

Living a Good and Meaningful Life

There is little argument that everybody, including people with a learning disability, autism or both, regardless of whether they have a mental health diagnosis or use behaviour described as challenging as a form of communication, is entitled to a good and meaningful life. This is protected by certain laws including the Human Rights Act, the Equality Act, and the Care Act. And yet this is still not a reality for so many people with a learning disability, autism or both despite the closure of long stay campus style provision, white papers, reform programmes following each scandal and report after report. The Assurance Transformation data for March 2023 shows there are currently 2,065 people with a learning disability, autism or both in mental health services. This represents only a 29% reduction since 2015. The target for 2020 was 35%.

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life for people with major disabilities supported by good services will often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management.

Mansell report, 2007

Whilst there are several models of care and support which aim to promote a good and meaningful life, they all include key components:

Person-centred care and support

[Person-centred care and support](#) provides your relative choice and control over their life: where they want to live, the type of housing, how they spend their time and the staff who support them.

Read the CBF's 8 ways to get a house and planning your house:



[Click here to read 8 ways to get a house](#)



[Click here to read planning your house](#)

This visual from Helen Sanderson Associates summaries what good care and support planning looks like:



[Click here to see the visual](#)

Use this resource from United Response which explains person centred support through video clips:



[Click here to access the resource](#)

Read about Pathways Associates approach to person-centred planning:



[Click here to read more](#)

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Communication

Ensuring your relative's care and support is person centred means they should be given the opportunity to communicate, in the way that suits them, their likes, dislikes, wishes, feelings, values and beliefs to people who understand them and listen.

Getting the right staff

Read this information from NDTi about matching staff to the people they support. There is a simple tool to fill in to help with this.



[Click here to read the article](#)

Once completed this information can be used to develop a job description and person specification for the role of caring and supporting your relative. For example, if swimming is an activity your relative enjoys and likes to do regularly, then support staff should be able to provide support and participate alongside your relative. If your relative likes to be out and about but can't use public transport but they do have their own car, then support staff should be able to drive.

Your relative and you (family carer) should be involved in the recruitment of support staff.

Visit the Skills for Care website which has information about employing and training staff (including how you can apply for funding for specialist training such as sign language). They also have templates for job descriptions, person specifications, contracts, which can be adapted to suit your relative's personal circumstances.



[Click here for more information](#)

A Community presence

The term 'community' will be used frequently in your relative's life as an aspirational place to live and be a part of but really it just means that your relative has the right to have the freedom to live in an ordinary street and access community-based resources on a day-to-day basis for both functional e.g. where they do their shopping, GP and dental surgery and leisure activities e.g. gym, swimming pool, places to make and maintain friendships – just as you do. Going 'out in the community' should not be a cause for celebration, it is a Human Right!



[Click here for a diagram about good community support](#)

Key message:

The principles of the Mental Capacity Act should always be used in any decision making. The Mental Capacity Act allows your relative, like everyone else, to make decisions that others may not agree with. Even if your relative is assessed as lacking the capacity to make all the decisions in their life, every effort should always be made to include them as much as possible. You (family carer), other family members, friends and anybody else who knows your relative well should be asked to share their knowledge, particularly if they have complex communication needs.

Positive risk taking



What good is it making someone safe, if it merely makes them miserable?

Source: Justice Munby in 2010



[Watch this video clip from SCIE about positive risk taking and quality of life.](#)

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Part of living a good and meaningful life should involve new experiences e.g. getting a volunteer role or paid job, trying different leisure activities, going on holiday, having a go at cooking. This is likely to involve planning and may include a risk assessment. Risk assessments should always be seen as a way of ensuring your relative can participate, not a list of all the reasons they can't, participate in an activity. We all take risks every day and whilst we may not fill out a risk assessment form, we carry out some form of checking what we need to consider.

Your relative's entitlement to reasonable adjustments under the Equality Act should ensure that they can be requested if it increases their opportunity to participate in community activities, e.g. access to a quiet area to change at the swimming pool.

Read this factsheet "Making it happen" from the CBF which explains how to manage risk positively. Although it was written for Covid, it still applies:

[Click here to read the factsheet](#)



Being independent

In addition to trying new experiences, your relative should have the opportunity to develop their existing skills and independence. This relies on being surrounded by people, including support staff, who are trained and skilled in providing capable environments and understand programmes such as active support.

