8. Keeping an eye on things
Keeping an eye on things

In this planning guide we have suggested different ways in which you can help make your relative's future settled and secure, ensuring they have choice and control over their lives as well as keeping them safe from harm and abuse. Families often say that these are the issues that cause them most concern when they think about a time when they won't be around to keep an eye on things.

Throughout this guide we’ve emphasised the importance of planning and taking steps to build a safe and happy future for your relative. These include:

• Creating as many opportunities as possible for them to make decisions and speak up for themselves: this includes putting together information about the best way of supporting them to make decisions and understanding their way of expressing what they prefer.

• Making sure that person-centred information about them has been put together (by your relative, you, and any other close family and friends) in a format that will help other people to understand who they are and what is important to them. This will help them obtain services and support that match their needs rather than having to fit into what is offered.

• Involving as wide a group of people as possible in your relative’s life so that they know there is someone who they can talk to if they have any worries and who will ‘keep an eye on things’ when you are no longer able to do so.

• Involving your relative where possible in discussions about when you may no longer be around so that they are better prepared to cope with loss and bereavement – this should make them feel less vulnerable when they have to go through difficult times.

This section gives additional information about what to look out for when your relative is moving from the family home:

• What to consider when choosing somewhere to live and/or support;

• Keeping an eye on things after a move;

• What to do if you have concerns.

What to consider when choosing somewhere to live and/or support

Using the information in Section 6 you may have decided on the model of housing and support but still need to decide between different providers of that model. Don’t be afraid to ask questions: the more information you have, the easier it will be to make an informed choice and to avoid any unexpected problems. Service providers should welcome families who are interested and informed.

Not all of the questions in the table below will be relevant to your relative – it will depend on whether they are living on their own, in shared accommodation, moving to a place where housing and support are provided together etc.
# Overall impression

The questions below are suggestions to be considered, but you should also trust your gut reaction when you visit. Is there a welcoming and homely atmosphere? Does the physical environment seem to be well looked after and reflect the culture and interests of the people living there? Do tenants/residents appear to be confident and relaxed and at the centre of things, behaving as though they know it is their home? Is there plenty of choice of things to do? Do the staff seem motivated and respectful towards the people they are being paid to support? Do they communicate with people in an adult and warm manner?

<table>
<thead>
<tr>
<th>Organisation(s) providing the housing and/or support</th>
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<tbody>
<tr>
<td>Find out as much as possible about the organisation(s) – is it local, regional or national? Is it a private company or a not-for-profit organisation? Does it only provide support to people with learning disabilities? Does it offer any specific expertise such as communication, complex health needs, positive behaviour support or building community connections? Look at its website and any information leaflets it produces – are they written in a person-centred way? Does the organisation produce accessible versions of its information? Has it produced any documentation, such as a personalisation charter setting out the standards you can expect around individualised support or a family charter saying how it involves families? Ask to see its policies on quality improvement, making complaints and safeguarding – are these written in a person-centred way? All housing and support providers should have a complaints procedure including an easy to read version if they are providing a service to people with learning disabilities: you will be able to gauge the provider’s attitude to improving their service from the way it is written. Find out how they support someone with a learning disability to understand the process. Do they welcome complaints as a way of improving the service they provide?</td>
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<table>
<thead>
<tr>
<th>Do we need to ask about this?</th>
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<tr>
<td>Yes</td>
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<tr>
<td>No</td>
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<tr>
<td>Location and safety of property</td>
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<td>--------------------------------</td>
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<tr>
<td>Would your relative know people in the area and would they be able to travel safely to visit people and places they know?</td>
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<tr>
<td>Does the area feel safe to live in and to be out and about in?</td>
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<tr>
<td>What are the security features in the house (for example door and window locks) and is there good lighting in the area around the house?</td>
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<tr>
<td>Is there a sense of local community – for example a Neighbourhood Watch Scheme, corner shop, community hall?</td>
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<tr>
<th>House sharing</th>
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<tbody>
<tr>
<td>Does your relative know the other people they would be sharing with?</td>
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<tr>
<td>Do they get on with them and are there plenty of opportunities to get to know other tenants/residents before a move?</td>
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<tr>
<td>What support is provided if people find they do not get on together?</td>
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<tr>
<td>If someone wanted to move out, how would they be supported to do so and how would the other tenants/residents be involved in choosing who would move in?</td>
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<tr>
<td><strong>Do we need to ask about this?</strong></td>
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<tr>
<td>Are meetings arranged so that tenants/residents can talk and make decisions together about what they would like to happen in their home? How often do these meetings happen, what might be discussed and who would be responsible for making sure they lead to changes or improvements?</td>
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<tr>
<td>What bills are there and how are they shared?</td>
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<tr>
<td>Do the tenants buy shared furniture and equipment? If so, what happens if something gets broken or someone moves out?</td>
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## Quality of support

