

COMMISSIONING ADVOCACY SERVICES FOR INDIVIDUALS WITH SEVERE LEARNING DISABILITIES

A Pamphlet for Commissioners



**making a difference
to the lives of people with
severe learning disabilities**

www.challengingbehaviourfoundation.org.uk

Contents

Introduction.....	3
Why Commission Advocacy for these Individuals?	4
Implementing Policy and Legislation	5
Case Study – The Medway Advocacy Project: A model for non-instructed advocacy.....	6
Receiving good advocacy support	Error! Bookmark not defined.
Recommendations for Local Authorities to ensure effective advocacy provision for individuals with learning disabilities.....	8

Introduction

Independent advocacy services are a **crucial resource for vulnerable individuals**, including those with learning disabilities.

“Good quality advocacy is so important to this group of particularly vulnerable people. It can deliver positive outcomes for people – in everyday ways as well as for the big decisions” – Viv Cooper, OBE, Chief Executive, Challenging Behaviour Foundation

Legislation now places increased importance on **individual choice and control** when making decisions about meeting needs and providing support. Local Authorities must consider the wishes and views of the individual in the decision-making process, regardless of the complexity of their needs.

There are many occasions when someone may need help to speak out to those who support them, so long term independent advocacy can give people a voice.

This guide has been produced to help those responsible for learning disability services to plan and increase the availability, and quality, of independent advocacy services for individuals with learning disabilities who display behaviour that challenges.

Non-instructed Independent Advocacy

- Non-instructed independent advocacy is **essential for vulnerable individuals**, for example those who lack capacity to make decisions about their own lives or who are unable to communicate their needs.
- There is **an absence of the skills** that are required to advocate for young people and adults with severe learning disabilities who have complex needs and may display challenging behaviour.
- There is also a **general unawareness of specific issues** that may affect the care this group of individuals receive, and their quality of life. These issues include limited choices, lack of community inclusion, and the frequent use of restraint and medication to manage behaviour.

“It’s vital the person advocating for someone with severe learning disabilities whose behaviour is described as challenging knows enough about the issues affecting quality of care to identify and challenge poor practice” – Professor Peter McGill, Tizard Centre, University of Kent.

Why commission advocacy for these individuals?

The Benefits

- Independent advocates provide a voice for the person.
- **Advocates perform a protective role**, ensuring the safeguarding of vulnerable individuals.¹
- Individuals with learning disabilities may display challenging behaviour (such as aggression and self-injury), which can place them **at risk** of out of area placement or restrictive management practices. Independent advocates can encourage care providers to take a more proactive approach to understanding and preventing challenging behaviour.
- Good advocacy may also reduce social services expenditure on safeguarding activities, care proceedings and provision.²
- Independent advocacy can ensure choice, well-being and enable person-centred care.

Benefits of Non-Instructed Independent Advocacy

- Statutory advocacy is generic and issue-based. **Individuals with severe learning disabilities and complex needs** require sustained, non-instructed independent advocacy.
- Non-statutory independent advocacy is provided by charities and organisations whose long-term funding is often uncertain.
- Non-instructed advocacy that can be provided on a more enduring basis should be funded by Local Authorities. This would **increase access and availability of skilled advocates**.

“There tends to be statutory advocacy and not really that more protective advocacy, the type where you can get to know someone enough to speak out for them” – Holly Butcher, Family Support Manager, Challenging Behaviour Foundation.

