‘Living Longer, Living Well’

Survey Findings Report –

“good now, uncertain future”

October 2026

www.arcni.org.uk

Executive Summary

The survey shows that many respondents are happy with their lives today, but are less certain about future housing, health, independence and support. Earlier, accessible planning is needed to help people maintain their quality of life as they age. Our key message is the **"good now, uncertain future"** finding. The very high satisfaction figures initially make the survey look overwhelmingly positive, but the responses on future housing, ageing, family support and later-life planning expose a substantial gap in preparedness and age appropriate services.

1 Introduction

As part of Learning Disability Week 2026, ARC NI and the learning disability community celebrated the fact that people with a learning disability are living longer. However, people with a learning disability continue to face inequalities and this is not ok.

The Living Longer, Living Well survey sought to understand what matters to people as they get older, their experience of current support and services, and what needs to change to help people live longer, healthier and fulfilling lives. TILII Translates developed an Easy Read survey which explored health, housing, choice and independence, friendships, social opportunities, transport, employment, information and planning for later life. ARC NI circulated a PDF and survey monkey link throughout its networks and promoted the survey on its website.

In total, 174 people with a learning disability completed the survey. The findings describe this survey sample and should not be assumed to represent everyone with a learning disability, but rather describe a snapshot of the issues.

2 Who responded

Respondents represented a broad age range, from 18–24 through to people aged 65 and over. The age groups recorded in the updated survey were:

- 18–24 years — 15 respondents
- 25–34 years — 32 respondents
- 35–44 years — 37 respondents
- 45–54 years — 32 respondents
- 55–64 years — 29 respondents
- 65 years+ — 23 respondents

The age groups listed total 168 respondents. Six people selected "Prefer not to say".

People lived in a range of settings. The two largest groups were living with family (71) and supported living (66). Others lived in residential care (12), on their own (8), or other arrangements (15), including nursing care and living independently with support. Two people did not answer this question.

A significant proportion currently rely on either family or formal support. Concerns about what happens when parents or other family members are no longer able to provide support feature strongly in the responses.

3 Key messages

People are generally happy with their lives now

People shared positive messages about their current quality of life. Of those answering the relevant questions:

- 92% said they were happy with life.
- 95% said they felt safe.
- 88% felt they had enough choice.
- 83% felt listened to.
- 87% said they had enough friends.
- 87% felt they got out enough.
- 94% said they could do the things they enjoy.

People frequently described being happy with their home, staff, family, friendships, activities and opportunities. These findings demonstrate the value of good support, meaningful relationships, choice and opportunities to participate.

However, there was also some that wanted more time with staff, more opportunities to go out, greater independence, more activities and opportunities to make friends. Having a good life was described as having relationships, fun, being active and being part of the community, as well as services.

Health is the clearest priority

Health and access to appropriate healthcare emerged as strong themes throughout the survey. Most people reported positive experiences of their current health support:

- 83% said they could access health checks.
- 88% felt there was enough support to stay healthy.

137 of 168 respondents (82%) said they could see their GP when needed however commented on needing the support of staff or family. One person said “It is really hard to get an appointment when I need one, I have to make lots of calls.”

Only 64% said they understood information about their health. A further 25% were unsure and 11% said they did not understand the information they received.

One person stated, “Sometimes talking about my health is overwhelming. People need to speak slow and explain.” Another said, “Need easy reads as information can be too difficult. I cannot read but pictures really help.”

Respondents called for more learning disability knowledge among healthcare professionals, better mental health support, accessible health information, and more support to remain physically active.

One person stated “I’m worried about experiencing menopausal /hormonal changes.”

In short, people need timely, accessible healthcare delivered by professionals who understand learning disability and individual communication needs.

One person shared, “When I am going to GP's I need support because I am scared of needles.”

Staying healthy helps people live longer and live well
When asked what one thing would help people live longer and live well, consistent answers related to health, exercise, diet and staying active. People talked about exercising and walking more, eating healthier food, maintaining mobility, attending health checks, getting healthcare when needed, taking part in sport and remaining socially connected.

One person shared, “staff are always sharing how to eat healthy and to exercise each day.”

People recognised the importance of prevention and maintaining good health however they need practical opportunities and support throughout life to exercise, eat well, understand their health and maintain physical and mental wellbeing.

One person suggested, “I would like more health checks especially as I get older. Once a year is not enough.” Another suggested “Start some groups where people talk to us about our health. Everything is online or goes through my mum.”

Current housing works well but future housing is less certain
91% were happy where they currently live, while 96% said their current home meets their needs. When asked whether their home would continue to meet their needs as they got older, only 57% said yes, 36% were unsure and 7% said no.

A person stated “I want to stay where I am but I know I cannot. It’s so difficult as I am happy.” Another said “Sometimes the house is too big as I am not very good with a hoover, duster or mop and washing machine.”

Respondents raised future mobility, adaptations, accessible bathrooms or bedrooms, additional support and whether they could remain in their existing home. Some were clear that they wanted to remain in their own home as they aged.

One person shared, “It does now but I worry about when I get older, I will need more changes like a downstairs bedroom and wet room.”

Housing planning needs to take place before circumstances reach crisis point. It should consider accessibility, adaptations, changing support requirements and people’s right to have a meaningful say in where and with whom they live.

Ageing brings significant uncertainty
39% said they were worried about getting older, 39% were not worried and 22% were unsure. Comments revealed concerns about declining health, losing mobility and independence, loneliness, illness, moving home, losing parents or other family members and uncertainty about future support.

For some, the concern was what ageing might mean for their independence, relationships, home, health and support. Several specifically worried about what would happen when their parents died or could no longer support them.