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<th>Question</th>
<th>Do we need to ask about this?</th>
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<tr>
<td>When you go with your relative to see a potential place to live or to meet a support organisation, take the person-centred information you have gathered and share this with them. See whether they respond positively and seem keen to meet your relative’s needs in a creative way.</td>
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<tr>
<td>Ask how the service is externally monitored. If it is done by the Care Quality Commission (i.e. residential homes and domiciliary support organisations) ask to see any reports. Do they have an independent quality-checking service and are people with learning disabilities and families involved in it?</td>
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<tr>
<td>Ask how people at a senior level in the organisation find out about the views and experiences of people with learning disabilities and family carers. Are people with learning disabilities or family carers on their Board?</td>
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<tr>
<td>Ask how the service is monitored and managed by the organisation – who is the responsible manager and how much time do they spend there?</td>
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<tr>
<td>Find out about staff turnover – is there a mixture of people who have worked for the organisation for a while as well as new people who have brought fresh ideas?</td>
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<tr>
<td>You could ask how long support workers usually stay. You might want to find out how staff are contracted – do they have permanent or temporary contracts?</td>
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<tr>
<td>Do they have ‘zero hours’ contracts where they are paid only if there are support hours available for them to work? Some people like flexible work hours but for others it creates uncertainty and they will not be committed to the organisation.</td>
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<tr>
<td>Ask how the organisation provides support, training and personal development to staff who would be working with your relative.</td>
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<tr>
<td>If your relative has specific needs, will the organisation pay for staff to have training to meet those needs?</td>
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If you feel hesitant about any of these matters, talk to other people (friends, other family carers, a carers’ support group or a care manager) and find out what they think. It is always best to look at a few organisations and places to live before making a decision as you can then make comparisons. If you do not feel positive about a support organisation or place to live that has been suggested by a care manager let them know your reasons: this should help them to understand what would work better for your relative.

Keeping an eye on things after a move

If your relative moves away from the family home, you, other family members and their circle of support still have a valuable part to play in making sure things are going well. You are likely to see your relative try new things and feel confident about their achievements: your new relationship will probably be a combination of worry about the challenges and risks they are facing and pleasure at seeing them cope in their new situation. We all have to balance taking risks and trying out new things. The key is to try new things in a way that minimises risk. It will help your relative if you can combine expressions of pleasure and respect for their new achievements and decisions they have made for themselves (even if you don’t always agree with them) whilst also keeping a watchful eye for any signs of unhappiness or worrying changes in behaviour.

You may find that your relationship will gradually change. How you shape this different involvement in your relative’s life will depend on how much you feel able to do, where your relative has moved to, the level of support they need to make decisions and what you and your relative feel would work well.

Using person-centred information to shape their support

After a move families can continue to be involved with person-centred planning and are often central in keeping it going. Your relative may also choose new people in their life, those they are living with or being supported by, to contribute. They will hopefully bring new ideas and connections. If your relative has a circle of support aim to keep it going after a move; people involved can help to make a move go well and think of new opportunities.

If your relative has difficulty communicating verbally it is important to make sure they have a ‘communication passport’ that describes their communication and how to support them to make decisions and also explains how they express emotions and feelings such as pleasure or pain.

You can help your relative to choose photos and items to take with them to their new home: these can trigger conversations with new people providing support. A life story book can capture important times in your relative’s life and these can be shared in future years (see pages 32 and 55 for more information and ideas).

