

Life begins at home

A guide to housing for families and children with autism/
learning disabilities who display challenging behaviour







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With thanks to the families and professionals that gave us the feedback and support we needed to develop this guide and for sharing your stories and time.

H&SA

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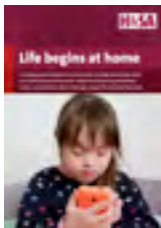
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To download the *Life begins at home* guide, training pack and resources that have been shared with us, and to view the accompanying videos, visit:

 www.housingandsupport.org.uk/life-begins-at-home

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Life begins at home



The purpose of this guide is to help families and front line housing, health and social care professionals understand the housing choices available to them.

We encourage local authorities and NHS Trusts to adapt this guide for local use. If you would like a text only version of the guide to adapt, please contact **enquiries@housingandsupport.org.uk**.

We ask that you acknowledge the Housing and Support Alliance in adapted versions of this guide.

This guide is accompanied by a training pack and films that help health, housing and social care professionals reflect on and understand their role in helping families get the housing they need.

To download the Life begins at home guide, training pack and resources that have been shared with us, and to view the accompanying videos, visit:

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1. About this guide

This guide is for families of children with autism/learning disabilities who display challenging behaviour.

The aim of this guide is to enable families to get the housing they need to remain together in their communities and avoid unnecessary placements of the child outside of the family and community.

Many families live in housing situations that make the behaviour of their children with learning disabilities and autism more challenging. Often, with straightforward and affordable interventions, families could get alternative housing or adapt current housing to create an environment where they can manage their child's behaviour more effectively.

This guide offers practical advice for families on the choices they have to get housing or adapt current housing to meet their needs.

This guide tells you about:

- What families say they need from housing
- How families can manage their situation with better housing
- How families can get the housing they need
- Paying for housing and adaptations
- What the law says about housing for families of disabled children
- Getting more help

This guide is written by the Housing and Support Alliance with support from the Challenging Behaviour Foundation and funded by NHS England.

2. What families say they need from housing

Every family wants a home that is safe and secure, with enough space to live healthily and happily. Clearly families with children with autism/learning disabilities who display challenging behaviour, want the same things from their home, however there are additional needs that come from having a child that displays challenging behaviour.

Many families say that simply having an extra bedroom will mean that they can manage their child's behaviour better. For others it may be having an extension where the child can receive care from paid carers without encroaching on family life.

It may be that some extra space is needed for a sensory or quiet space or an extra large bath that helps the child manage their behaviour better. Sometimes assistive technology can be used to help keep the child safe, such as sensors that alert parents or carers that the child is having a seizure, is out of bed or is going to the front door.

For some families, a house with a big garden or situated next to a park so the child can spend more time outdoors could make all the difference.

In housing, health and social care, professionals are often programmed to think about meeting needs in a particular way. We understand physical disability better and can think about housing

It's about improving the quality of life

We need a house that is big enough and detached so that the noise which is a feature of our daughter's behaviour does not disturb neighbours

It's not just about access and "getting by" but about improving quality of life for both the disabled child and the rest of the family.

FAMILY MEMBER

and adaptations more easily in this context. For families with children that need support with behaviour, housing, health and social care professionals are less knowledgeable and often resort to solely dealing with the child's behaviour and mental health rather than looking at environmental and practical solutions within the family and the home.

Sometimes policy and regulation within the housing, health and social care sectors is applied in a rigid way and does not allow for more creative, family centred and often more simple and cost effective solutions. Children with autism/learning disabilities who display challenging behaviour are too often placed in hospital, residential colleges or residential care because the housing and community support they need is not available. In some situations this may be the right solution, but most families want to find a way to stay together and keep their child in the family home. To do this, housing, health and social care professionals need to respond in a more flexible, family centred and creative way.



3. Housing options

This section tells you the basics about the housing choices you have.

3.1 Home ownership

Buying a home on the open market is the way that families can have the greatest control over where they live and the environment they live in. Home ownership also gives long term security. Clearly being able to buy a home is based on affordability and your financial situation. Families with children with autism/ learning disabilities who display challenging behaviour find it more difficult to be flexible about the area they live in because families are often already connected with a school, live near family and friends where they can get support and have services in place. For many families, earning power is limited because of their caring responsibilities and home ownership is harder to achieve than other types of housing. It is possible to get help with buying a home through the governments Equity Loan Scheme. It is also possible to get help to pay the mortgage to buy a home *more suited to the needs of a disabled person* if you are in receipt of benefits, although house prices in many parts of England make this difficult or impossible.