One person shared, “What happens when I am on my own. Mum and Dad won’t always be here.” Another stated “My sister died recently so I am worried about what will happen to me.”

Too few people are planning for later life
When asked whether anyone had talked to them about getting older, 38% said yes, 48% said no and 14% were unsure. Only 28% said they had made plans for later life; 48% had not and 24% were unsure.

One person stated, “I would like to talk about getting older.” Another stated “I would like to be buried in Graceland with Elvis.”

72% had either not made plans or were unsure whether they had. Where planning had taken place, respondents frequently referred to funeral arrangements, wills and burial wishes. These are important, but later-life planning needs to be broader.

Planning should explore where people want to live, what happens if their health changes, how they will stay connected to friends and activities, who will support them, what happens as parents or carers get older, and what support they would want at the end of life.

One person shared, “I’m scared of dying and I’m afraid of the dark.” Another stated, “My family have taken care of this but I don’t know the details.”

Some respondents referred positively to involvement in Advance Care Planning films, describing how these helped them understand and think about the future.

One person stated, “We made films about Advanced Care Planning so I learnt a lot about it.”

Accessible, person-centred resources can enable people to participate meaningfully in planning their own lives.

People need greater certainty about future support
Around 65% said they knew who would support them in the future. A further 26% were unsure and 9% did not know. Many identified parents, brothers, sisters or other relatives, often alongside support staff or social workers.

One person shared, “I’m worried about when my dad dies, and keeping healthy.” Another said, “I’m worried about my mum dying, this scares me. I’m also worried about becoming ill and having a terrible death myself.”

Some recognised that parents were getting older and relatives had jobs and responsibilities. Future planning cannot assume that family support available today will remain available throughout a person’s lifetime.

One person stated, “What happens when I am on my own. Mum and Dad won't always be here.”

Social connection and opportunities matter
Although most reported having friends and doing things they enjoy, requests for more social opportunities appeared repeatedly. People wanted more clubs and social groups, evening and weekend activities, opportunities for older people, outings, sport, concerts, cinema, community activities, friendships, employment, meaningful placements and greater choice in day opportunities.

One person shared, “I can be bored and get lonely. I’m happy when I have money, but managing this is difficult and can make me sad. My seizures can make me unhappy with life.”

Several wanted opportunities appropriate to their age. Friendship, relationships, employment, meaningful activity, community participation and having fun are all part of living well.

Transport is a barrier for a significant minority
73% said transport was not currently a problem. However, 22% said it was a problem and a further 5% were unsure. For those affected, transport can determine access to healthcare, employment, social activities, day opportunities and friendships.

Respondents described buses reportedly accommodating only one wheelchair user at a time, preventing siblings from travelling together, and difficulty obtaining wheelchair-accessible taxis. One person said, “My sibling and I can’t travel together”. Others requested more accessible gyms, bigger lifts and improvements to uneven footpaths.

A person shared, “I don’t get much chance to do many things on my own and there aren't many activities for me to do where I live.”

Some people, particularly those in rural areas, highlighted difficulties accessing suitable community transport. Transport enables independence: better services and opportunities will have limited impact if people cannot reliably access them.

People want more independence with the right support
Respondents wanted to go out independently, live on their own with support, learn new skills, get a paid job, rely less on parents, choose activities and receive enough staff support to participate in ordinary community life.

One person said, “I would like more groups for people my own age. Someone else to talk to that isn't always my parents.”. Another said “I don't want grey hair.”

For many, independence meant having the right support to make their own choices and do more for themselves. This should be central to the development of future services.

4 What people say needs to improve

Accessible and appropriate healthcare
Timely access to GPs, health checks, mental health support and professionals who understand learning disability is needed. Health information should be accessible, including Easy Read.

Other responses requested counselling, more visual aids and clearer information about available support. One respondent described services addressing learning disability or physical disability, but not always both, highlighting the need for support that responds to combined needs.

Prevention and healthy lifestyles
People want opportunities to exercise, remain mobile, eat well and understand how to look after their health throughout life.

Planning for ageing
Accessible conversations should begin earlier and cover housing, health, relationships, finances, support and future care, alongside funeral and end-of-life arrangements.

Housing that meets changing needs
Housing planning should anticipate changes in mobility, accessibility and support, enabling people wherever possible to remain in their chosen home and community.

Support beyond the family
Future support arrangements should be discussed before family circumstances change, particularly for people who depend on ageing parents and relatives.

Meaningful social opportunities
More age-appropriate clubs, activities, exercise, employment and day opportunities are needed, including evenings and weekends.

Independence and choice
People should have opportunities to learn skills, make decisions, work, travel and participate in their communities with the support they require.

Listening to people
People with a learning disability need to be directly involved in decisions about policies and services affecting their lives. Other respondents asked people to stop talking over them and described feeling brushed off. These comments reinforce the need for respectful communication and support that enables people to express their own views.

One person summarised the message as: “We need good support to live our lives well.” Another stressed the importance of being valued, respected and heard: “You just need to listen to us.”

5 Conclusions

Many respondents are happy, active and positive about their lives today. Most feel safe, enjoy where they live, have friendships and feel they have choice. The challenge is sustaining this quality of life as people age.

Our key message is the **“good now, uncertain future”** finding. The very high satisfaction figures initially make the survey look overwhelmingly positive, but confidence falls when people consider future housing, support and later-life planning. Declining health, loss of independence, the death or ageing of parents and relatives, loneliness and uncertainty about support are substantial concerns.

Planning for an ageing learning disability population should cover health, independence, relationships, a suitable home, meaningful activities, community connections, choice and control throughout life.

Respondents want to remain healthy, active, connected, listened to and supported to live the life they choose. Policy and service development should support earlier planning, with people with learning disabilities involved in designing good support in later life.