

South East Essex LD Advocates Pack



Introduction and Welcome

Advocates are everywhere doing great work in South East Essex. Some of them are professional, some of them are exceptional carers who are using their lived experience to go that one step further and some are just the people who want everyone in their community to count.

This pack has been funded by those who play the National Lottery to cover SE Essex which means these areas: Southend-on-Sea, Castle Point, Rayleigh and Rochford. Our statutory partners on this journey include one relatively small unitary Local Authority, Southend-on-Sea City and the other is the much larger Essex County council which covers most of Essex.

Royal Mencap describe Advocacy as a fancy word helping people to speak for themselves. They say **“Advocates don’t speak on behalf of people with a learning disability – they make sure a person's own voice is heard.”**

Although we agree that this must be central to being an LD Advocate, unfortunately, to successfully navigate access to services requires that the person taking on this role must also be able to understand and explain the hugely overcomplicated forms which need to be filled in. These heavily rely on LD Advocates also being skilled in using technology to be able to even begin to help which means they need support to keep up to date with the systems needed to help adults with LD voice their concerns and make sure they are getting what they deserve and need.

LD Advocates need to be there to support those with high support needs to develop the skills, confidence and knowledge they need to voice their concerns and make sure they are being treated fairly. Therefore, the Supporting the Supporters project was created to bring together everyone who was trying to help adults with LD access information and services, explore choices and options and speak out about issues that matter to them.

This pack is part of the Making Care Fair campaign, for more details please visit our website: www.makingcarefair.org



What is a Learning Disability?

Royal Mencap’s definition of Learning disabilities – was the simplest that we could find.

A Learning Disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.

If you think of what most adults in South East Essex have to do to be able to have a home, job or education – how many forms to fill in, how many new skills have to be learnt every week and imagine not being able to understand complicated information easily, then you can understand why these residents need all kinds of support.



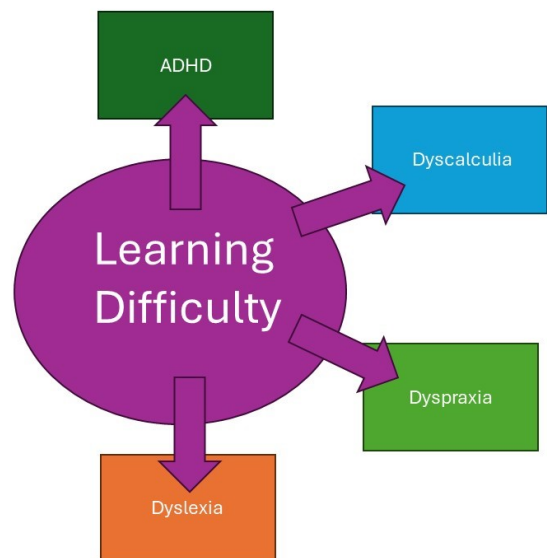
What is a Learning Difficulty?

Learning disability is often confused with learning difficulties such as dyslexia, dyscalculia and dysgraphia.

The government include ADHD (Attention Deficit Hyperactivity Disorder) as a learning difficulty where some organisations do not.

Mencap describes *dyslexia* as a “learning difficulty” because, unlike learning disability, it does not affect intellect.

As with learning disability, learning difficulties can also exist on a scale. A person might have a mild learning difficulty or a severe learning difficulty.



What is an Learning Disabilities Advocate?

The word advocacy means active support of a cause or an idea; in this context, an advocate is a person that speaks with and up for someone with learning disabilities. Advocacy for people with learning disabilities is hugely important, as they are often at risk of being ignored because they may not be able to communicate in a 'conventional' way.

An independent advocate will help to change things for another person and help them to live as independently as possible, helping them to make their own choices and achieving their goals and ambitions – in short, helping to give them more control over their own lives. Advocacy is all about placing the person at the centre of the support, planning or action.

Different Types of Advocacy

Everybody is an individual and their needs are different, and may change through their life. A range of approaches to advocacy have been developed to try to address these varied needs, which can be adapted and used when required. Here are the types of advocacy as outlined by the British Institute of Learning Disabilities:

1. **Self-Advocacy:** As the name suggests, self-advocacy means speaking up for oneself. Most people are able to do this, and it is an ideal way to ensure that appropriate support needs are realised. But although many people with learning disabilities are able to self-advocate, it can be difficult for them to get others to listen; this is where self-advocacy groups can help. They allow people with learning disabilities to join together to support each other and build confidence, helping to achieve desired results.
2. **Peer Advocacy:** Sometimes two or more people with a learning disability may share comparable experiences through living in similar environments or experiencing the same challenges. Peer advocacy is when two people have shared the same kind of experiences, and so are able to relate to each other and offer empathy and support – two very important qualities.