3.2 Shared ownership

Shared ownership schemes are provided through housing associations. You buy a share of your home (25% to 75% of the home's value) and pay rent on the remaining share. In general, shared ownership policy says that you can buy a home through shared ownership if:

- your household earns £60,000 a year or less (or £71,000 a year or less in London for a 1 or 2 bedroom property, or £85,000 a year or less in London for a 3 or more bedroom property)
- you're a first-time buyer (or you used to own a home, but can't afford to buy one now)
- you rent a council or housing association property

Shared ownership can be a more achievable way for families to get the housing they need, especially in more expensive parts of the country.

 www.gov.uk/affordable-home-ownership-schemes/shared-ownership-schemes

3.3 Renting social housing

Social housing is when you rent from a council or a registered provider with the Homes and Communities Agency (usually housing associations). The main purpose of social housing is to provide accommodation that is affordable to people in priority housing need and on low incomes. Limits to rent increases are set by law

Buying a shared ownership property makes Jenny and Kyle's lives better

Kyle is 14 years old and has epilepsy, autism and behaviour that challenges. His Mum, Jenny, is a lone parent and found it increasingly difficult to care for him. He was hospitalised when he was 12 because Kyle was self-harming and Jenny found herself unable to cope any more.

Kyle was in hospital for over a year and Jenny wanted him to come home. When making a plan to bring Kyle back home with some support, it became clear that the flat they lived in made their lives more difficult. Jenny was constantly worried about the noise Kyle made and how that affected the neighbours.

One thing that always made Kyle feel better when he was distressed was being out in the open air and playing. They had a small 2 bedroom, second floor flat and lived a 20 minute walk from the park- it was not always easy to get Kyle there if he was feeling distressed.

With some help from their social worker and some specialist housing advice, Jenny was able to buy a 2 bedroom house with a garden through a shared ownership scheme. As she is in receipt of welfare benefits, she was eligible to have the interest on the mortgage paid using Support for Mortgage Interest. She took out a 100% loan for her share of the property and pays rent on the remainder for which she gets Housing Benefit.

Kyle was able to leave hospital and Jenny had some extra support at home to help her manage. Kyle loved being able to just go out into the garden whenever he wanted and Jenny feels that this has made a big difference to his behaviour.

mean that rents are kept affordable. Social housing can be applied for through the local authority's allocation scheme. Councils can decide who is, or isn't, eligible but the law says that certain groups should be given 'reasonable preference' including those with medical needs or those who need to live in a particular area for social or welfare reasons. It also says that local eligibility criteria should be openly published.

There is a limited supply of social housing, so therefore choice and control over the house and environment will be more limited than with other options. However renting social housing will provide longer term security and therefore can be a good solution for families that have a child with autism/learning disability who displays challenging behaviour.

3.4 Renting from a private landlord

There is a large supply of rented housing in the private sector and, in theory, this should mean that families can find housing that meets the needs of the family and child. The main problem with privately rented housing is that there is no long term security and this is often needed, particularly with children with autism/learning disabilities who display challenging behaviour. If adaptations are required this may also present a problem if the landlord refuses to accommodate the adaptations. However there are some landlords that want to let their properties out on a long term basis and are happy for the property to be adapted, so this option should not necessarily be excluded. Help with paying the rent is available to those on a low income or in receipt of benefits but will be restricted to the Local Housing Allowance within Housing Benefit.

3.5 Staying put and adapting or extending your property

Some families could adapt or extend their current home to make it work for their situation. Adaptations may be a solution for physical or sensory needs. An extension may provide the extra space you need to support your child better or enable carers to provide support.

3.6 Setting up an independent housing solution for your child

If you cannot continue to care for your child within the family home, a housing and care solution can be developed around their individual needs in their community and close to their family as an alternative to placing them in a care situation.

Extending the family home meant Jude and his family could be more relaxed

Jude is 12 years old and since he was a young child, he has been very sensitive to noise and has constantly sought a quiet space to be alone.

As Jude's two siblings grew up and they wanted to do ordinary things around the house, like play music and have their friends around, Jude has become increasingly distressed. Jude's distress has impacted on his behaviour and he has been aggressive towards his family.

Jude's parents found it hard to balance the needs of all of their children and found themselves restricting the freedom of their other children so that Jude would not get upset. This created tension in the house so the family sought help from their social worker.

The social worker recommended that the family talk with the council's occupational therapist and she recommended that they create an extra

room for Jude so that he could have more of his own quiet space.

They successfully applied for a Disabled Facilities Grant to build a small extension for a downstairs room. They also applied to a charitable trust for sensory equipment for Jude to help him relax. Jude now has his own quiet space, a bubble machine, a projector that projects light onto his ceiling and his own music system that he can control.

Family life has been much easier since having the extension and sensory equipment which Jude uses to relax. Jude's brother and sister have more space to do what they want to do but also like spending time with Jude in his new room.

