DOWN'S SYNDROME ASSOCIATION

Report



It's My Life Survey

Headline findings

The Down's Syndrome Association is the only charity in England, Wales and Northern Ireland focusing solely on all aspects of living successfully with Down's syndrome.

Our aim is to help people with Down's syndrome live full and rewarding lives.

Established in 1970, the DSA has evolved from a parent member organisation into a leading national charity which strives to improve the lives of people with Down's syndrome and raise awareness of the condition.

Summary

People with Down's syndrome require care and support, and are entitled by law to that care which has been assessed as relevant to their eligible needs.

Through the many calls, letters and emails to our helpline service and discussion with our members we have become increasingly concerned at the level of social care support available to adults with Down's syndrome.

We surveyed a sample of our members to help us get a better view of the good experiences as well as the negative issues. The survey asked for personal experiences of adults (18+) needs assessment, planning, care support and the review process, and two separate surveys were devised- survey 1 for parents/carers and survey 2 for adults with Down's syndrome and there were 634 and 602 responses respectively.

We found that care and support offered is often poor in quality and quantity and seriously lacks attention to health conditions (sadly some people have died). Support is often inadequately funded and can be cut at review with no justification. Families are expected to continue to provide care and support which many do willingly; others because they feel there is no choice.

Family carers and people with Down's syndrome report long delays in accessing a service, inadequate services and increasing costs not being met, which are all contributing to a significant decline in the well-being of our members.

Reduced levels of social activity, engagement in education and employment, poor surveillance of health issues and lack of support for the activities of daily living result in isolation, depression, poor physical health and worrying changes to behaviour.

The costs to the individual, the family and the support services are enormous.

Key findings – needs assessment

Almost all people with Down's syndrome will need a social care assessment and some level of support - in the vast majority of cases, no assessment means no social care support. Under the Care Act 2014 local authorities (LAs) have a statutory duty to assess an adult's needs however:

- 43% of carers said their adult child was in need of an assessment
- 19% were still waiting for an assessment, some as long as 2 years
- 33% of carers were not satisfied with the resulting needs assessment record
- Many carers reported that the needs assessment record was not shared with them or their adult child
- 45% were not satisfied with response times from the social care team, with some families waiting for more than 2 years to arrange a meeting
- 27% were unhappy with the quality of support provided around needs assessment, with some reporting social workers lacking the expertise and professionalism and knowledge (even basic) to provide a good service
- 45% of carers reported that the assessor did not consider all relevant needs
- 12% of carers reported that no care and support plan was produced following the needs assessment
- 33% of carers said that many relevant needs were not considered during the assessment process. Cost, carer provision of support and transport were among the reasons cited for the non-consideration of relevant needs
- 50% of carers said the assessment was not being reviewed annually
- 4% of carers reported that the care plan had never been reviewed at all
- 92% of people did not get an initial 6-week review as recommended in the Care Act guidance

Key findings – personal budgets and care planning

- 61% of carers reported their adult son/daughter received no hours of support for education
- 28% were concerned about the level of overnight support provided
- 42% of carers were not satisfied with the level of support for evening and weekend activities
- 66% said they received no support for accessing employment
- 25% of carers felt that support for weekday activities was unsatisfactory

- 12% reported receiving no support for weekday activities
- 31% reported that there was no support for evening activities
- 30% said there was no support provided for weekend activities
- 82% carers reported they were satisfied with the quality of support (where available)
- 73% were satisfied with the consistency of support provided (where available)
- 33% of carers reported that they were unsatisfied with adaptations required for the home

Key findings – health and wellbeing

- 33% of carers are concerned about inadequate support for emotional and mental health issues
- 27% of respondents are having difficulties in accessing annual health checks
- 36% of carers reported satisfaction around the addressing of physical health issues

Key concerns

- Assessment and recording errors by professionals
- Care and support planning delays
- Poor assessor knowledge regarding Down's syndrome
- Not receiving any assessment
- Not being provided with a copy of completed assessment
- Unacceptable delays in the assessment and review process
- Lack of access to a social worker
- Assessors failure to follow Care Act guidance around eligible outcomes such as accessing and engaging in work, training, education or volunteering and use of public transport, recreational facilities or services
- Assessors appearing more concerned with provision and available funding ahead of assessed needs
- Low emphasis on extending education or gaining employment
- People with Down's syndrome having to pay to achieve outcomes related to their well-being, for example having to pay to go to work
- Limited support provided outside of term times