Southend Mencap members at the Novel Coffee Shop for Robbie's Coffee Morning.

3. Independent Citizen Advocacy: A citizen can independently volunteer to speak up for a person with learning disabilities, representing them as their 'citizen advocate'. The individual being spoken up for is known as the 'advocacy partner', and is usually a person who actively requires help in making their wishes, choices and decisions made known, otherwise the advocacy partner risks being ignored. Citizen advocates undertake this role independently and on a voluntary basis (without payment) The partnership is based on trust, loyalty and confidentiality. The citizen advocate communicates their advocacy partner's wishes, decisions, choices and opinions in an unbiased way, exercising no influence of their own. Advocacy schemes are now running in order to help match voluntary citizen advocates and their partners.

4. Paid Advocacy: This is usually a short-term arrangement, whereby an advocate steps in to assist in circumstances where large numbers of those requiring assistance with advocacy are required. Paid advocates may operate in larger organisations and look after several people at once, eventually handing over to one-to-one advocacy partners.

5. Case Advocacy: There are times when an advocate is required at short notice, on a temporary basis – this may be due to a crisis situation, or in cases where extra assistance is required, such as moving house, gaining employment or in financial matters. In these circumstances, a case advocate may step in to assist alongside citizen advocates or peer advocates as they often have a special expertise suited to the particular situation.

<https://www.bild.org.uk/>

What is the role of the LD Advocate?

The LD Advocate assists adults with a learning disabilities by:

- Empowering them in making choices to have more control over their lives.
- Helping them to get the Care Package they are entitled to receive.
- Assisting in the application for relevant benefits.
- Ensuring that they have the relevant information to make the right decisions about your goals in life and issues that matter to them.
- Speaking on their behalf if adults with LD want this during meetings and appointments.
- Enabling them to express their thoughts and ideas to make informed choices.
- Assisting adults with LD to represent their interests and exercise their rights.
- Supporting them to access the services they need.
- Supporting access to voluntary sector services, social care and health services.
- Assisting adults with LD when there is conflict in accessing these services.
- Guiding them towards service providers that offer services appropriate to their needs.
- Promoting adults with LD full participation in mainstream society.

When we talk about support, we understand that everyone's needs are different. Some people with learning disabilities need very little support, others need a lot. The same is true of support to be able to use technology successfully. The LD Advocates who have contributed to this pack believe that the following three points are vital to have been considered before starting to work with an adult with LD :

Firstly, has the adult with LD been supported to make informed decisions about whether or not they want to use technology, and what they might use technology for.

Secondly, whether they are supported to be active rather than passive users. An example of support to be a passive technology user is where the supporter switches on the device and logs in for the person, rather than supporting them to do it themselves.

Thirdly, that where a person is unable to communicate or advocate for themselves, any support provided is based on accurate, up to date knowledge of their needs and desires rather than assumptions.

LD Advocates are there to make the mainstream community accessible to those adults with LD in a way that suits them as individuals.



Southend Mencap Advocacy

The Southend Mencap Advocacy Service has been in operation since 1999 and, over the years, it has grown into a much sought after and dependable service to people with learning disabilities within the area they support Southend, Rochford, Rayleigh and Castle Point.

The need for the service has grown to such a level of demand that from 2015 Southend Mencap went from one full time advocate to two full time advocates, as well as a part time administration assistant who herself has learning disabilities.

Due to how the other advocacy services in the area have changed, this has had a direct impact on the increase in demand for our advocates and they are regularly supporting in excess of 50 students each per month.

The aims of the Southend Mencap Advocacy Service are:

To support people who might not otherwise find an independent voice and/or whose needs might be ignored or forgotten.

To ensure people know their rights and have the information to make informed choices.

To empower people to speak up for their rights, making sure that their needs are met and the service they need are provided.

The Southend Mencap Advocacy Service is for all people with a learning disability, age 15+, who live in Southend, Castle Point, Rochford and Rayleigh.

They can help with a wide range of issues including:

Benefits

day services/access to other service

accommodation

employment

choices e.g. holidays

conflict resolution with families

conflict resolution within the immediate community

understanding money/finance

sexuality and relationships



To make a referral to Southend Mencap Advocacy Service or find out more information about what help it can provide, our advocates can be contacted on (01702) 334514 or via email at southendmencap.advocacy@hotmail.co.uk.