A bespoke housing solution can be created in the same way as described for families but is built around the child's needs and a care package is put in place to support them to live there. This is not a typical solution for a child but is possible. Whilst the child is under 16 years of age, the funding for the housing would need to be secured through health and/or social care budgets. Once a child turns 16 years old, they can get help with housing costs in the same way an adult can, therefore making this possibility more straightforward to set up.

For more information and help:

 www.housingandsupport.org.uk

 www.shelter.org.uk

4. How families can manage their situation with better housing

In this section we will cover the various ways that families can use a housing solution to help manage their child's behaviour better.

4.1 Working out what is needed

The first step is working out if, and how, housing and the environment impact on the child's behaviour.

The Challenging Behaviour Foundation (CBF) says that there is always a reason for challenging behaviour. In many cases, it's a way for a person to control what is going on around them and to get their needs met. They also might be ill or in pain, or want to get something, and there is a lot that can be done to prevent or reduce challenging behaviour.

They recommend that families keep a record of the behaviour and ask their GP/social worker if the child can get a referral for a 'functional assessment' to better understand the reasons behind their behaviour.

A 'functional assessment' is a way to find out the exact causes of a person's behaviour. This is usually carried out by a Psychologist or behaviour nurse.

A garden should be viewed as not just desirable but essential.

Having a private space away from gawping members of the public to run around in circles or make unusual noises does a lot for the wellbeing of the child and the whole family.

Supervising children and young adults with this type of behaviour in public places is exhausting because one has to be 100% vigilant because it is dangerous for everyone if one isn't. A garden allows caregivers to relax as much as their charges and that directly helps with managing challenging behaviour.

A MUM

The Challenging Behaviour Foundation has resources on assessing behaviour:

 www.bit.ly/CBF-understanding-behaviour

4.2 Assessing housing and environmental need

For most families, it is obvious what the environmental and housing needs are. For others it may not be as obvious and needs some exploration. When thinking about how housing and the environment may impact on the child's behaviour:

- Think about exactly what happens before the challenging behaviour and whether something triggers the behaviour
- How does your child respond to noise?
- How does your child respond to enclosed or open spaces?
- How does your child respond to particular activities?
- How does your child respond to people and other members of the household?
- In what situation is the child most content and happy?
- How does your child respond to light?
- How does your child respond to colour?
- Do you need to keep your child away from certain rooms, appliances or objects to keep them safe?
- How does your child sleep at night and do their sleep patterns, or the sleep patterns of other members of the household, cause problems?

Once you determine the environmental triggers for the challenging behaviour, you can use the information to plan how to reduce the challenging behaviour or lessen the impact on the child and family. This may involve adapting the environment or changing the environment totally.

 www.pavingtheway.works/project/wp-content/uploads/2016/02/Autistic.jpg

4.3 Adapting your home

Depending on your child's needs it may be that you can carry out relatively small adaptations that make a big difference, or your home may need major work to make the environment safer or better for your child and family.

Making furniture and fittings safe may help manage difficult behavioural situations better. Totally redesigning a room to provide more open or closed space could help the child feel less anxious about being in particular rooms or with particular people.

Creating a space where the child feels safe and can relax may be a priority for families. Transforming one area or a room to create a sensory-focused space where lighting, acoustics, furniture and layout can help the child relax, reduce anxiety and manage behaviour.



www.kingwood.org.uk/images/downloads/research/sensory_preferences_all.pdf

The following checklist gives an overview of the many home adaptations that may be needed to make the family home safer.

4.3.1 Housing Design & Fitting checklist for children with autism/ learning disabilities who display challenging behaviour

LOCKS

- Key locks/fingerprint locks can be provided to external doors, bedrooms or any room containing dangerous equipment or chemicals
- WC and bath/shower with sliding bolt locks that can be opened from the outside in case of emergency
- A lock system can be adopted with a master key override for all internal rooms, with a separate master key for external doors
- Lockable fuse boxes and radio thermostats
- Key operated locks to windows

DOORS AND DOORWAYS

- Reinforced door frame fixings
- Outward opening doors on wc/shower and bathrooms
- Internal doors to be sturdy/fireproof with more hinges
- Sensors on external doors to alert carers
- Vision panels with venetian blind panel on internal doors to allow for supervision and privacy
- Stable doors in bathroom/kitchen where safety is an issue and the child can be supervised
- Double door entrance
- Width for wheelchair access

BATHROOM

- Regulated temperature on taps
- Lever or push taps
- Enough space around toilet/sink/shower/bath to assist with personal care
- Floor drains in bathrooms
- Concealed cistern for wc
- No exposed water pipes
- Magnetic shower/towel rails that can be put up easily if pulled down
- Nova- flo to prevent bath/sink overflow/magi-plug to empty bath if it overfills
- Bath/sink in heavy gauge enamel pressed steel