“There can be difficult relationships between families and independent advocates, particularly if families feel advocates have been brought in to counter their input. But the combination of the two, working together in the best interest of the person with their own perspectives and experience can be very powerful. I will always advocate for my son – but I welcome a well-informed independent advocate who has got to know my son well and who understands him, as an additional “voice”. We work together to ensure he has a good life” – Family carer

Implementing Policy and Legislation

There are a number of laws, regulations, guidance and policy initiatives that emphasise the importance of advocacy:

- Public authorities are legally required to respect an individual's rights in accordance with the **Human Rights Act (1998)**³. In addition, they must take action to secure the rights of groups protected under the **Equality Act (2010)**⁴.
- Local Authorities are required to provide access to an **Independent Mental Capacity Advocate** when individuals lack the capacity to make decisions and there is no family member to express their wishes, in accordance with the **Mental Capacity Act (2005)**⁵.
- The **Mental Health Act (2007)**⁶ ensures that an **Independent Mental Health Advocate** is provided to people who are detained under a section of the Act⁷, to enable them to participate in decisions about their care and treatment.
- The **Health and Social Care Act (2012)**⁸ set up the NHS Independent Complaints Advocacy service (ICAS), to provide the support of an independent advocate, where required, to assist individuals through the **NHS Complaints Procedure**.

Recent changes in the law and new guidance also emphasises the importance of non-instructed, independent advocacy:

- The **Care Act (2014)**⁹ places new *advocacy duties* on Local Authorities in which they must arrange independent advocacy if: 1) it is thought the individual would find it difficult to participate fully in their assessment, and in the preparation and review of their Care and Support Plan; and 2) there is no one appropriate available to represent the individual's needs and wishes.
- Access to independent advocacy is also recommended in national guidance frameworks, including the **Ensuring Quality Services**¹⁰ and **NICE Guidelines on Challenging Behaviour and Learning Disabilities (2015)**¹¹.

Case Study – The Medway Advocacy Project: A model for non-instructed advocacy

This pilot project was a collaboration between the Challenging Behaviour Foundation, the Tizard Centre and the Young Lives Foundation.

A **model of non-instructed advocacy** was used, which involved appointing two advocates for each client - an independent advocate and a family or friend advocate.

Aims of the project:

- To develop the skills, and improve the confidence, of advocates working with individuals with severe learning disabilities who display challenging behaviour.
- To trial a model of advocacy designed to match the specific needs of this client group.
- Provide an additional mechanism for vulnerable people to achieve a better quality of life.

The project demonstrated several successes:

1. Clear **benefits of long term, consistent, person-centred advocacy** for individuals with severe learning disabilities and complex needs;
2. Evidence to support **the enrichment of lives and increased social network** of both clients and independent advocates;
3. Supporting evidence of **the need for consistent relationships** in non-instructed advocacy for individuals with severe learning disabilities and complex needs;
4. Valued and informative supervision meetings, demonstrating the **importance of ongoing support and guidance for independent advocates**.

“It worked for Joe* ... gave a fresh pair of eyes and enhanced his community participation” – Support staff member

“It was such a positive experience. I can’t thank the trainers enough for giving me the opportunity, but I also ... can’t thank Deborah* enough for facilitating my learning” a MAP advocate

*Names changed to protect identities of individuals accessing support services.

Receiving good advocacy support

Advocacy services need **the resources to deliver good quality, sustained, advocacy that extends beyond assessment and review, through transition, and provides ongoing support.**

The very varied needs of individuals with learning disabilities must also be recognised. Individuals with milder learning disabilities may require support voicing their concerns and protecting their rights. Individuals with more severe learning disabilities may not have the capacity or verbal ability to express themselves or instruct an advocate. They may require an advocate to speak on their behalf, to protect their rights or address a particular issue. All advocacy provision should work with individuals' existing family and social networks which, for many people with more severe learning disabilities, are already advocating for the individual.