South Essex Advocacy Services



SEAS is an independent advocacy service based in Westcliff-on-Sea that supports isolated, excluded, or vulnerable adults by empowering them to make informed choices, challenging barriers to access appropriate services and to ensure they are included in decisions about their health, care and wellbeing. They work Monday to Friday and you can call the office for a face-to-face or online appointment by calling them on: 01702 340566 or emailing: advocacy@southessexadvocacy.org

SEAS is a small, independent charity that advocates on behalf of adults experiencing financial and/or, social difficulties, and their advocates help adults who may benefit from someone to support them and to ensure their voice is heard. SEAS helps its clients and



understands that navigating the benefits system can be extremely complex and they offer help with completing Benefit Assessments and some of the Benefits forms – and if they can't help they can point you towards someone who can.

SEAS provide free, confidential and impartial advice and information, in a range of ways to suit the needs of clients looking for support. This advice can be given over the phone, or with clients' consent, to friends, family members, or professionals. They also offer Statutory Advocacy including the Independent Mental Capacity Advocacy, Care Act, Independent Mental Health Advocacy and Paid Representative advocacy and Community Advocacy. The SEAS website is available at www.southessexadvocacy.org

SEAS also provides services as part of the SOS Advocacy Hub in partnership with BATIAS, SHIELDS, and Livewell Southend where the community can find help with IMCA, IMHA, Care Act, Financial Advocacy, Community Advocacy, and NHS Complaints Advocacy. Details of their work can be found at: <https://www.sosadvocacyhub.org/>



Essex County Council Advocacy

Essex County Council works with Rethink Essex Advocacy to provide an accessible all age advocacy service to residents in Essex.

To contact the Rethink Essex Advocacy service call :0300 790 0559

Email: essexadvocacy@rethink.org

Website: <https://www.rethinkessexadvocacy.org>

Services include:

- Digital Inclusion & Benefits
- Housing & Homelessness
- Cost of Living
- Emergency Food Support
- Children and Young People
- Community Development
- Information
- Volunteering and Work Experience
- Training and Life Skills



From their website:

The Essex All Age advocacy service represents and empowers vulnerable people in various areas of their lives.

Independent Mental Health Advocates (IMHAs) are dedicated advocates who assist individuals receiving mental health treatment, particularly under the Mental Health Act.

Independent Mental Capacity Advocates (IMCAs), on the other hand, represent individuals who may lack capacity to make specific decisions about their health and welfare.

Independent Care Act Advocacy (ICAAs) provide support to individuals who require care and support under the Care Act 2014.

Independent Health Complaints Advocacy (IHCAs) help individuals navigate the complaints process related to their National Health Service (NHS) care or treatment.

Paid Relevant Person Representatives (RPRs) act on behalf of individuals detained under the Deprivation of Liberty Safeguards (DoLS) or the Liberty Protection Safeguards (LPS).

Rethink Advocacy works to ensure that the rights people are acknowledged, respected, and protected. We work with passion and dedication to promote social justice, equality, and fairness by raising awareness, influencing policies, and providing assistance to people who need it.



What is LD Advocacy in Local Authority Social Care?

Advocates in social care are independent from the local authority (local council) and the NHS. They are trained to help you understand your rights, express your views and wishes, and help make sure your voice is heard.

Am I entitled to an advocate in England?

The Care Act 2014 says that, when decisions are made about your social care, it's important that you should be able to participate as fully as possible, your views, wishes, feelings and beliefs should be taken into consideration, all your relevant circumstances are taken into account.

The law says that you need an advocate if you have difficulty in any one of these areas: understanding relevant information, retaining information, using or weighing information (for example being able to see the advantages or disadvantages in different options) communicating your views, wishes and feelings.

Local authorities are under a duty to involve you in decisions made about your care and support. If you have difficulty being involved in these decisions, then your local authority must provide an advocate, unless there is someone else suitable to support you.

When doesn't the local authority have to provide an advocate?

The local authority doesn't have to provide a person with high support needs with an advocate if there is an appropriate person to support and represent you, like a: family member, unpaid carer, friend.

However, it is complicated as a person cannot be an appropriate person if: they are already the person's professional or paid carer or the person with high support needs doesn't consent to them being their appropriate person, If the adult with high support needs lacks the capacity to decide who should be their appropriate person, and/or the local authority considers it's not in the adult with high support needs best interests for them to be their appropriate person.

Local Authorities are responsible in making sure that any LD Advocate doesn't have any reason why they shouldn't take on the role. A person with high support needs is entitled to the support of an advocate when they're having a needs assessment during the care planning process, when a care plan is being revised when safeguarding enquiries and reviews are being carried out.