ELECTRICAL EQUIPMENT/APPLIANCES

- Lockable/secure electrical sockets
- Cool surface electric induction hob and wall mounted oven
- Avoid sharp edges to domestic worktops
- Boxed in radiators/radiators with cool surface
- Cables channelled in to walls
- Easy to use domestic appliances
- Cupboards with polycarbonate windows to store television/stereo equipment
- Under floor heating
- Additional light switches located outside of the room

WALL COVERINGS

- Washable paint with protective washable finish
- Padded wall cladding (to reduce injury for some individuals)
- Polycarbonate sheets on walls to cover pictures, photos and posters

WINDOWS

- Strengthened safety glass or polycarbonate/acrylic windows
- Window locks
- UPVC window frames or strong plastic edging strip on wooden window sills to avoid biting/picking

FLOORING

- Vinyl flooring or durable washable carpet to keep more easily clean and odour free
- Flooring fixed securely to the floor- bolt safe flooring

FURNISHING

- Waterproof chairs/sofa with removable covers
- Durable/heavy duty tables and chairs
- Wardrobes/cupboards/drawers fixed to walls with lockable doors/drawers
- Television cabinets with polycarbonate screens
- Curtains hung on velcro or integral blinds

BEDS & BEDDING

- Heavy duty mattresses
- Beds fixed to the floor

GARDEN

- Safe garden or patio area that can be used as an additional living space
- Non toxic planting
- Solid fittings- gates etc (avoid wood or materials easily broken)

MAKING BETTER USE OF SPACE

- Wide corridors
- Larger communal space/s
- Choice of exits from communal rooms
- More than one communal space

ACOUSTICS

- sound absorption materials
- sound resistant plasterboard or acoustic tiles
- Acoustic glass for road-facing windows

LIGHTING

- non-flickering lighting for light-sensitive children
- indirect lighting to minimise glare

SENSORY SPACES

- lighting and projection
- water, hot tub, jacuzzi
- hanging fabrics
- beanbags, cushions, water mattress
- playhouse/shed in garden

i www.bit.ly/specialist-equipment-sheet

i www.housingandsupport.org.uk/assistive-technology

i www.bit.ly/helen-hamlyn-centre



When his school placement broke down and we had 6 people each day in our home to support him, it destroyed life for the rest of the family. Our son is now in a residential school. The rest of the family and other children needed their space too and there was not enough for all these people and the family. We can manage short visits home now. No thought or planning has been given to what will happen when he is 18/19. I think having their own bedroom is vital for children with challenging behaviour so they have their own space to retreat to when they are overwhelmed; challenging behaviour usually presents when children and young people are distressed. Having a space that is their own to control is extremely helpful, knowing that their possessions have not been moved and freedom to do what they need to do to keep calm is essential. Having a sibling with behaviour that is challenging is difficult: to share a bedroom with such a sibling is too much to ask of older children and teenagers so again adequate bedrooms are essential.



4.4 Extending your home

For families with children that require a large amount of extra space to help manage behaviour or to accommodate paid carers coming in to your home, you could consider an extension to the family home.

This could be anything from a small extension for an extra room or a self contained extension that enables your child to receive paid support entirely independently of the family home and may have a separate kitchen, bathroom, living space or bedroom.

In some properties and areas, building an extension is possible and achievable and will rely on getting planning permission from the council. The application will be stronger if it is supported by social services and/or an Occupational Therapy assessment. Look at similar properties in the street and check what type of extensions they have been able to get planning permission for, and this will give you a sense of what is likely to get permission.

Families renting their property will need to get permission for any extension from their landlord. When the changes you are seeking permission for are to do with adapting your home for a disabled family member, your landlord should not refuse permission unless they have a good reason. In some cases, your landlord may be responsible for making the changes.

4.5 Moving home

For some families, remaining in the current home will not work. It may be that there simply is not enough space, or the environment exacerbates the child's behaviour and cannot be changed. Some families find that by simply moving to a quieter area, or a house with a garden, or with an extra bedroom for example, that the child's behaviour improves.

Moving home is clearly more complicated than adapting your current home, but for some families it may be what makes the situation manageable and the only action that can stop a child being placed away from the family.

4.5.1 Moving home when you rent social housing

If your social housing does not meet your needs, you can apply for a transfer to a property that does. Whether you will be successful in getting a transfer to the right property will depend on the policies of your local council and landlord. It is also dependent on availability of property in the area you want to live. By law, local authorities must give priority for social housing to certain groups of people that

include those with medical needs or those who need to live in a particular area for social or welfare reasons, but each local authority is also free to decide who else gets priority in their area. It is important that you make clear the housing needs of your family, especially in relation to having a child with autism/learning disability who displays challenging behaviour and the risk of the child being placed away from the family.