- People with Down's syndrome reported a lack of support to undertake activities, but also showed concern about the limited choice of activities available, resulting in boredom and restlessness
- Cuts to their services, meaning the few activities they had previously been supported for were disappearing
- Parent/carers mostly provided all support for health and safety issues
- Obesity being a major area of concern reported by our families
- Local Authorities not routinely offering Individual Service Funds
- Removal of overnight support without adequate risk assessment
- Local authorities not paying providers adequately for support services
- Carers having to leave their jobs in order to provide support

Conclusion

There are a number of difficulties with accessing fair care and support in practice. Legislation is in place in the form of the Care Act 2014, along with suitable guidance for local authorities, who have responsibility for social care support. There are 174 unitary authorities and upper tier county councils in England and Wales, but they all have local arrangements in place. However, the significant problems faced by people with Down's syndrome and their carers are universal and should not be subject to individual legal action to remedy a common problem.

Family carers across England and Wales report that support offered can be poor in quality and quantity, not relevant to the person's needs, lacking attention to health issues, inadequately funded, and cut at review with no justification. The onus is on family to continue to provide care and support (and many do, willingly, others because they feel that there is no choice), the process is painful and the time taken for services to respond can be extreme.

The following points should be considered:

- Adequate care and support will prevent deterioration.
- Assessment for care is frequently inefficient, inaccurate, wasteful of both time and funding, for those whose needs will rarely reduce significantly and may increase.
- Local arrangements can breed laxity and neglect as well as innovation and diversity.
- Assessing the fitness of LAs as well as providers.
- The stress caused by this process is high on the group of people who should benefit from the support available.

The core purpose of adult care and support is to help people achieve the outcomes that matter to them in their life. We would like to see a commitment to a robust and effective process that underpins the core legal entitlement for adults to care and support.

The current process is clearly not working for the group of people who should benefit; it is not value for money, and is stressful for those who should be supported.

What the Care Act 2014 says:

"A local authority must carry out an assessment in a manner which— (a) is appropriate and proportionate to the needs and circumstances of the individual to whom it relates; and (b) ensures that the individual is able to participate in the process as effectively as possible"

What the DSA is asking: That individuals receive an assessment and it is delivered in a timely manner in accordance with individual circumstances and needs.

What the Care Act 2014 says:

"The importance of having assessors appropriately trained and with the experience and knowledge necessary to carry out the assessment"

What the DSA is asking: That LA's ensure their workforce of assessors understands Down's Syndrome and are also properly skilled in undertaking assessment.

What the Care Act 2014 says:

"During the assessment, local authorities must consider all of the adult's care and support needs, regardless of any support being provided by a carer"

What the DSA is asking: That assessments properly consider all of an adult's needs – in particular around work, training and ongoing education.

What the Care Act 2014 says:

"After assessment, the person and anybody else must be given a record of the assessment. The person must also receive a written record of the eligibility determination. The local authority must give a copy of the final plan which should be in a format that is accessible to the person for whom the plan is intended, any other person they request to receive a copy, and their independent advocate"

What the DSA is asking: That LA's ensure they have robust and effective processes in place to make this happen.

What the Care Act 2014 says:

"Local authorities should consider whether the carer can continue in their job, and contribute to society, apply themselves in education, volunteer to support civil society or have the opportunity to get a job, if they are not in employment"

What the DSA is asking: That carers receive the support they need to achieve a caring and work / life balance so that caring is not detrimental to their physical and mental wellbeing.

What the Care Act 2014 says:

"It is the expectation that authorities should conduct a review of the plan no later than every 12 months, although a light-touch review should be considered 6– 8 weeks after agreement"

What the DSA is asking: That people receive a review of their support plan to which they are entitled.

What the Care Act 2014 says:

"The local authority should not set arbitrary upper limits on the costs it is willing to pay to meet needs through certain routes – doing so would not deliver an approach that is person-centred or compatible with public law principles"

What the DSA is asking: That LA's ensure that decision making around funding takes account of individual need and not just the budget position.

"Assessment and care planning, and how care is paid for, remain some of the biggest areas of complaint. Even more concerning is that the issues we see demonstrate a shift from one-off mistakes to problems with whole systems and policies, or procedures being incorrectly applied.

"Adult social care has seen sustained high levels of complaints upheld compared to our general work. We know authorities are operating under an enormous amount of pressure and financial challenge to deliver care services. The stark reality of this is now playing out in the complaints we see.

"Despite this, when it comes to service delivery, we simply can't make concessions for these pressures in the recommendations we make."

Michael King, Local Government and Social Care Ombudsman

Annual review of adult social care complaints (November 2018)

Source: https://www.lgo.org.uk/

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

DSActive
Activities for people with Down's syndrome
www.dsactive.org

WORKFIT®
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