J Intellect Dev Disabil*. 2019;44(4):396–409.

Brown, M, MacArthur, J, Higgins, A, Chouliara, Z. Transitions from child to adult health care for young people with intellectual disabilities: A systematic review. *J Adv Nurse*. 2019; 75: 2418– 2434. <https://doi.org/10.1111/jan.13985>.

Brown, M, MacArthur, J, Truesdale, M & Higgins, A (2022) *The transition from child to adult health services for young adults with intellectual disabilities: An evaluation of a pilot of an online learning resource for Registered Nurses*. *Nurse Education in Practice*, Volume 64. <https://doi.org/10.1016/j.nepr.2022.103424>.

COPNI (2013-2015) *Corporate Plan: Hope Confidence Certainty*. Available from: <https://www.copni.org/media/1132/copni-corporate-plan-hope-confidence-certainty.pdf>.

DHSSPSNI (2011) *Transforming Your Care: A Review of Health and Social Care In NI*. Belfast: DHSSPSNI.

DHSSPSNI (2011a) *The Learning Disability Service Framework*. Belfast: DHSSPSNI.

DHSSPSNI (2011b) *Improving Dementia Services in Northern Ireland – a Regional Strategy*. Belfast: DHSSPSNI.

DHSSPSNI (2006) *Caring for Carers: Recognising, Valuing and Supporting the Caring Role*. Belfast: DHSSPSNI.

Department of Health Review: *Winterbourne View Hospital: Interim Report Winterbourne View Review: Concordat: A Programme of Action. Transforming care: A national response to Winterbourne View Hospital* (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf).

Flynn, S., Hastings, R.P., Burke, C. et al. *Online Mindfulness Stress Intervention for Family Carers of Children and Adults with Intellectual Disabilities: Feasibility Randomized Controlled Trial*. *Mindfulness*

11, 2161–2175 (2020). <https://doi.org/10.1007/s12671-020-01436-0>.

MENACP Report (2012) Housing crisis will turn back the clock for people with a learning disability Housing crisis will turn back the clock for people with a learning disability (mencap.org.uk).

McCarron, M., McCallion, P., Reilly, E., Dunne, P., Carroll, R., & Mulryan, N. (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of Intellectual Disability Research*, 61 (9), 843–852. <https://doi.org/10.1111/jir.12390>.

NICE Guidelines on Challenge Behaviour and Learning Disability (2015): <https://www.nice.org.uk/guidance/ng11>.

NICE Guidelines on Mental Health and Learning Disability (2016): <https://www.nice.org.uk/guidance/ng54>.

NICE Guidelines on Older People and Learning Disability (2018): <https://www.nice.org.uk/guidance/ng96>.

Schmidt, E.K., Brown, C. & Darragh, A. Scoping Review of Sexual Health Education Interventions for Adolescents and Young Adults with Intellectual or Developmental Disabilities. *Sex Disability* 38, 439–453 (2020). <https://doi.org/10.1007/s11195-019-09593-4>.

Ryan, A., Taggart, L. & Truesdale-Kennedy, M. (2014): Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. *The International Journal of Older People Nursing*, 9 (3). pp. 217-226.

Slevin, E. McConkey, R. Taggart, L. Barr, L. & Sowney, M. (2011): A rapid review of literature relating to support for people with intellectual disabilities and their family carers when the person has: behaviours that challenge and/or mental health problems; or they are advancing in age. Ulster University. (Laurence Taggart – Research output – Ulster University).

The Disability Discrimination Act (1995). London: Stationery Office. Available from: <http://www.legislation.gov.uk/ukpga/1995/50/contents>.

Taggart, L. (2016): 'Better Futures Project Final Report: "They ask and they listen and they act and they care."' Ulster University, Newtownabbey.

Taggart, L., Truesdale-Kennedy, M., Ryan, A. & McConkey, R. (2012): Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, 16 (3), 217-234.

Tassé, MJ, Wagner, JB, Kim, M. Using technology and remote support services

to promote independent living of adults with intellectual disability and related developmental disabilities. *J Appl Res Intellect Disabil*. 2020; 33: 640– 647. <https://doi.org/10.1111/jar.12709>.

Truesdale, M., Taggart, L., Ryan, A. and McConkey, R. (2021), Experiences of Reciprocal Caring Among Adults With an Intellectual Disability Caring for an Older Family Member. *Journal of Policy and Practice in Intellectual Disabilities*, 18: 240-248. <https://doi.org/10.1111/jppi.12380>.

United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol (2006). New York and Geneva: United Nations. Available from: <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>.





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