If you have a severely disabled child who is unable to share a room because of their disability, they are always entitled to their own room.

More information about transfers:

 www.bit.ly/transfers-and-exchanges

4.5.2 Homeowners that need to move home

Families that own their own homes are not usually provided with help from the local authority or Clinical Commissioning Group to move in the same way that a family that rents from a council or housing association may be. This means it can be difficult for families to achieve a move if they own their own home and cannot afford to buy a larger home and increase their mortgage.



4.5.3 Ways that homeowner families can buy alternative property

i. The local authority can make a Disabled Facilities Grant (DFG) (or other grant) to extend a new property to make it large enough for the child to remain in the family home.

The maximum DFG is £30,000 and in some situations, this is unlikely to be enough to fund an extension. Local authorities may give discretionary assistance in addition to mandatory disabled facilities grants. (see page 23 for more information)

ii. The local authority can make a grant or a loan for the additional capital to enable the family to purchase the property required

Local authorities have the powers to lend or grant money for housing using the well-being power under Section 3(5) of the Local Government Act 2000. This is likely to only be used for exceptional cases. For example, if the child is at risk of being placed in care and this could be avoided by making a grant or a loan towards a property.

The Regulatory Reform (Housing Assistance) (England and Wales) Order 2002 gives councils greater powers to provide discretionary assistance. This may take the form of low cost loans and equity release as well as grants to private homeowners and others to help them to renovate, repair or adapt their home. The Order also enables councils to provide other sorts of assistance, for example, helping someone move to more suitable living accommodation if it is satisfied that this would provide a similar benefit to improving or adapting the existing accommodation.

iii. Purchase a new property under a shared ownership arrangement

Most shared ownership schemes are not eligible for people that currently own a property and a special case will need to be made to the council housing department and the housing association that administers shared ownership schemes.

As a homeowner, to be eligible for shared ownership, you will need to show that your current property is unsuitable for you. You will need to get support for your application from your local authority. You must sell your current property before you can exchange on a shared ownership property.

For more information and help:

 www.legislation.gov.uk/ukpga/2000/22/contents

 www.bit.ly/shared-ownership-schemes

5. Paying for housing and adaptations

This section outlines the main ways that housing and adaptations can be paid for.

5.1 Housing Benefit

Housing benefit is help to pay your rent. You may be eligible for housing benefit if you are on a low income, have less than £16,000 in capital, or are claiming benefits. Housing benefit helps pay for rent and some types of service charges.


All tenancies not classed as supported housing in social housing and privately rented housing will be subject to a Local Housing Allowance (LHA) for all new tenancies from 1st April 2016 (previously only private tenancies were subject to LHA) . LHA is set according to the rents in the local area which you can find on this website.

 www.lha-direct.voa.gov.uk

Housing benefit can be paid to children from 16 years of age and if they are in receipt of DLA medium or high care component, they will be entitled to housing benefit for a 1 or 2 bedroom property, depending on their need for overnight support.

 www.bit.ly/what-is-housing-benefit

Housing benefit can be paid, in some circumstances, on two properties for a short period of time. This is often needed when a disabled person is moving to manage the transition between two homes.

 www.bit.ly/housing-benefit-for-two-homes

5.1.1 Under Occupancy Penalty (also known as the Bedroom Tax)

The Under Occupancy Penalty restricts the amount of housing benefit that a family can receive in relation to family size. The rules allow for an additional room for a 'child who cannot share a bedroom'. To be entitled to housing benefit for an extra room, the child who cannot share a bedroom must be under 16, entitled to the middle or highest rate of Disability Living Allowance/Personal Independence Payment care component and the local authority must be satisfied that, because of his/her disability, the child cannot reasonably share a bedroom with another child.

5.1.2 The benefit cap

The benefit cap restricts the amount of income available from welfare benefits including housing benefit to £500 for families with children who are unemployed. If a child is entitled to disability living allowance (DLA) or a personal independence payment (PIP), the benefit cap does not apply, and so many families with disabled children who are out of work will be exempt from the cap.

5.1.3 Discretionary housing payments

Families that are entitled to housing benefit may have a shortfall in the rent because their rent is higher than the LHA cap. In this situation families can apply for additional temporary assistance in the form of Discretionary Housing Payments (DHPs). DHPs are administered by the local authority.

5.1.4 Buying to let to relatives and friends

Some families have made arrangements where someone they know has purchased a property to rent to them in a commercial arrangement. Some families enter into this type of arrangement with their disabled offspring who rent the property from their family member and claim Housing Benefit to pay the rent.

The Housing Benefit regulations are clear that this arrangement is legitimate if:

- i. The property is separate from the family home (this could be a self contained extension)
- ii. is a commercial arrangement and
- iii. not contrived to exploit the Housing Benefit system.