What is the Care Act?

The Care Act 2014 is the law that applies to anyone cared by or working to supply social care in England. It was written to replace a large number of laws dating back over sixty years. The Care Act came into force in April 2015 and applies to the whole of England. It mainly covers adults with care and support needs and adult carers. It is the key piece of law guiding local authorities in their decisions about support for people with a learning disability and their carers. There are a number of big changes introduced in the Care Act which make it a useful piece of law. However, many carers believe that local authorities may not always be fulfilling their legal duties in practice.

The wellbeing principle underpins all other points in the Care Act. This means all decisions made by local authorities about a person's care and support must be guided by the aim of promoting their wellbeing.

The Care Act introduces a number of general responsibilities for local authorities. There is a strong focus on preventative services. This means local authorities have a duty to provide help and information to people which will help them lead a healthy life, stay independent, and avoid needing a lot of care and support. Local authorities must also help to stop carers from reaching crisis point.

Secondly, your local authority must also now provide all information in formats that people can understand. For example, the local authority should make sure that all information sent to people with a learning disability is available in easy read.

Thirdly, local authorities now have to make sure there is a wide range of good quality care and support services available locally.

If your local authority is failing to meet these general responsibilities, for example they are failing to give you the required amount of information and choice, you should challenge them.

If you are interested in becoming an Advocate for the LD community then you can find the Care Act 2014 at this website: <https://www.legislation.gov.uk/ukpga/2014/23/data.pdf>

Or a guide to the Care Act is available from Royal Mencap: <https://www.mencap.org.uk/sites/default/files/2016-11/Know%20your%20rights%20-%20.pdf>



Background on Benefits: Personal Independence Payments (PIP)

Since the new PIP system has been brought in each person who is receiving a care package from their Local Authority in England is assessed to contribute towards the cost. Local Authority officers then calculate the level of contribution necessary by considering all income, less expenditure, that is pre-determined by the rules set by the UK National Government.

Certain disability-related expenditure or DRE is supposed to be taken into consideration, but this is set locally by Southend-on-Sea City Council and Essex County Council as to what can be used to make the contribution to the care package costs lower.

Each LA applies its own criteria which means that it is hard to understand the rationale applied. There is no awareness of the affordability concept and, in some cases, adults with Learning Disabilities have withdrawn from services altogether simply because they can't afford the contribution. This then puts them and their families into a potential crisis. It is very difficult where families and carers are renting because it means that they (the carers) have to pay all of the rent for the person they are looking after.

All Local Authorities are struggling to afford to pay Adult Social Care costs for their area so they are forced ask adults with LD to make substantial contributions towards their care packages and in many instances, this is putting families into hardship.

The main area for concern is when a client still lives with their family/parents: some carers are reliant upon their cared-for person to contribute towards the home costs, and in many cases the carer has given up work to provide the care and they themselves are on a limited income. Contributions are regardless of package sizes, plus contributions have also been known to cost more than the actual cost of the care package provided.

The Independent newspaper reported that the government is finding a record number of disability benefits claimants have been wrongly rejected by its own assessments as the cost of correcting these errors soars, new figures show.

Campaigners have pointed to "flaws in the system" that led to almost 80,000 Personal Independence Payment (PiP) decisions being overturned at initial review last year. The findings have led to warnings that ministers are "throwing disabled people's lives into turmoil" by putting them through "long stressful" waits to get the right support, while presiding over an "appalling waste" of taxpayers' money.



Where to get training?

City and Guilds: Level 4 Independent Advocacy Practice (3614-04)

<https://www.cityandguilds.com/>

This qualification is for those individuals who act as independent advocates in both statutory and/or non-statutory roles. It has been designed to meet the needs of independent advocates working in England and in Northern Ireland.

The qualification provides the opportunity to develop both the skills and knowledge required to provide independent advocacy. It is suitable for those individuals who act as Independent Advocates where there is a statutory entitlement requirement for individuals to have access to an independent advocate. The qualification provides a way of recognising the competence of independent advocates:

in specialist areas such as mental health and mental capacity advocacy

where qualifications for independent advocates are mandatory in England

in independent advocacy roles where there is no statutory entitlement

who work in a range of other contexts.

University of Essex: Social Work BA Degree

<https://www.essex.ac.uk/courses/UG00375/1/BA-Social-Work>

Social work is all about people: it is an extremely rewarding and challenging profession. Applicants need to be hard working, adaptable, honest and, above all, passionate about finding long-term solutions and supporting positive changes for children, adults and families. The course will allow applicants to develop the skills, knowledge and understanding of how to support people to improve personal, practical, psychological and social aspects of their lives.

