Down's Syndrome Association
A Registered Charity No. 1061474

Social care and support

What is supported living

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Supported living usually describes the arrangement where someone who already has their own tenancy or own home in the community and alongside this has help from a "Care and Support" provider to enable them to live as independently and safely as possible. Ordinarily people will receive support and help with any aspects that are required to live an ordinary life as possible, this could be help with:

- Managing bills and money
- Cooking and healthy eating
- Getting a job
- Shopping
- Learning new skills for independence
- Personal care and well-being
- Managing medication
- Accessing employment, sports and social activities

People who live in supported living arrangements can live in a variety of different settings for example:

- With another person or others that they have chosen to live with in shared accommodation e.g. a shared house in which they all contribute to the bills and upkeep of communal areas.
- On their own in flat/house or bungalow etc
- Support provided in ranges from 24/7 to just a few hours a day – depending on the needs of the tenant

What does it look like for people who have Down's syndrome?

There is no one single set route into supported living, and it will look different for everyone, for example, some people live in a shared house with other tenants who have learning disabilities, whilst others live on their own. What will work for your relative will depend on a number of factors, including individual support needs, what your relative wants out of supported living and what is available locally.

Supported living is not just for people who already have more independent living skills. Those who need higher levels of support can live in their own home, with the right planning and help.

Preparing for supported living

Promoting choice from an early stage can help people who have Down's syndrome to get used to the idea of deciding things for themselves. Teenage years can be a good opportunity to encourage choice, even on the basic level of how to spend pocket money and buying clothes and groceries. These small choices can help prepare for bigger life decisions.

Making choices about where to live

The transition meeting in Year 9 is a key time to start thinking about preparing for adulthood and thinking about your relative's hopes for the future, including where to live. However, it is never too late to start considering these questions. Here are some key questions you may wish to consider with your relative to get you started:

- Where would you like to live?
- Who would you like to live with?
- Would you like to live on your own, or with friends?
- What do you like to do during the day?
- Where do you need to get to/what transport do you need?
- What help do you need to do things you want to do?

Your relative may need support to understand and make a decision. Easy read tools, audio visual resources, images/symbols and adequate time to process information are all useful aids for supporting choice.

A 'talking mats approach' can be helpful for people who have difficulties with communication. The 'talking mats' approach involves using 3 sets of picture symbols with text underneath on a mat. The 3 sets of pictures are topic, options about that topic and how you feel about that option. Your relative can use this approach to select options about different choices, for example, whether to live alone or with friends, etc.

Decision making and mental capacity

Everyone who is part of your relative's life should work from the assumption that he or she can decide where to live. However sometimes, even with support and communication aids, some people are not able to make this decision or communicate their choice.

The Mental Capacity Act (2005) says that it must be assumed that any person aged 16 or above can make decisions unless it can be shown otherwise. This is called assuming that the person has mental capacity.

Mental capacity is a person's ability to make a particular decision at a particular point in time. It is assessed on a decision by decision basis; your relative cannot lack mental capacity simply because they have a learning disability. Your relative has the mental capacity to make a particular decision if he or she can:

- Show some understanding of the information given

- Retain that information long enough to be able to make the decision. Notebooks, photographs, posters, videos and voice records can help people record and retain information.
- Weigh up the information and use it to make a decision.
- Communicate the decision. This could be by talking, using sign language or other communication aids, blinking or squeezing a hand.

If your relative lacks mental capacity to make a particular decision, a decision will be made on a best interests basis. Anyone interested in your relative's welfare (including family) must be included in this decision making and family members can challenge a decision if they do not believe it is in your relative's best interests. Most disagreements can be easily resolved by good communication between social workers, care staff and families. See our information about making everyday decisions post 16.

Initial planning and people to contact

Once you have a clearer idea of your relative's wishes, you can start thinking about what to do next. Some things to consider are:

- What does my relative want out of moving home? what housing options are available locally?
- Are there others in my local area in a similar situation, or who have already been through the process?
- Who does my relative want to live with, if anyone? what support is needed for all this to happen? who needs to be involved?
- What practical arrangements need to be made?

To help you answer these questions, here are practical things you can do in the early stages:

- Look at your council's website and find out what they offer adults who have learning disabilities.
- Search for supported living providers and schemes in your area. The Care Quality Commission has inspection ratings of support providers on their website.
- Some local authorities have specific properties for people who have learning disabilities who want to live in their own home. If not, your local housing department can tell you about other housing options.
- Other local families can provide invaluable peer support and information about local options – a local support group or carers' group can be a good place to start, particularly if there are other families with relatives at the same stage.
- A transition worker can support your relative as they move into adulthood, including looking at where to live. Not every local authority has transition workers – ask your local authority if they offer this service.

- Your relative's social worker can support you to plan ahead for leaving the family home. If you do not have a social worker, we suggest that you contact adult social care. They can assess your relative and support you to start planning ahead.
- Some local authorities offer a housing brokerage service. A housing broker helps people who have learning disabilities explore housing options and find suitable properties. They will work with the family and liaise with different departments, such as the local housing department, private landlords, letting agents, etc. to source a suitable property. Ask your local authority if they offer this service.

Remember…supported living is a journey!

It can feel a little overwhelming when you start thinking about supported living. It might be helpful to think of moving into supported living as a journey.

Just as every person who has Down's syndrome and their family is different, so is everyone's journey towards supported living and there may be bumps along the road. That doesn't mean your relative won't get there in the end.

