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How to be a great

autistic individual employer

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and Skills for Health, 4th Floor, 1 Temple Way, Bristol, BS2 0BY
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Skills for Care is the employer-led strategic body for workforce development in social care for adults in England. It is part of the sector skills council, Skills for Care and Development, and is the home of the National Skills Academy for Social Care.

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This guide explains what people with autism and their families think is important to consider when employing a personal assistant (PA).

Throughout the guide you will find links to other resources where you can find more information. These may not all be autism specific.

To accompany this guide we have produced resources two additional guides called 'how to be a great personal assistant for someone with autism' and 'how to do a great assessment for someone who has autism', as well as two videos called 'important things to remember as a personal assistant for someone with autism' and 'important things to remember when doing any type of assessment with someone with autism'. These resources can be found online at www.skillsforcare.org.uk/autism.



Autism affects each person in a unique way; so it is important you find a PA who understands you and can provide the support you need in the way you want it.

It is also important that you understand how your autism will affect your role as an employer.



This guide is divided up into the following sections:

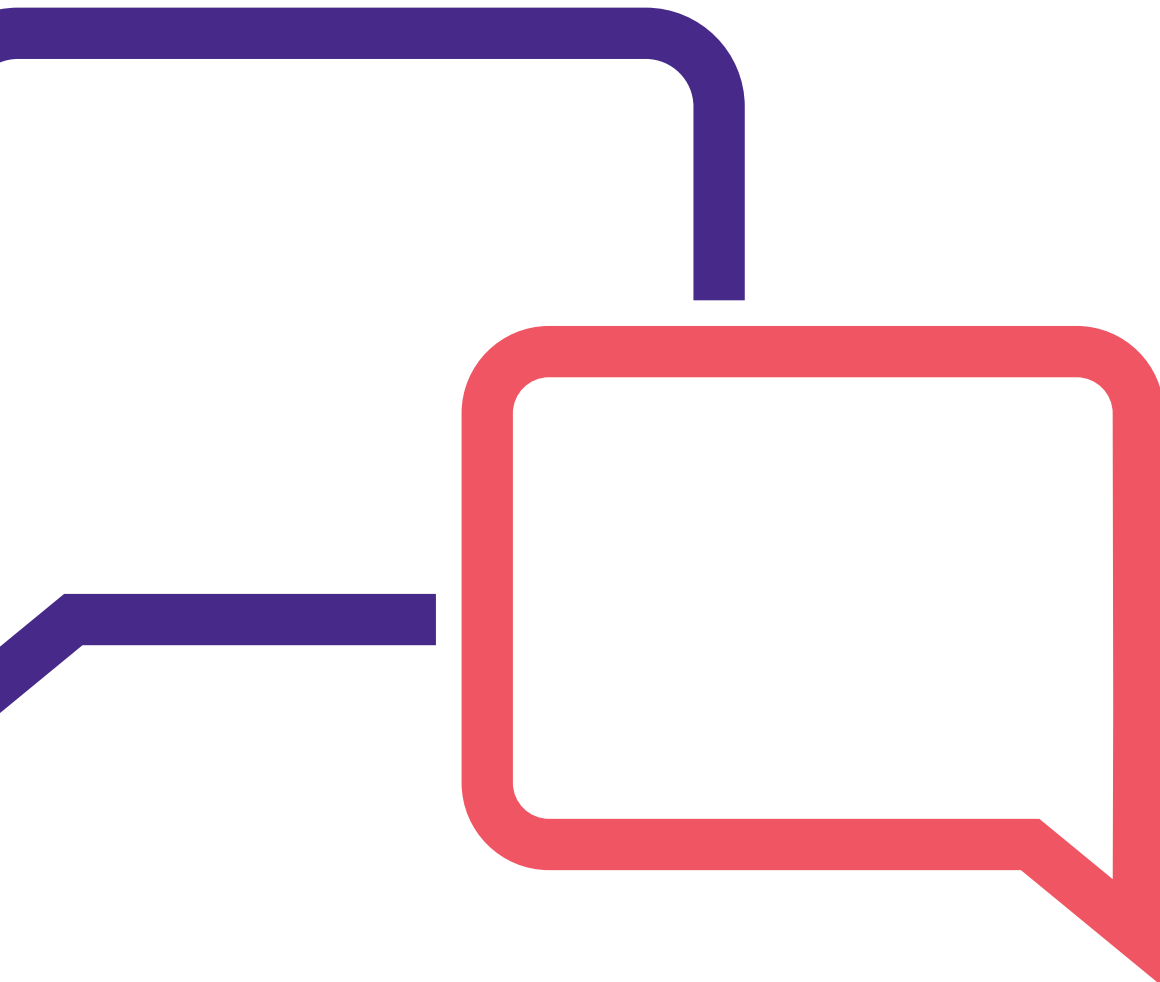
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1 I have autism and I am thinking of employing a personal assistant

- A social worker, community nurse or care coordinator may be talking to you about helping you to be independent.
- You can use individual budgets, personal health budgets or direct payments to employ someone to help you, or you may be self-funding (where you use your own money rather than benefits).
- Some people employ more than one personal assistant. You can choose who you employ and what activities you ask them to do if you have enough money to pay for it, and if it is reasonable and legal. If it is funded by the local authority or health authority then it must be in line with your needs as they have assessed them.

