

Life begins at home

A training and development resource for housing, health and social care staff to help families with children with autism/learning disabilities who display challenging behaviour.



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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



Life begins at home

Life begins at home- a **training and development resource** for housing, health and social care staff to help families with children with autism/learning disabilities who display challenging behaviour to get the housing they need

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

Life begins at home



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 resource is accompanied by a guide for families. 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**

About this resource

Every family wants a home that is safe and secure, with enough space to live healthily and happily. Families with children with autism/learning disabilities who display challenging behaviour want the same things from their home as other families, however there are often additional needs that come from having a child with behaviour that challenges. This resource is about helping health, housing and social care professionals understand how best they can help families get the housing they need.

In the housing, health and social care world, professionals are often programmed to think about meeting needs in a particular way. We understand physical disability better and can think about housing 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 a more creative, family/child centred approach or 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. For some families, 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.

1.1 How to use this resource

This resource can be used for training within health, housing and social care teams that support families and children with autism/learning disabilities who display challenging behaviour.

It can also be used to understand what works and doesn't work locally and help develop the local offer to families and children with autism/learning disabilities who display challenging behaviour that have housing needs.

This training and development resource will be more effective if you use it to bring local families, health, housing and social care professionals together to understand what happens locally and how you can find solutions together.

This resource is set out in a way that encourages a questioning and exploratory approach to local issues so that they can be understood and shared, and local solutions can be developed together.

This resource contains the following:



Life begins at home: A guide to housing for families and children with autism/learning disabilities who display challenging behaviour

A series of 7 short films exploring the following themes:

1. What families say they want
2. The issues that families with children with autism/learning disabilities who display challenging behaviour face
3. What helps keep the child in the family home
4. What helps families get the right housing
5. Examples of good housing solutions
6. What housing departments can do to improve
7. Top tips for health, housing and social care staff

The films feature real examples of what families have said they want in getting the right home environment for their children. They also feature a range of professionals who have experience of helping families and children have better lives.

With thanks to:

- All the families that told us about their experience but chose to remain anonymous
- Nicola Gitsham- NHS England
- Maria Mc Cafferty- CCG commissioner
- Sam Sly- In Control
- Holly Butcher- Challenging Behaviour Foundation
- Tim Keilty- New Prospects
- Nigel Devine- Independent person centred planner
- Alicia Wood- Housing & Support Alliance

1.2 Discussion themes

The following are 7 themes for discussion and a concluding film.

Put aside at least 3 hours to go through all of the points. If using this resource to bring a wider range of people into the discussion, you will probably need longer.

The easiest way to structure discussions is to watch one of the short films and form your discussions around the main points in the film and the specific questions asked in each section in turn.



Video 1. What families say

Watch <https://youtu.be/rezgunTy7ms> (2.45 mins)

Main themes in the video

This video contains quotes from families that were surveyed for this resource

Families were asked about both good and not so good experiences they have had in getting housing. This first section is to reflect on what is important to families and how you work with families locally.

Questions for discussion:

- What do local families say?
- What do we do to find out what is important to them?



Video 2. What issues do families with children with autism/learning disabilities who display challenging behaviour face?

Watch <https://youtu.be/psgide8bhCU> (5.28 mins)

Main themes in the video

Not enough information

Families and front line professionals need information about housing, aids and adaptations, how to pay for them, rights and the law, if they are to develop solutions that work for them.

Overcrowding/Space

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

Processes for housing do not recognise behavioural needs and take too long

Applying for housing, adaptations and funding is a long process where families are often left in situations where they cannot manage to care for their child. This is often when the child needs to be placed away from the family home and could be avoided if reasonable adjustments are made in processes.

Need to live in particular location

Families with children with disabilities often need to rely on the support of family and friends more than most families do. Children with learning disabilities, autism and challenging behaviour may also have physical and sensory needs that require a particular type of environment; a garden, a park nearby, a quiet street, that will reduce their levels of stress and help the family manage behaviour.

Needing help with all types of housing

Homeowners and private renters are just as likely to require help as those in social housing, but housing systems are sometimes only geared towards helping social housing tenants.

Children being placed in hospital or residential care instead of supported to remain with the family

The lack of the right housing solution is sometimes (not always) a factor in the decision to place children in hospital or residential care. This usually happens because local services cannot meet the needs of the child adequately.

Questions for discussion:

- What other issues do we have locally?
- Do children in our area get placed away from families because of a lack of local services?
- Do we recognise the particular housing needs of families and children with autism/ learning disabilities who display challenging behaviour?



Video 3. What helps keep the child in the family home?

Watch <https://youtu.be/hXa6cdycRiA> (5.07 mins)

Main themes in the video

Good professional support

A solid network of professional support including Education, Health, Social Care, and Community organisations coming together around the child and family's needs and aspirations

Health professionals coming out of their silos

Community therapies, occupational therapy, speech and language therapy, paediatricians and GP's working together and understanding how health impacts on everyday life, including where people live.

Thinking holistically about supporting the child and family

Professionals and families having the information, support and resources they need and knowing who to contact to get the right help.

Real listening

Really listening to the child and family and understanding what is needed from all of their perspectives. Understanding what triggers behaviour.

Starting from knowing what an ideal situation would be

Don't start by thinking about the usual services, resources and grants but help the family think through what could be an ideal situation and then work from there.

Questions for discussion:

- How do we work together locally between health, education, social care and housing to make sure families and children get the support they need?
- Do we have a culture that enables good listening, assessment and person centred planning with children and families?



Video 4. What helps families get the right housing?

Watch <https://youtu.be/QmoTQ3Gq7uY> (2.35 mins)

Main themes in the video

Advice and support that is person centred and flexible, to help you think through what works for you and explores all options

Families need people to support them who listen to them and they can trust. They need support that helps them navigate the complexities of getting housing and sticks with them to make it happen.