For more information about housing benefit regulations:



www.councilfordisabledchildren.org.uk/media/1089713/chapter-6.pdf



www.housingandsupport.org.uk/renting-accommodation-to-relatives

5.2 Support for Mortgage Interest (SMI)

SMI can meet the interest payments on a loan up to £200,000. Property for sale on the open market can be purchased outright but more commonly SMI is used to buy part of a property being sold by a housing association offering shared ownership.

The regulations say: “Housing cost shall be met in any case where the loan was taken out, or an existing loan increased, to acquire alternative accommodation more suited to the special needs of a disabled person than the accommodation which was occupied before the acquisition by the claimant”. *Schedule 3 IS (General regulations) para 4 sub para 9 (SI 1995 No 1613)*.

The rules apply to a disabled adult or a family with a disabled family member.

 www.bit.ly/hsa-buying-a-house-using-support-for-mortgage-interest

 www.mysafehome.info

 www.bit.ly/My-Home-Ownership-Service

5.3 Disabled Facilities Grant (DFG)

DFG is a grant you can get from your council if you're disabled and need to make changes to your home. It is often used to improve physical access such as widen doors and install ramps, improve access to rooms, provide a heating system suitable for your needs, and adapt heating or lighting controls to make them easier to use. DFG can also be used to meet the sensory and behavioural needs of a disabled person and can pay for many of the adaptations listed previously.

Depending on your income, you may need to pay towards the cost of the work to the property. Disabled children under 18 can get a grant without their parents' income being taken into account. Your local authority will normally provide you with disability equipment and small adaptations costing less than £1,000 free of charge, as long as you've been assessed as needing it and you are eligible.

 www.bit.ly/disabled-facilities-grant

5.4 NHS-funded adaptations

The NHS has the power to fund adaptations and will do if it is not possible to fund using DFG. The 2012 National Framework for NHS Continuing Healthcare encourages partner bodies to 'work together locally on integrated adaptations

services’ and that ‘Clinical Commissioning Groups should consider having clear arrangements with partners setting out how the adaptation needs of those entitled to NHS continuing healthcare should be met, including referral processes and funding responsibilities’. The guidance says, *where individuals require bespoke equipment (and/or specialist or other non-bespoke equipment that is not available through joint equipment services) to meet specific assessed needs identified in their NHS continuing healthcare care plan. CCGs should make appropriate arrangements to meet these needs.*

 www.bit.ly/nhs-continuing-healthcare-and-nhs-funded-nursing-care

5.5 Help to buy- equity loans

Equity loans are for both first-time buyers and home movers on to new-build homes with a purchase price up to £600,000. With an equity loan you’ll need to contribute at least 5% of the property price as a deposit and the government will give you a loan for up to 20% of the price. You’ll need a mortgage and/or capital of up to 75% to cover the rest

 www.gov.uk/affordable-home-ownership-schemes/help-to-buy-equity-loans

5.6 Meeting the costs of moving

When moving to a new home, families often need urgent help with the expenses involved in moving and with the purchase of essential items such as curtains, carpeting and white goods. Local authorities should offer help under section 17 of the Children Act 1989, that includes discretionary housing payments as well as emergency provision through cash payments or vouchers and payments in kind through local services such as food and furniture banks. Applications are usually made directly to the local authority.

There may be other costs associated with the child’s disability, and the local authority’s children’s services may also be asked to help with these costs through an assessment under the Childrens Act 1989.

 www.councilfordisabledchildren.org.uk/media/1089695/chapter-3.pdf

5.7 Charitable funding

There are many organisations and charitable trusts that offer support and funding for disabled children. The following are focussed on aids and adaptations needed in the home.

Lifeline 4 Kids

Provides essential equipment to help improve the lives of children with disabilities and special needs.


 www.lifeline4kids.org/

Some charitable funds will help with aids and adaptations in your home. Turn2Us have a grant search service to help you find the right charitable trusts to apply to.

 www.turn2us.org.uk/

The Sequal Trust

Helps raise money for communication equipment.

 www.thesequaltrust.org.uk/

The ACT Foundation

ACT provides grants of up to £2,500 to individuals with the aim of enhancing the quality of life for people in need, including disabled children. They provide help with funding building adaptations where a Disabled Facilities Grant (DFG) has been awarded and there is a shortfall, mobility aids, specialised beds and sleep systems, sensory toys and equipment, room padding, communication aids and specialised software.

 www.theactfoundation.co.uk

5.8 Personal Budget/Personal Health Budget

If you are in receipt of social care funding or Continuing Healthcare funding, you may be able to get a Personal Budget to meet the support needs of your disabled child flexibly. Where providing a housing solution helps to achieve the outcomes agreed in a plan, a personal budget can be used to buy equipment, fund adaptations or extensions and pay the extra rent required to provide the housing needed.