The idea of employing a personal assistant (PA) can be daunting as there are lots of things to think about. If you want to find out more about employing your own personal assistant read the employing personal assistants toolkit, available online at:

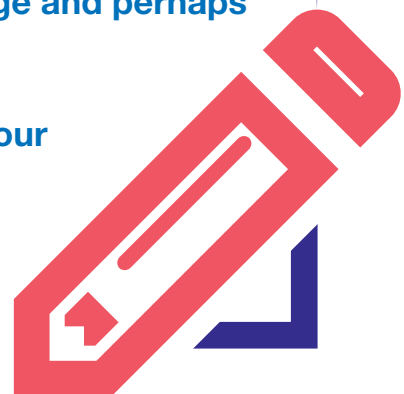
www.employingpersonalassistants.co.uk.



2 I want to become a great autistic individual employer

Autism affects everyone differently and so it is important you find a personal assistant (PA) who understands you and can provide the support you need in the way you want it. The list below contains some top tips to consider if you want to be a great autistic individual employer.

- ✓ **Share what you know about yourself as part of a good induction.**
- ✓ **Think about using a one page profile 'all about me' form with your PA.**
- ✓ **Plan for the personal assistant's learning and development.**
- ✓ **Understand that the PA might not realise what's important to you – you will have to let them know.**
- ✓ **Understand professional boundaries; you will have a formal employer / employee relationship with your personal assistant. You may also be friends with them but a personal assistant may not want to have a friendship with you.**
- ✓ **Try to be flexible as an employer but explain you need notice of any changes.**
- ✓ **Be involved in recruiting your PA, maybe by reading applications, planning questions for the interview and reading references– you know what you like and don't like.**
- ✓ **Make sure there is enough travel time in the PA's schedule.**
- ✓ **Consider employing someone with autism.**
- ✓ **Pay a proper wage – at least the national minimum wage and perhaps consider paying the living wage rate.**
- ✓ **A good support plan is key to getting the right PA - if your support plan is poor then you may well end up with a wrongly matched PA.**



Some of the characteristics of autism might affect how you act as an employer. A good employer/employee relationship is based on having a shared understanding of what is needed from the personal assistant and a way of working through difficulties. This can be helped by having clear support plans and job descriptions, good supervision and management of the personal assistant and clearly talking through any problems. It helps to agree up front what plans you have to deal with any problems or grievances.

People with autism often have difficulty with understanding other people's communication and in communicating their own needs and feelings. If you have these difficulties you might find it helps if someone else can help you with some of your responsibilities as an employer. This could be a friend or family member, a social worker or someone from an organisation that supports people with autism or other individual employers. They might help you work out the important things you need to communicate and have good ideas about how to do this. This might be especially helpful if you are unhappy with the way your personal assistant is working.

3 What sort of things can a personal assistant (PA) do for me?

Employing a PA can help you to live independently and in the way you choose. There are many things a PA can do for you or help you with, such as:

- help you manage your money and correspondence
- explain things to other people when you are feeling too overwhelmed to do it yourself
- help you understand, prepare for or reflect on stressful situations
- help you plan and carry out tasks like housework and personal hygiene routines, menu planning, shopping and cooking
- help you to care for your children, other relatives, your pets or garden etc.
- help you plan days out and/or support you in social activities, work or travel.

Personal assistants can support you in the things that are important to you. You might want different personal assistants to help with different things.

There are many benefits of employing a PA. They work for you, so within the limits of what is reasonable and legal, you decide and agree with them what you want them to do and when and where you want them to work.

4 What sort of person should I employ as my personal assistant?

This is a very important question. You need to think about what matters to you.

Below are some examples of the attitudes, knowledge and actions some people with autism and their families look for in a good personal assistant.