As a student of BA Social Work at Essex applicants will experience a lively, informal environment with many possibilities to pursue their own interests whilst being part of a multidisciplinary school.



Making Care Fair—A Campaign to Help Everyone with Learning Disabilities

Over the last few years, PIP has replaced the Disability Living Allowance (DLA) for people aged between 16 and 64 living in England and Wales. This has been disastrous for some families/carers of those adults with Learning Disabilities.

This Making Care Fair Campaign aims to highlight what needs to be changed to make sure that families/carers and adults with Learning Disabilities are being given the best support possible.

“We are penalising our families/carers who are already saving the government huge amounts of money in care costs. If they were to place their loved ones in a care setting/ supported living scheme this would be costing the government so much more in the long run. Why are we so blinkered not to see this?”

I am contacted daily by people feeling deeply worried about these charges and how they are going to afford to live day-to-day. This is continuing to put many of the families we support into crisis.

I would really like to see some changes with regards to these contributions as the ‘blanket one rule fits all’ policy doesn’t work. Each person needs to be assessed individually. No two people are the same and each family faces different challenges daily.”

Alison Halton (Southend Mencap Learning Disabilities Advocate).



Southend Showstoppers session in Southend. Through the study of drama Southend Showstoppers promote confidence and enjoyment and develop self-expression, self-awareness, friendship and cooperation within a fun, safe and trusting environment.



Useful resources

Mencap have created the following factsheets to help you with the benefits application, Care Act *assessment* and follow-up process.

Underline text = online links for e-version of this document

Italic text = links for the physical version of this document

[Delays in receiving benefits](#) (PDF, 52 KB) - this factsheet explains the options that may be available to you whilst you're waiting for your first payment.

(www.mencap.org.uk/sites/default/files/2017-10/Delays%20in%20Receiving%20Benefits%20Factsheet.pdf)

[Mandatory reconsiderations](#) (PDF, 48 KB) - this factsheet explains what to do if you wish to challenge a benefit decision.

(<https://www.mencap.org.uk/sites/default/files/2017-10/Mandatory%20reconsiderations.pdf>)

[Reasonable adjustments](#) (PDF, 425 KB) - this factsheet explains what changes should be made by the Job Centre and DWP for people with a learning disability who are looking to claim benefits.

(https://www.mencap.org.uk/sites/default/files/2017-10/Reasonable%20Adjustments-UPDATED_May2017_AH.pdf)

[What happens next](#) (PDF, 367 KB) - this factsheet sets out what should happen after your Care Act assessment.

(https://www.mencap.org.uk/sites/default/files/2017-10/Social%20Care%20Assessments-what%20happens%20next_UPDATED_AH_May2017.pdf)

[Reviews and new assessments](#) (PDF, 219 KB) - this factsheet is for people who already receive care and support through a package of social care and what they can expect from the review and assessment process.

(https://www.mencap.org.uk/sites/default/files/2017-10/Care%20and%20support-reviews%20and%20new%20assessments-UPDATED_AH_May2017.pdf)

[Direct payments](#) (PDF, 72 KB) - this factsheet explains how people with a learning disability and their families can receive *direct payments* to arrange their social care support themselves.

(https://www.mencap.org.uk/sites/default/files/2018-03/Direct%20Payments%20overview_0.pdf)



Royal Mencap

Mencap has a website dedicated to helping people with learning disabilities and their families.

This can be found at: www.mencap.org.uk
with information available at <https://www.mencap.org.uk/advice-and-support>

There is a lot of information and help with:

Everyday living

Friendships & relationships

Early years & children

A Guide to services

Information about the Learning Disability Helpline



This pack is the first version and will be updated by the SE Essex Advocacy Network. If you spot a mistake or think we need to work on something to make it more understandable, please just get in touch with us at contact@makingcarefair.co.uk or call Beth or Alastair on 01702 533191.

Thank National Lottery players for the funding that has made this work possible.
To all members so far of the South Essex LD Advocacy Network thanks for everything.
To all new members, please do get in touch we'd love to hear from you.
To everyone at Southend Mencap and Southend Showstoppers thanks for everything.
To all the members of Carers' Unite Group for their advice.
To all the adults with high support needs, your parents and carers in SE Essex who would much rather do it themselves and not need our help thank you for taking part. Hopefully, the Adult Social Care system in the UK will improve rapidly and you'll no longer need the Making Care Fair Campaign in the future.

For more information on the Making Care Fair campaign see our website at: www.makingcarefair.org or our Facebook page at facebook.com/makingcarefair