Access to independent advocacy is inconsistent across Local Authorities¹². Therefore, those commissioning advocacy services for individuals with learning disabilities should consider:

- Identifying, encouraging and supporting independent advocacy providers who can provide **both instructed and non-instructed advocacy**
- Ensuring advocacy services are **well signposted**
- Providing support for advocates **who may face challenges** in advocating for some individuals, particularly where capacity is in question or when issues of best interest may arise (e.g. consent to treatment, including medication)
- **Supporting collaboration** with family members
- Working with service providers to **ensure understanding of independent advocacy and promote its value**

“Advocates need to work with the provider and support workers, and all those involved with the person so they’re really clear about the role, that it’s a positive thing. It is not checking up to criticise but trying to deliver good outcomes together” - Viv Cooper, OBE, Challenging Behaviour Foundation,

“Most vulnerable people should have an advocate, definitely not employed by [the service provider]... have to be an outside agency” – Service Provider

Recommendations for Local Authorities to ensure effective advocacy provision for individuals with learning disabilities

Local authorities should:

- 1) Ensure that **a range of independent advocacy services** are available and accessible to individuals with learning disabilities, including those with complex needs.
- 2) **Provide information about advocacy services in a range of accessible formats** to individuals with learning disabilities and their carers.
- 3) Help **identify and obtain the revenue needed** for sustained delivery of independent advocacy services.
- 4) **Support the training** of independent advocates and provide them with the skills necessary to deliver non-instructed advocacy to those with severe learning disabilities, and whose behaviour challenges.
- 5) **Ensure compliance** under the Equality Act (2010) and the Care Act (2014) for advocacy duties and guarantee provision of independent advocacy as laid out in statutory guidance.
- 6) Incorporate in their commissioning arrangements a requirement for advocacy services to **produce an annual report** to be published alongside the local authority's annual complaints report.
- 7) **Enable individuals' voices to be heard at a more strategic level.**

“There is general agreement that advocacy for individuals with learning disabilities is a good thing, and potentially a very powerful thing, and yet when you try to unpick that ... who's ultimately responsible to ensure that there's the availability of advocates?” - Viv Cooper, OBE, Challenging Behaviour Foundation.

Acknowledgements

This guide has been produced by the Challenging Behaviour Foundation. The Challenging Behaviour Foundation is a charity that aims to support families and professionals who care for someone with a severe learning disability who also displays behaviour described as challenging.

With thanks to the National Children's Society for design and presentation privileges and Clare Melvin, a Doctoral candidate from the Tizard Centre, University of Kent, for conducting the evaluation report on which this resource is based.

The information provided constitutes some of the findings from The Medway Advocacy Project, a pilot study that investigated the provision of non-instructed independent advocacy for individuals with severe learning disabilities and complex needs who display behaviour that challenges.

For a copy of the full Medway Advocacy Project report or easy read version please visit:
<https://www.challengingbehaviour.org.uk/information/for-commissioners-and-advocate.html>

To request print copies of the above or for copies of this pamphlet please contact:

Tel: 01634 838739

Email: info@thecbf.org.uk

References

- ¹Faulkner, A., & Sweeny, A. (2011) *Prevention in adult safeguarding: a review of the literature*. London, Social Care Institute for Excellence.
- ²Bauer, A., Wistow, G., Dixon, J., & Knapp, M. (2014) *Investing in advocacy for parents with learning disability: what is the economic argument?* *British Journal of Learning Disabilities*, 43, 66-74.
- ³*Human Rights Act* (1998). HMSO, London
- ⁴ *Equality Act* (2010). HMSO London
- ⁵ *Mental Capacity Act* (2005). HMSO, London
- ⁶ *Mental Health Act* (2008). HMSO, London
- ⁷ including those on Community Treatment Orders
- ⁸Department of Health (2012) *Health and Social Care Act*. Part of [Choice in health and social care NHS efficiency](#).
- ⁹Department of Health (2014) *The Care Act*. Part of *Health and Social Care integration and Choice in Social Care*.
- ¹⁰Ensuring Quality Services. Local Government Association, London
- ¹¹National Institute for Health and Clinical Excellence (2015) *Guidelines on Challenging behaviour and learning disabilities*. Clinical Guideline 11. London: NICE.
- ¹²Equality and Human Rights Commission (2010) *Advocacy in social care for groups protected under equality legislation*. Equality and Human Rights Commission Research Report Series, No.67.
- Brady, L (2011). *Where is my advocate? A scoping report on advocacy services for children and young people in England*. London: OCC.