Keeping in touch

Try to arrange for your relative to have regular contact with family and/or family friends. This helps to give the message to support providers that, as a family, you are still committed to your relative having a good life and also that there are people who are keeping an eye out. There shouldn’t be any restrictions on when you can call in and sometimes it is good to call in without advance warning (especially if you are concerned about something). Between visits you can keep in touch by
phone, emails or Skype – a method of making video calls which means that you can connect with your relative even if they have little or no verbal communication. When you are visiting you should try to have some time on your own together so that your relative can talk about any worries (however small). Although you would not expect to go into other people’s rooms, no other areas in a nursing or residential home should be ‘out of bounds’. The situation is different if your relative is sharing a house as a tenant as you will need to respect the fact that it is also somebody else’s house.

If there are no family members or friends that could visit your relative, you could consider putting money in a discretionary trust to pay an advocate or other interested person to visit.

**Building a relationship with people supporting your relative**

A good support provider will welcome the involvement of family and friends and create opportunities for you to meet in a variety of ways (for example they could support your relative to invite you for a meal). Communicate regularly with the provider and let them know how you would like to be involved.

Give positive comments when you see something good happening; it is demoralising only to receive criticism. If you have established a good relationship with the support provider, it will also be easier to raise concerns and ideas for change. Discuss any concerns with support providers at an early stage as that should make them easier to resolve. Your involvement in raising concerns will depend on how able your relative is to speak out about things they are not happy with. If they are able to explain the concern themselves you could support them to think about the best way of doing so and who could help them.

**Making decisions**

If your relative has difficulty making some or most decisions you will want to keep an eye on how decisions are being made on their behalf (see Section 1: Making decisions). After a move, an organisation providing support must (under the Mental Capacity Act) still involve family members in the process of assessing whether someone has the capacity to make a specific decision and in making best interests decisions. If this is not happening or you feel decisions are being made that do not seem to be in the best interests of your relative and you are not being listened to, you should ask for an independent advocate to be involved who could help to make sure your relative’s wishes are properly understood. Alternatively, you could follow the complaints procedure described below.

**Quality checking**

In some areas, or in some organisations, there is a quality-checking service that employs people with learning disabilities and sometimes also family carers. A quality-checking service that asks residents and tenants their views about the support they receive helps to give people with learning disabilities a sense of their right to good support and to speak up. Quality-checking teams usually use a set of standards such as the REACH standards (see glossary) against which services are monitored. It may be helpful to look at the REACH standards (see glossary) to know what is realistic to expect.

**Knowing how to keep safe**

It’s important that your relative feels safe where they live. Some considerations are door and window locks, regular smoke alarm and fire safety checks. Tenants should also know to check for ID badges when there are callers to their house. As long as they know the basic rules to follow, the internet
offers a safe way for people to keep in touch and make arrangements with friends and family. (see http://www.learningdisabilities.org.uk/content/assets/pdf/publications/staying-safe-online.pdf)

Your relative also needs to know about the procedures that exist to help them keep safe and secure. Most local authorities have produced an Easy Read guide to help people understand about keeping safe or ‘safeguarding’ (see below), and housing and support providers should have an Easy Read complaints procedure.

It is important that your relative feels safe when they are out and about too. Do they know how to ask for help if they go out on their own? Is there a Safe Places scheme in the area? Under this scheme, local shops and businesses train to be a ‘safe place’ and put a sticker in their window to alert people with learning disabilities that they can ask for help. There is a lot of information on the internet for people with learning disabilities about how to keep safe when they are out and about; for example travelling on public transport, getting in a taxi, being out at night and looking after valuables. (see http://www.learningdisabilities.org.uk/publications/safeoutandabout/)

Alternatively, you could talk to a local advocacy group which is likely to have Easy Read information on keeping safe.

What to do if you have concerns

It is natural to worry when your relative is living away from home and it is always best to raise any concerns you may have at once, even if it is over a minor issue, for peace of mind and to prevent the problem from escalating.

Likewise, it is important to listen to any concerns that your relative may express and trust them if they indicate that something has happened to them or to others. This may be through words or through changes in their behaviour; they may seem more anxious, or be avoiding people or places.

You can take different levels of action, depending on the nature of the concerns. You may feel that something specific is not working well, support is of a generally poor quality or you may have noticed something that makes you worried that some kind of abuse is taking place. You should not hesitate to raise any concerns: it is through openness and discussions that serious harm is prevented and the quality of services is improved. Family carers often worry about raising concerns as they fear it will be ‘taken out’ on their relative. This should never be the case and would be cause for serious concern in itself. If you are fearful that this might happen, you should ask a carers’ support organisation or the care management team to help you raise your concern.