How to be a great personal assistant for someone with autism		
Attitudes	Knowledge	Actions
<ul style="list-style-type: none"> ■ Have empathy. ■ Believe in the person you support – the things they can do and the things they want to achieve. ■ Believe that all support can be improved. ■ Be friendly, warm and compassionate. ■ Act with respect and encouragement to make good stuff happen (it doesn't matter what you believe). ■ Be enabling and encouraging. ■ Be willing to learn. ■ Be honest and trusting. ■ Don't forbid someone from taking risks. ■ Believe that people have capacity to make decisions unless assessed otherwise. ■ Be flexible and adaptable. ■ Use creative thinking. 	<ul style="list-style-type: none"> ■ Understand that people with autism may show emotion differently (sometimes not at all) but still have feelings. ■ Remember that if it feels easy you probably aren't working hard enough. ■ Understand trauma and causes of anxiety. ■ Don't compare the person's autism with other people's, or with other conditions such as mental health problems. ■ Work at the individual's own pace. ■ Understand the person may need time to process and respond to questions or information. ■ Understand that there will be a reason that some routines need to be followed – others might be less important or your employer might want help to change them. ■ Recognise controlling and influencing behaviour e.g. PA says "Jenny, this is what you want to say, isn't it Jenny?" rather than "Jenny, what did you want to say?". ■ Get to know your employer as an individual. Build a relationship with them. 	<ul style="list-style-type: none"> ■ Listen actively. ■ Don't let your emotions spill out on to your employer. ■ Continuity and consistency. ■ Explain, explain, explain. ■ Have a good work life balance. ■ Do what I would like, not what you want. ■ If you are going to be late let your employer know in the way you have agreed – they can get anxious when they are left in the dark. ■ Dispose of your rubbish and wash up your dishes. ■ Don't help yourself to their food. ■ Don't steal their stuff. ■ Communicate well. ■ Don't try to normalise people with autism. ■ Be understanding and willing to assist with strategies to help with coping with certain situations. ■ Be prepared for every day to be different, or the same, depending on the person. ■ Help people understand the risks and consequences of decisions then support them in their decision. ■ In an interview – wait for the employer to shake your hand – they may not be comfortable doing so.

You might agree with some of these statements and not with others. It is important that you feel comfortable with the people you choose. Try and work out which attitudes, knowledge and skills are right for you. You could adapt the list above to show what matters to you and then use it to choose and train your personal assistants.

5 How do I find the right person to be my personal assistant?

- It can be someone from your family or friends (for them to be employed as your personal assistant they usually must not live in your house) or someone they know.
- If you have a social worker they will have information on where to look.
- A local or national organisation of people with autism, or disabled people or carers may have useful information.
- You could advertise in the job centre or in a local newspaper.
- If you want someone part-time then students from a local college or university might be interested.

Thinking about how you find a personal assistant is very important as it might mean the people you have to choose from are from a particular group of people or one local area.

There are lots of things to do before you actually start the recruitment process. To find more out about the key tasks involved read 'recruiting a personal assistant'. It will take you through each of the key tasks one at a time. See the 'finding a personal assistant' page within the 'Being an employer' section of the Information Hub for Individual Employers at www.skillsforcare.org.uk/iepahub.

The best way to find someone you are comfortable with might not be by having formal application forms and interviews. You might want to meet them informally, or ask them to write a letter or send you a short video about themselves. You could ask someone who knows you well to help you choose. This is also a good time to let the potential personal assistants know about you, and the support that you need and the things that matter to you, so they can choose whether the job is right for them.



6 I have used the 'employing a personal assistants toolkit' and employed a personal assistant - what next?

There are a number of specific activities you will need to do before your personal assistant starts work. These are set out in part three of the Employing Personal Assistants toolkit 'before your personal assistant starts', available online at www.employingpersonalassistants.co.uk.

Always remember that:

- You can do these yourself.
- You can get help from someone you trust.
- If you have a social worker they will know about organisations that can help you.



7 What if I have a problem with my PA once they are working for me?

People often do not want to think about things going wrong, but sometimes they do and it is good to have a plan of how to deal with problems. Sorting out problems can be less daunting if you:

- agree in advance with your PAs how and when you will give them feedback on how they are doing so you can let them know when they are getting things right and if they get things wrong they have a chance to put it right quickly.
- talk to somebody you trust, taking the time to think about what to do.
- remember there are rules (and laws) to follow – the laws are about employment and the rules will depend on how you are paying for your personal assistant.
- try to be calm and always respectful.

8 How was this guide developed?

In June and July 2015 a group of people worked with Skills for Care and Skills for Health to develop the content of this guide. Development of the guide was funded by the Department of Health. The group included:

- people with autism
- carers and family
- advocates
- personal assistants
- direct employers
- health and social care professionals with a specific interest in autism.

9 Useful links and references

Employing personal assistants toolkit, Skills for Care.

www.employingpersonalassistants.co.uk

The information hub for individual employers and personal assistants, Skills for Care.

www.skillsforcare.org.uk/IEPAhub

The autism skills and knowledge list, Skills for Care/Skills for Health, 2011.

www.skillsforcare.org.uk/autism

10 Acknowledgements

Autism guides development group (which included individuals and groups representing people with autism, family carers and professionals working in social care, health and the police)

Autism guides wider consultation group

Leeds Asperger Adults - www.leedsaspergerblog.wordpress.com

Leeds Autism AIM - www.autismleeds.org.uk

The National Autistic Society - www.autism.org.uk

Insight Autism Consultancy - www.insightautism.co.uk

Department of Health - www.gov.uk/government/organisations/department-of-health

Skills for Care - www.skillsforcare.org.uk

Skills for Health - www.skillsforhealth.org.uk



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Health

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Skills for Health
Head Office
4th Floor, 1 Temple Way
Bristol
BS2 0BY

T: 0117 922 1155
E: info@skillsforhealth.org.uk

skillsforhealth.org.uk

© Skills for Health 2015

Skills for Care
West Gate
6 Grace Street
Leeds
LS1 2RP

T: 0113 245 1716
E: info@skillsforcare.org.uk

skillsforcare.org.uk

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