Capable environments

[Read this paper which describes the characteristics of a capable environment](#)



[or download this infographic](#)



Active Support

The main principle of Active Support is engagement in meaningful activity and relationships and there are four essential components:

1. Every moment has potential
2. Little and often
3. Graded assistance
4. Maximising choice and control

This resource provides more information, including case studies about how Active Support works in everyday life for people with a learning disability, autism or both:



[Click here to read the resource](#)

This resource explains how active support successfully works alongside positive behaviour support:



[Click here to read the resource](#)

Trauma Informed Care

Like everyone, there may be times when life for your relative becomes a challenge. This can be due to events which have happened in the past, in the here and now or a combination of both, e.g. historic or current abuse. Not managed well this can result in a deterioration in emotional and mental health e.g. depression, an increase in behaviour described as challenging or both. Ultimately this could lead to admission to a mental health service. Once your relative is admitted to a mental health service, discharge and returning to a good and meaningful life in the community is difficult for many reasons, including:

- loss of skills
- deterioration in mental health and/or an increase in behaviour described as challenging

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- lack of local presence
- loss of relationships

The average length of stay for people with a learning disability, autism or both currently in mental health hospitals is 5.3 years. The data for March 2023 shows that there have been 220 delayed discharges. The main reasons include:

- lack of suitable housing
- awaiting residential home
- lack of social care support

One way to support your relative's emotional and mental health and/or increase in behaviour described as challenging is to ensure that trauma informed care is an integrated part of their care and support.

[Click here to read more](#)



Crisis prevention and intensive support

Crisis prevention can also support your relative to lead a good and meaningful life in their community instead of admission to a mental health service. There are times when some people will need additional support. Some areas have "intensive support teams" who can provide additional support and expertise. Evidence from family carers identifies a number of key life events which can contribute to deterioration in emotional and mental health and/or increase in behaviour described as challenging which often led to admission to a mental health service. These include:

- Poor transition planning from children to adult services. Of the 2,065 people with a learning disability and/or autistic people currently in mental health hospitals, 220 are children (Assuring Transformation data – March 2023)
- Personal or family crisis
- Placement breakdown

- Deterioration in physical health
- Puberty/adolescence
- Change of living arrangements such as leaving the family home



[Visit this link to download survival guides from Bringing Us Together](#)



[Visit SCIE's webpage about prevention and wellbeing](#)

Family carers should always challenge any suggestion that their relative is admitted to a mental health service. The Mental Health Act is very clear that care, support and/or treatment in the community should always be considered first. The professionals suggesting admission should be able to give clear evidence why this is the only option. If your relative is at risk of admission, e.g. they have previously been admitted, have a mental health diagnosis and/or behaviour described as challenging then there should be a crisis plan in place which includes proactive strategies. Part of managing the risk associated with behaviour described as challenging is the use of functional analysis. This means acknowledging that all behaviour is a form of communication and trying to identify the message.

Visit this link from the CBF which includes information about understanding behaviour described as challenging, finding the reason and supporting change:



[Click here to read more](#)

What is the responsibility of the local authority and NHS to ensure my relative has a good and meaningful life:

- Your relative is entitled to a robust transition plan to ensure a successful move from children to adult services.
- A Care Act assessment will identify your relative's needs and entitlement to care and support to ensure their wellbeing. As a family carer you are also entitled to an assessment to ensure that you can continue in your role for as long as you want too
- Integrated Care Boards (ICBs) are required to develop and maintain registers to identify people with a learning disability, autism or both who are at risk of admission to mental health services because of their mental health, or behaviour described as challenging or both and ensure that they have community services available to provide the necessary support.

The Care Act and Wellbeing

'Wellbeing' includes:

- personal dignity including treating your relative with respect
- physical and emotional and mental health
- protection from abuse and neglect
- control by your relative over their day-to-day life including over care (e.g. limiting independence) and support provided and the way they are provided
- participation in education, training, work or recreation
- social and economic wellbeing
- domestic, family and personal circumstances
- suitability of your relative's living accommodation
- contribution to society

[This CQC report Home for Good](#) celebrates successful community support. It includes 8 stories of people with a learning disability, autism or both who have previously been admitted to mental health services. All are now thriving in community services across England. There is no single model of care and support that explains this success. Each story is different. However, common threads emerge:

- **Services must be bespoke and truly person-centred.** This entails understanding and acting on what a person wants and needs. This includes recruiting and training specialist staff teams.
- **Agencies should work in partnership.** In particular, service providers should co-operate with clinical and health professionals and community teams e.g. occupational and speech and language therapists. This must happen during service planning and once a service commences.
- **Appropriate housing and environments are essential.** This might mean specially building property or considerable adaption of an existing property.
- **When people are labelled as having challenging behaviour which includes self-harm and physical or verbal aggression, this should be understood as communication of distress or need.** This understanding often comes from the use of a Positive Behaviour Support approach.

