

Leading my life, my way

A briefing on young disabled people's experiences of living independently

Scope
About disability

Scope is a charity that exists to make this country a place where disabled people have the same opportunities as everyone else. Until then, we'll be here.

Introduction

Leading my life, my way is a new research report by Scope, which looks at the experiences of young disabled people who use support services to live independently. Our research suggests a significant proportion of young disabled people feel many of these services are failing them across a number of key areas in their lives.

We found the main areas requiring improvement are the range of support services that young disabled people receive; their care and support plans; access to advocacy, information and advice; and the impact of social care on their ability to achieve greater independence. In addition to these unmet needs, we also found some young disabled people are left feeling socially isolated because of a lack of support for them to participate in their communities. [Read the full report here.](#)

“...am I going to have the right level of staff to support my needs? How do I explain the rules?’ There are all these issues that were never explained to me as a younger person in that process.” Murphy, 26, North West

What is independent living?

For many young disabled people, independent living is not just about choosing where to live, it's also about:

- Choice and control over life decisions such as education and employment
- Being active in their community
- Having the right support to enter employment or study
- Getting support with essential tasks like getting out of bed, showering and going to the bathroom.

Support services

Some young disabled people need improved support to achieve greater independence in their lives. 29 percent reported support services, specifically social care services, do not support them to live independently. In particular young disabled people told us they have unmet needs in areas such as transport, where to live and employment.



29 percent of respondents don't think the social care services they use support them to live independently.

Recommendation

Social care teams supporting young disabled people should build partnerships with local specialist employment services to support people who use their services to access up to date information and support that is relevant to them. This should be underpinned by both a commitment from central Government, and cross-departmental collaboration, to join up support for young disabled people within the forthcoming Green Paper on disability, health and work.

Care and support plans

A key indicator of adequate choice and control in a person's life is the extent to which disabled people feel they are able to exercise their rights in their daily decisions. Whilst over half of respondents said they can make decisions, one in ten said they were unable to make any decisions in their care and support plans. This demonstrates that some care users are not fully in control of the care they receive. This is contrary to the Care Act, which places the care user as the person most able to determine their care plans. Additionally, one in five young disabled people feel the support they have received is generally worse than what was agreed in their care plan.



One in ten respondents said they have not made any decisions in developing their care and support plan for 2016.

Recommendations

Local authorities should make care workers and assessors aware of their Care Act duties. Resources commissioned by the Department for Health, and delivered by the Social Care Institute for Excellence, and Think Local Act Personal, offer examples of best practice and information on delivering the Care Act. It is imperative that the care and support planning process is one led by the care user themselves.

Access to advocacy, information and advice

Survey respondents reported a disparity between the demand and service availability of information, with the most common areas they would like to access for advocacy, advice and information, not being the areas currently provided. Smartphone apps are an increasingly common form of communication. We found 20 percent of our respondents want to use apps for information and advice but just one percent can. It is important that support services are engaging with young disabled people with their preferred communication platforms. These can be simple, cost-effective, and efficient ways of communicating with young disabled people to ensure they are able to find the right support for them, or to make informed decisions on different aspects of life quickly and easily. In particular, our respondents want more information and advice on employment, various aspects relating to social inclusion, and community involvement. (See figure 1 for a breakdown of areas young disabled people require more support on.)

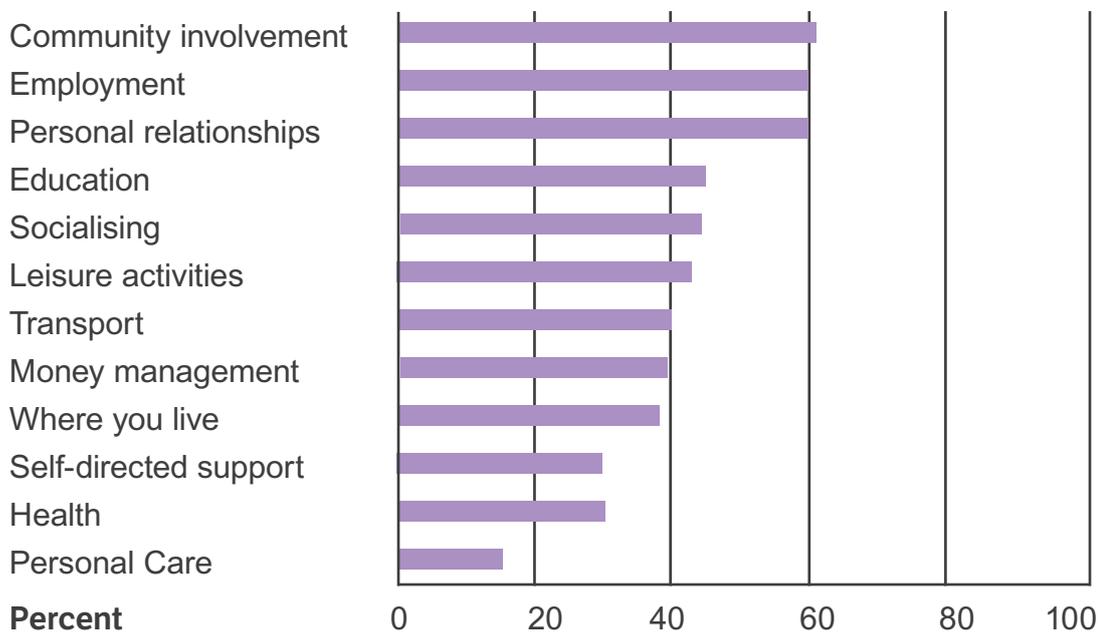


20 percent of respondents want to use mobile phone apps for information and advice services but only **one percent** can.

Recommendation

Local authorities should work closely with young disabled people and third sector partners to create information products that meet the needs of young disabled people that are delivered in ways that are tailored to them.

Figure 1: Areas where respondents seek greater support



Impact of social care

For young disabled people that require extra support to live independently, social care is essential. Our research suggests care standards are only meeting the basics, and many young disabled people are not being supported to live independently. Two thirds of respondents reported a significant setback to their social care that has prevented them from living independently, with 82 percent waiting at least six months for a solution. The Care Act mandates that local authorities resolve a care issue within six months. These findings suggest in some areas social care services are unable to meet their statutory duties to support an individual's wellbeing

Recommendation

A sustainable funding settlement would increase the capacity and resources of local authorities and meet the standards set within the Care Act to enable independent living.

For further information or to discuss the research and recommendations further, please contact Jonathan Lima-Matthews, Policy Adviser

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