Questions for discussion

- How do you support families and children to plan and get the right housing locally?
- How do you make sure staff work in a person centred, flexible and creative way to get the right housing solutions?



Video 5. Examples of good housing solutions

Watch <https://youtu.be/NEy6gfoFvVo> (6.04 mins)

Main themes in the video

Personalised adaptations in the home and garden

Play and sensory equipment that helps reduce stress levels for the child and family. Assistive technology that helps with safety, monitoring and independence. Adaptations and modifications in the family home that make better use of space and/or reduce noise.

Move on housing options

Making sure a range of ordinary housing options are explored, such as shared ownership, or equity loans. Making the rules for getting/transferring to social housing more flexible to accommodate families.

Extending the family property

Extensions can be a good solution to give more space to meet the child's and the family's needs and although it can appear to be a more expensive solution, it is more cost effective than a placement in a hospital or residential care home.



Read Section 3 Housing Options, Life Begins at home:
A guide to housing for families and children with autism/learning disabilities who display challenging behaviour

Questions for discussion:

- Are you able to offer information, advice and support with all of the housing options outlined in Section 3 Housing Options, Life Begins at home: A guide to housing for families and children with autism/learning disabilities who display challenging behaviour?
- What can you put in place to make sure families can get information, advice and support with a range of housing solutions?
- How do the housing, health and social care teams work together to offer support on housing and adaptations?

How does the NHS England Transforming Care service model impact on how you provide housing? In particular, how you meet the requirements set out in the Service Model:

5.1 People should be offered a choice of housing, including small-scale supported living. This choice may be circumscribed by the Ministry of Justice (MOJ) in some instances if the individual is on an offender pathway.

Choice about housing should be offered early in any planning processes (e.g. in transition from childhood to adulthood, or in hospital discharge planning) and should be based on individual need and be an integral component of a person's person-centred care and support plan (see principle 2).

Where people live, who they live with, the location, the community and the built environment need to be understood from the individual perspective and at the outset of planning.

5.2 Everyone should be offered settled accommodation. This should include exploring home ownership, or ensuring security of tenure.

5.3 Commissioners need to work closely with housing strategy colleagues to ensure that the future needs of this group are understood, considered and planned for strategically and form part of local housing strategies.

Key actions for health and social care commissioners:

- Commissioners should co-produce local housing solutions leading to security of tenure, that enable people to live as independently as possible, rather than in institutionalised settings.
- CCGs could consider allowing individuals with a personal health budget to use some of their budget to contribute to housing costs if this meets a health need and is agreed as part of the individual's care and support plan.
- Strategic commissioners need to work with housing strategy colleagues to ensure strategic housing planning.

NHSE Transforming Care Service Model



www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf



Video 6. What can housing departments do to improve?

Watch <https://youtu.be/hULqJecZz7o> (2.51 mins)

Main themes in the video

Have transparent processes and clear, accessible information

Adapt the bidding processes to work for families and young people, explain all options clearly to families and include a full range of options as well as social housing.

Understand the future housing needs of young people with autism/learning disabilities who display challenging behaviour

Many young people need a home of their own before reaching adulthood. If local housing needs are not planned for, young people end up being sent away from their communities and families.

Questions for discussion:

- How do we provide information about housing, aids and adaptations?
- How do our housing, adaptations and grant processes help or hinder families and children with autism/learning disabilities who display challenging behaviour?
- Do we know the future housing needs of young people with autism/learning disabilities who display challenging behaviour.



Video 7. What do we need to do?

Watch https://youtu.be/_fsN3TLfWfE (7.30 mins)

Main themes in the video

This video asks presenters what their ‘top tips’ are for getting housing right for families and children with autism/learning disabilities who display challenging behaviour.

There has long been a problem in how we support families and children with learning disabilities, autism and challenging behaviour to stay together in their communities. Very few areas are likely to be doing all aspects of getting the right housing solutions well and in some areas, there will be a long way to go. This section is to help you focus on what your priorities locally are and develop action from those priorities.

Action planning

What are we doing that works well?

From previous discussions, write up a list of what is working well.

What do we need to work on?

To make an action plan workable, it is better to focus on 3-4 main actions over a 6-12 month timeframe.

From previous discussions, write up a list on flip chart or post it notes of what you have identified needs development. Make sure that the list can be seen clearly by all those participating in the discussion.

In a group discussion, look at each of those areas and discuss the following:

- What exactly needs to be done
- What would happen if you did what needs to be done
- What would happen if you didn't do it

Agree priorities for action

Depending on the size and the make up of the group;

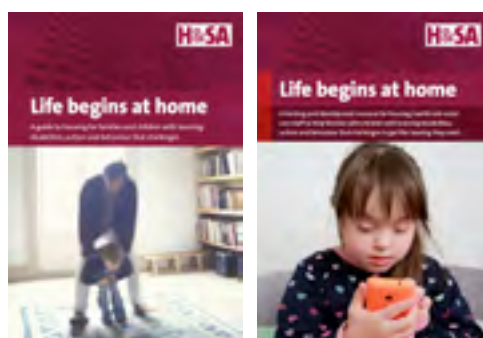
If a small group/team, you can simply agree 3- 4 priorities for action by debating and seeking consensus within that group.

In a larger or a mixed group, ask participants to vote on their priorities by:

- giving each participant 5 points (this could be a sticky dot, or a mark with a pen)
- asking participants to give a point/s to the areas they believe should be a priority
- the participants can give more than one point to an area or spread their points out evenly
- Select the 3-4 areas with the most points as priorities for development.

Action plan - agree the following:

- The action you are going to take
- When you are going to take the action by
- Who is responsible for taking/leading the action







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Challenging Behaviour Foundation

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