Family involvement in all aspects of service planning and delivery increases the chance of a good outcome.

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Family Carer Advocacy

As a family carer you have an important role to play in ensuring your relative has a good and meaningful life. You can share your unique knowledge about your relative: their likes, dislikes, wishes, feelings, values and beliefs and how they communicate these. You can provide information about care and support and/or treatment for your relative which has been either successful or unsuccessful and any trauma your relative has experienced. You are entitled to be involved in your relative's life and there are laws which protect your right to do this, e.g. Human Rights, Care, Mental Health and Mental Capacity Act.

Professional Independent Advocacy

If your relative does not have anybody to advocate on their behalf and they need this support, they may have a statutory entitlement to a professional independent advocate, e.g. Care Act processes, when detained under the Mental Health Act, or if decisions are being made with or on their behalf under the Mental Capacity Act. Some advocacy organisations also provide additional professional independent advocacy services, e.g. peer advocacy. This is usually dependent on funding.

Further information

Every month the NHS publishes data summarising the current admissions to mental health services. It includes a breakdown of the data e.g. by age, length of stay, reasons for delay in discharge:

[Click here to read more](#)



The BASW is a professional organisation for social work and social workers. Visit their website for details of key documents to support social workers to work preventatively to support, advocate and challenge on behalf of people with a learning disability, autism or both who are currently in assessment and treatment units or restrictive settings to enable a return to home as soon as possible:

[Click here to read more on the BASW website](#)



Read the Learning Disability Professional Senate Rights and Equality Based Outcomes for Learning Disability Services, including 'I' statements and case studies explaining how the Human Rights and Equality Act can be used to influence an ordinary life:

[Click here to read more](#)



Read this service model guidance for commissioners about supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

[Click here to read more](#)



Family Carer Advocacy Resource

This guide from the Challenging Behaviour Foundation guide outlines “What does good support look like for adults with learning disabilities who display challenging behaviour”:

[Click here to read the guide](#)



This guide is part of the Meeting the Challenge series which includes:

- Understanding challenging behaviour
- Difficulties in supporting a family member
- My family member has been sent to an inpatient unit
- Concerns about poor care or abuse
- Planning a successful discharge
- Transitioning to adulthood

You can download the other guides here:

[Click here to download the other guides](#)



Read this guide: Getting the Best Support Package – 10 top tips from the Challenging Behaviour Foundation:

[Click here to read the guide](#)



Watch the trailer for the Challenging Behaviour Foundation’s Everybody Matters video about Shaun and Colleen who have experienced poor support, restrictive practices and felt unhappy and sometimes unsafe in the past. Their stories show that with the right care and support everyone can live an ordinary life in their community. If you are a family carer you can contact the CBF for a copy of the DVD:

[Click here to watch the trailer](#)



The Challenging Behaviour Foundation has produced a pamphlet for professionals who commission services for adults with severe learning disabilities who display challenging behaviour:

[Click here to read the pamphlet](#)



Read how the CQC has incorporated a quality-of-life tool into their inspection process for services for people with a learning disability, autism or both:

[Click here to read more](#)



Download the PERMA Model booklet here:

[Click here to download the booklet](#)



PERMA stands for:

- Positive Emotion
- Engagement
- Relationships
- Meaning
- Achievement

and is one way of checking that your relative has all the core elements required to lead a good and meaningful life that is person centred. For example, Engagement celebrates the things your relative can do independently to make themselves feel happy, which might include listening to the same song, or watching something spin.

Ask whether your relative can be included in the Dynamic Support Register. This means that the relevant professionals will be aware of your relative's increased risk of being detained (sectioned) without the right care and support or early intervention (e.g. community intensive support team) at times when they are in crisis:

[Read more here](#)