More about Personal Health Budgets:

 www.bit.ly/about-personal-health-budgets

More about Personal Budgets and Direct Payments from your local authority:

 www.bit.ly/social-care-and-support-guide-to-personalisation

5.9 Home Improvement Agencies

Home Improvement Agencies (HIAs), are also known as Care & Repair or Staying Put schemes. They help older and disabled people maintain independence in their own homes.

They help with adaptations for disabled people, including help with Disabled Facilities Grants. The HIA can help with any work you need to have carried out on your home, such as drawing up plans, getting estimates and liaising with local authority grants officers and occupational therapists.

HIAs also help with home repairs and 'odd jobs' such as putting up curtains or moving furniture, minor adaptations, falls prevention measures etc. as well as making homes more energy efficient. They can advise on money to help you repair or adapt your home.

 www.findmyhia.org.uk/

For more information and help with funding adaptations:

 www.independenceathome.org.uk/help_for_you.html

 www.aidis.org/

6. What the law says about housing for families of disabled children

Disabled children and their families need suitable housing like everyone else and all the same housing laws apply. Disability and equality laws say that the additional needs of disabled people must also be taken into account. This may mean that specific adaptations are needed to meet individual needs, or that housing in a particular area or of a particular size or type is needed, or that a housing authority or landlord must provide what is needed to help a disabled person access housing and live in their home.

This section outlines what the main laws say about housing for families with disabled children.

We have started to look in to finding the right kind of housing but have found that social services are not interested because of her age and tend only to deal with those in crisis situations.

A MUM

6.1 Rights to housing

Local housing authorities must pay specific regard to the needs of disabled people, including disabled children under the Chronically Sick and Disabled Persons Act (CSDPA) 1970. This duty requires housing authorities to stop ‘disabling’ environments through planning and housing design. In deciding who has priority for public housing in their area, local authorities must give a ‘reasonable

preference' to individuals (including disabled children) who need to move on medical or welfare grounds. Local authorities must publish a set of rules which explain how they decide who gets social housing. Your current situation, position on the housing register and local availability of housing are the main factors that determine whether you will get suitable social housing. All of these factors are important in assessment of social care needs, including an assessment under the Children Act 1989 (paras 3.30–3.46)



www.bit.ly/children-act-guidance-2015

6.2 Accommodation suitable to the needs of a disabled child

Local authorities responsible for housing are required to ensure that accommodation provided is suitable to the particular needs of a child CA 1989 [section 22C(8)(d)]. The law recognises that the needs of disabled children can be very different according to the nature of the disability and the impact of the disability on the child's functioning and individual circumstances.

The guidance recommends '*a thorough assessment of the child's needs, through the core assessment and any specialist assessments relating to the child's disability, must therefore be undertaken to ensure that any requirements necessary for his/her accommodation are identified and arrangements made to ensure the suitability of that accommodation.*'



www.legislation.gov.uk/ukpga/1970/44/section/3

6.3 Equalities Act 2010 and housing

Under the Equalities Act 2010 private and social landlords have duties to make reasonable adjustments for disabled people. The duties mean that landlords have to, depending on the circumstances, make reasonable adjustments such as changing practices policies and procedures, provide auxiliary aids and services, or change a term of a letting when requested to by a disabled person (or by someone on their behalf).

The act requires landlords to respond reasonably to the requests of disabled occupiers or would be tenants. The guidance gives examples of the types of adjustments which could be made by landlords include providing tenancy agreements in alternative formats, large print, Braille, audio tape, easy read, waiving a no pets policy for a disabled person with an assistance dog, spending extra time with tenants who have learning difficulties to ensure they understand

their tenancy agreement, a temporary ramp could be provided for a wheelchair user who has a small step up into their flat. The guidance does not give examples about the needs of disabled people that have behaviour that challenges but it should be assumed that any housing need that arises from a disability should have reasonable adjustments made.

 www.bit.ly/disability-equality-duty

6.4 Homelessness

Homelessness can apply to situations where a family has accommodation but it is so unsuitable for their needs that it is not reasonable for them to continue to live there. Local authorities set their own rules about homelessness, but by law they must give priority for social housing to certain groups of people that include those with medical needs or those who need to live in a particular area for social or welfare reasons. Each local authority is also free to decide who else gets priority in their area. It is important that you make clear the housing needs of your family, especially in relation to having a child with learning disability, autism and behaviour that challenge and the risk of the child being placed away from the family.