Don't panic if you experience setbacks or your relative does not settle into his or her new home straight away. The road to independence is not a straight one and there may be times when your relative needs more support or experiences a problem. The important thing is to ensure that you and your relative are getting enough support.

The flow chart on the following pages explains the supported living process:

Initial information gathering

Find out as much information as you can. Suggested places to look are:

- Local authority website
- Adult social care department
- Local housing department
- DSA website
- Care and support provider rating websites such as the CQC, the NHS website etc

HOUSING

Looking at housing options

Housing options you can look at include:

- Rent privately
- Rent via a council or housing association
- Buy to let
- Purchase a property outright

Ask your local authority about housing options in your area.

HOUSING

Find the right property

If you plan to rent via the council or a housing association, get on the housing register as soon as possible. if you are privately renting or buying, make a list of your specific requirements before you start searching.

SUPPORT

Looking at areas where the person needs support

Come up with a list of tasks a person needs support with in daily life. This could include:

- Personal care (washing, going to the toilet etc)
- Cooking and preparing meals
- Looking after their home (cleaning etc)
- Travelling to daily activities
- Looking after their money

Remember, help can include prompting and reminding.

SUPPORT

Ask for an adult needs assessment

A social worker should come and assess the person face to face. You can attend the assessment if the person gives permission. The assessment should look at what they need support with and what would happen if they didn't get that support. Have a list of tasks the person needs support with.

HOUSING

Paying for housing

If the person is renting, you can apply for housing benefit. Ask your local council for a form. Housing benefit will depend on the type of housing. If purchasing, they may be eligible for support with the mortgage. Call our benefits adviser for more information about housing benefit and how to apply.

HOUSING

Tenancy

If the person is renting, they will need to sign a tenancy agreement. If the person is unable to sign the agreement, a best interests decision making process will need to be followed.

SUPPORT

Arranging support

The local authority will decide if the person is eligible for support based on the assessment and national eligibility criteria.

The person will have a financial assessment to assess their ability to pay for support. This is based on the person who needs care's ability to pay, not their parents or carer's.

The local authority must create a care plan telling you what support they will provide. You can ask for support as direct payments to you or the person to directly arrange the care yourself.

You can also choose for the local authority to arrange support for you. This can be easier but gives you less choice.

Supported living – a parent's experience

Cathy lives in the South East and has a daughter in her thirties in supported living. This is her experience.

Why did you start thinking about supported living?

We started thinking about supported living because we felt that our daughter, like us and her siblings, should move out of the family home around the age of 25. I knew of people in their 70s with sons and daughters in their forties living at home and it was not a satisfactory arrangement. Our daughter also wanted to be independent herself.

How did you plan the move?

We began thinking about it when our daughter went to residential college and started seriously thinking about it when she graduated 3 years later. We read what we could about supported living, and we visited some local schemes.

The move itself took place in two stages. The first lasted 9 months and involved a flat share with another person with Down's syndrome with overnight staff and day support from another agency. There were various problems, but these gave us experience and knowledge about how to and how not to set up the next move.

What problems did you face? How did you solve them?

In the first placement the problems included lack of communication and dissatisfaction with some day to day aspects of our daughter's care and support. The second scheme, which was shared ownership, began with problems finding a suitable flat. This process took a few months. Once a suitable flat was found the main problems were negotiating how much the local authority would pay for support. Recruitment of care staff was made easy because the local authority contracted an agency which did payroll and recruitment, etc.

What would have made the experience easier?

Less paperwork and more guidance around the maze of housing benefit. As I said, we were very lucky that a Housing Association had offered several flats to people with learning disabilities in the local authority. It was both enjoyable and frustrating house hunting.

We were lucky to have a very supportive care manager at the time [of planning the move]. There are a lot of things that would have made the first placement better, if we had been listened to and if the procedures had not been quite so bureaucratic.

How did you finance supported living?

We were able to pay for the quarter share of the flat, but if we had not been, we could have obtained a mortgage. The three quarters of rent our daughter pays to the Housing Association is paid for by housing benefit, the staff are paid through direct payments and her day to day living costs come from benefits such as DLA and ESA.

What are things like now?

We still have disagreements with the local authority about underfunding and we also get frustrated by the fact that her staff do not do all the things we would do! But this is compensated for by the fact that we all find it a good situation, and our daughter is well cared for.

What is your advice to families thinking about supported living?

Be confident and assertive with professionals because you know your son or daughter best. It should be genuine person-centred planning. You should write down a list of your relative's likes and dislikes, behaviour, routines, etc., to inform the planning and have common sense and compassion as the essential foundation for any scheme.

Watch our Supported Living films (see link below) to hear more from parents, people who have Down's syndrome and the support staff who work with them.

Resources

Supported living – an introduction for parents and carers

Supported living – our stories – Stories from people who have Down's syndrome

Making supported living work for people who have Down's syndrome: information for support staff

What is supported living (easy read)

Choosing where to live (easy read)

Choosing who to live with (easy read)

Getting ready to move out (easy read)

Supported living film series

This series of short films is about life in supported living. The films follow the journeys of five adults who have Down's syndrome who enjoy life in their own home.

We follow their daily lives and how they got to where they are now. Each film focuses on a different perspective: a parent, support workers and people who live in the house themselves.

Watch all the films on YouTube here.

We can help

If you have any questions about social care, please contact us using Tel: 0333 1212 300 or Email: info@downs-syndrome.org.uk. If our information officers are unable to help, they will refer you to our social care adviser.

Contact us

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