There are two main routes you can follow. If you think your relative, or someone else, is at ‘risk of harm’, the Safeguarding of Adults procedure should be used. Otherwise you can use an organisation’s complaints procedure.

Safeguarding of adults

If you have a concern about the safety of your relative and you feel they are in immediate danger or have been the victim of a crime, the police should be contacted. If you think they are at risk but not in immediate danger, you should report it to your local authority’s safeguarding adults team, who can be contacted through the main council phone number.
The Care Act puts adult safeguarding on a legal footing and states that local authorities are responsible for any adult in its area who:

• has needs for care and support
• is experiencing, or is at risk of, abuse or neglect, and
• as a result of those needs is unable to protect himself/herself against the abuse or neglect or the risk of it.

The Care Act recognises the key role of carers in safeguarding particularly in witnessing or reporting abuse or neglect.

Abuse can be of various kinds: physical, sexual, psychological, financial, material, discriminatory or institutional, or to do with neglect and acts of omission. Local social services are the lead coordinating agency for Safeguarding Adults Boards. Other organisations, such as the NHS, independent (private and voluntary) social and health care providers, housing providers, the police, the Crown Prosecution Service (CPS), the Probation Service and the Benefits Agency, also have responsibilities and they should all work together and share information as appropriate. When you contact your local authority to raise a concern, you will speak to a member of the safeguarding team who will have been trained to deal with concerns in a sensitive manner. They have responsibility for investigating concerns, so you only need to provide them with information about your concern and they will follow it up.

Making a complaint
Before deciding what action to take, you may find it helpful to write down your concerns and talk them through with other family carers or people who know your relative well. This should help you decide the best way of approaching the issue and provide you with a written record if needed. If you do make a formal complaint, it is advisable to keep a record of phone calls, letters and conversations with staff. Wherever possible, it is best to support your relative to be involved, so that they develop the skills and confidence to speak up for themselves.

Complaints can generally be made at three levels:

• Talking to the service provider/organisation or the care management team;
• Using a complaints procedure;
• Going to an independent regulatory body or ombudsman, if the complaint hasn’t been resolved at the first two levels.

Talking to the service provider: if you have already established a mutually respectful relationship with people working in a service it will be easier to raise any worries. You should feel that both you and your relative are being listened to and your worries properly addressed. They should also tell you about their complaints procedure in case you feel you have not been listened to.

Using a complaints procedure: every NHS, social care organisation and housing provider must by law have their own complaints procedure. You may want to use this if it doesn’t feel possible to resolve your concern through discussions or if your concern is with the management of a service and you feel you need to take it higher. You can ask for independent support when making a complaint – contact your local authority or the NHS to ask who may be able to help.

Going to an independent body: if you are not satisfied with the outcome following the complaints procedure, you can ask the local government ombudsman to review the way the complaint has been dealt with (if it is a council service) or contact the regulatory body such as the Care Quality Commission.
Questions to ask

What advocacy support is available locally for people with learning disabilities?

Is there locally produced, accessible information about making a complaint or about keeping safe?

What support/advocacy support is available for family carers when their relative is going through the safeguarding process?

Whom to ask

Contact your local authority, family support groups or advocacy/speaking-up groups.

As above.

Contact your local authority.

Notes
To find out more you could look at

The National Family Carer Network (NFCN) and other organisations worked together to produce three levels of resources about safeguarding for families with an adult relative who has learning disabilities: a 4-page ‘Top Tips’ guide, a more detailed ‘Essential Guide’ and a Resource Pack which includes video clips featuring people's stories. Visit the website for more information about all three.
http://www.hft.org.uk/safeguarding

Making Safeguarding Personal is a programme of work led by the Local Government Association to make sure safeguarding investigations lead to the changes the person wants in their circumstances (rather than focusing on the process). Information about this programme could be helpful in making a safeguarding investigation personal to you relative.

Staying Safe on Social Media and Online is an easy read guide for people with learning disabilities.
http://www.learningdisabilities.org.uk/publications/safeonline/

Staying Safe Out and About is an easy read guide for people with learning disabilities.
http://www.learningdisabilities.org.uk/publications/safeoutandabout/

The 11 REACH standards set out the ways in which people can have choice and control in supported living.