Disabled Children- a legal handbook (Legal Action Group 2015) says *“inadequate housing is putting a disabled child at risk of harm or impacting on the child’s family’s ability to meet their needs, this should be addressed in an assessment of the child’s need for services under Children Act 1989 s17 .Any assessment or planning arising from the assessment which ignores housing needs is unlikely to be lawful...”* and that *“Families with disabled children who live in accommodation which does not meet their needs may be able to obtain ‘priority’ to enable them to ‘bid’ successfully for a suitable home using local authorities’ choice based lettings schemes, or persuade a local authority to make a direct allocation of a suitable home”*.

 www.councilfordisabledchildren.org.uk/media/1089713/chapter-6.pdf

 www.legislation.gov.uk/ukpga/2002/7/contents

6.5 Rights to a Disabled Facilities Grant (DFG)

DFG is the main way for families with disabled children to get adaptations that make their home safe and accessible for their child. The grant is mandatory if the disabled child meets eligibility criteria and other requirements for the grant are

met. It is not lawful to refuse to make an adaptation to meet an assessed need if the only reason is shortage of funding or ability to assess.

The maximum amount of a DFG is £30,000 in England and local housing authorities have powers to supplement the DFG to pay for more expensive works or to pay for adaptations that don't meet the criteria for a DFG. If a disabled child is assessed as needing an adaptation to their home that costs more than the maximum amount for a DFG, the law may require the shortfall to be met by health, social services and/or the housing authority.



www.councilfordisabledchildren.org.uk/media/1089713/chapter-6.pdf

6.6 Children & Families Act 2014 (CFA 2014) Children's Act 1989 (CA 1989) Chronically Sick and Disabled Persons Act (CSDPA 1970)

The CFA 2014, the CA 1989 and the CSDPA 1970 are the main laws relating to provision for disabled children. All three laws require social services authorities and health authorities to take housing into consideration when assessing and providing services for a disabled child.

6.6.1 Education, Health and Care (EHC) plans and housing

An EHC plan is the document which replaces Statements of SEN and Learning Difficulties Assessments for children and young people with special educational needs. The EHC plan must meet a set of criteria to be legally compliant.

Section H1 of the EHC plan must specify all services assessed as being needed for a disabled child or young person under 18, under section 2 of the Chronically Sick and Disabled Persons Act 1970 (CSDPA). These services should include practical assistance in the home and adaptations to the home.



www.ipsea.org.uk/file-manager/resources/ipsea-ehc-plan-checklist-2014-sept.pdf

6.6.2 Local Offer

The CFA 2014 says that all local authorities in England must publish information about the provision available in its area for children and young people who have special educational needs or a disability. This should include information on education, health and care provision, educational and training provision and provision to assist in preparing children and young people for adulthood and independent living.

The provision to assist in preparation for adulthood and independent living includes provision relating to obtaining accommodation and participation in society. Your local authority must publish and regularly review the local offer.

6.6.3 Personal budgets and direct payments

The authority that maintains the EHC plan for a child or young person must provide a personal budget for them if asked to do so by the child's parent or the young person. The local authority must identify an amount available to secure provision that is specified in the EHC plan with an assumption that the child's parent or the child will be involved in securing the provision. This may include a personal budget made by a commissioning body under section 12A(1) of the National Health Service Act 2006 (direct payments for health care).

6.6.4 Duty to co-operate

Local housing authorities and other public bodies, including children's services authorities and health bodies, have duties to co-operate to ensure that disabled children's housing needs are met.

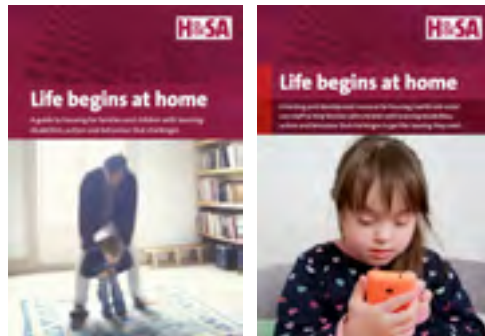
For more information and help:

 www.legislation.gov.uk/ukpga/2014/6/enacted

 www.bit.ly/disabled-children-a-legal-handbook

 www.councilfordisabledchildren.org.uk/media/1089713/chapter-6.pdf

Life begins at home







www.housingandsupport.org.uk/life-begins-at-home









Life begins at home – A guide to housing for families and children with autism/learning disabilities who display challenging behaviour was written by the Housing and Support Alliance with support from the Challenging Behaviour Foundation and funded by NHS England.

Housing and Support Alliance

-  www.housingandsupport.org.uk
-  www.bit.ly/HandSA-facebook
-  www.twitter.com/H_S_Alliance
-  www.youtube.com/HousingSupport

Challenging Behaviour Foundation

-  www.challengingbehaviour.org.uk
-  www.facebook.com/theCBF
-  www.twitter.com/CBFdn/
-  www.youtube.com/user/CBFoundationOrg