



**Bedfordshire, Luton  
and Milton Keynes**  
Integrated Care Board

## **BLMK ICB Learning Disabilities and Autism Suicide Awareness**

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# Learning from Lives and Deaths: people with a Learning Disability and Autistic People (LeDeR 2022)



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According to the latest national (LeDeR) Annual Report 2022, “suicide is shown to be a far less frequent cause of death for adults with a learning disability”. Suicide does not appear among the most common causes of death for adults with a Learning Disability. The LeDeR report accepts that this may be due to “a lack of data available on suicide among residents with a Learning Disability.” (19)

However, suicide, misadventure or accidental deaths were the among most common causes of death observed in LeDeR reviews for Autistic people without a Learning Disability. This has been attributed to “a lack of crisis escalation plans, or a lack of an awareness of the increased risk of suicide in autistic adults.”

# Autism in women and girls

According to the National Autistic Society “Doctors and other healthcare professionals can lack knowledge about how autism may present differently in women and girls. This means women and girls may be misdiagnosed with mental health issues or their autistic traits may be missed amid the symptoms of co-occurring conditions. Some tools used to diagnose autism are designed to identify autistic characteristics that may be more common in autistic men and boys. This means the process may not be as sensitive to characteristics more commonly found in autistic women and girls.” (20)

## Bedfordshire Luton and Milton Keynes Autism Population

Age Range	Gender		Grand Total	Gender	
	Female	Male		Female %	Male %
0-17	2885	7468	10353	27.87%	72.13%
18 +	2265	4967	7232	31.32%	68.68%
Grand Total	5150	12435	17585	29.29%	70.71%

The table above represents the population in BLMK with a diagnosis of Autism recorded by their GP as of the 25.11.2024. Source Data – BLMK SystemOne Electronic Patient Record reporting

# Autistic people without a Learning Disability

According to the Royal College of Psychiatry, “Autistic Adults with no Learning Disability are 9 times more likely to die by suicide than the general population. Suicide is the second leading cause of death for autistic people”.(21)

## Bedfordshire Luton and Milton Keynes Autism Population with no Learning Disability

Age Range	Gender		Grand Total	Gender	
	Female	Male		Female %	Male %
0-17	2716	6975	9691	28.03%	71.97%
18 +	1866	3927	5793	32.21%	67.79%
Grand Total	4582	10902	15484	29.59%	70.41%

The table above represents the population in BLMK with a diagnosis of Autism and NO learning disability recorded by their GP as of the 25.11.2024. Source Data – BLMK SystmOne Electronic Patient Record reporting.

# Autism suicide statistics

- “Autistic people are up to seven times more likely to attempt suicide than non-autistic people”(Autistica)(22)
- “up to 35% of Autistic people have planned or attempted suicide in their lifetime” (23).
- “Autistic Children are 28 times more likely to attempt suicide”(21)
- “Autistic people make up approximately 1% of the national population, but 11% of suicides, and with estimations that there are over half a million undiagnosed autistic adults in the UK, this percentage may be higher.”(24)

# Learning from lives and deaths – People with a learning disability and autistic people (LeDeR)



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What is a LeDeR review?

A LeDeR review is not a mortality review. It does not restrict itself to the last episode of care before the person's death. Instead, it looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. LeDeR reviews take account of any mortality review that may have taken place following a person's death.

LeDeR reviews are not investigations or part of a complaints process, and any serious concerns about the quality of care provided should be raised with the provider of that service directly or with the Care Quality Commission (CQC) via their [online system](#). - [NHS England » Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\)](#)

Between 01.04.2023 – 31.03.2024 in Bedfordshire Luton and Milton Keynes:

- There were 13 deaths among Autistic residents, of which 2 have received a LeDeR death notification.
- Of the 13 deaths recorded among Autistic residents, 3 were recorded as having a Serious Mental Illness, and 0 known suicides were recorded.
- It is possible that autistic suicides occurred that were not reported to the national LeDeR platform.
- Anyone can report the death of an autistic person to the national LeDeR team (Health Care Professionals, family, friends etc.) <https://leder.nhs.uk/report>

# Why are Autistic people at greater risk of suicide?

According to the National Autistic Society, Autistic people are at greater risk of suicide due to:

## Camouflaging

Camouflaging, or masking, is when an autistic person actively hides their autistic traits during social situations in order to be accepted by non-autistic peers. It negatively affects the mental health of autistic people and is associated with higher rates of suicidality (Bradley, L. et al 2021; Cassidy, S. A. et al 2020a; Cassidy, S. A. et al 2020b). Likewise, camouflaging can mean less support if professionals underestimate an autistic person's true level of distress (Camm-Crosbie, L. et al 2019). (25)

## Alexithymia

Some autistic people also experience alexithymia, making it difficult for them to identify and describe their own emotions (Costa, A.P. et al 2020). Therefore, an individual may not recognise they are in crisis or be less likely to seek help if they can't put their feelings into words. (25)

# Why are Autistic people at greater risk of suicide?

## Repetitive thoughts

Autistic individuals can also get stuck on or continuously mull over a particular thought or behaviour. If suicide crosses their mind, it may be more likely to stay there. This persistent thinking can lead to feeling trapped in an unbearable situation, with no hope of escape or rescue (South, M. et al. 2019; Arwert, T.G., Sizoo, B.B. 2020). (25)

Maori Word for Autism is takiwātanga, meaning ‘in your own space and time’.

## Lack of support

On top of everything, autistic people also experience an absence of appropriate support and services for mental health problems and suicidality (Camm-Brosbie, L. et al. 2019), and report a higher number of unmet needs compared with the general population. This lack of support is associated with an increased risk of depression and suicidality in autistic individuals (Cassidy, S. A. et al. 2018b). (25)

There are no treatments or prevention strategies specifically for autistic people who experience suicidality. A lack of professional knowledge and understanding of autism, means some autistic people may not seem ‘autistic enough’ for support (Camm-Crosbie, L. et al. 2019), or will receive support strategies developed for non-autistic people. Absence of, or inappropriate support, can cause feelings of disempowerment, burdensomeness, social isolation and hopelessness (Camm-Crosbie, L. et al. 2019). (25)



# Autistic people, mental ill-health, and service access

- Compared to non-autistic people, autistic people are:
  - 8 x more likely to be diagnosed with schizophrenia or other severe mental illnesses (1,2)
  - 3 x more likely to be diagnosed with an anxiety disorder (1,2,3)
  - 4 x more likely to be diagnosed with a depressive mood disorder (2,4)
- Autistic people represent a substantial proportion of patients in certain services, e.g.:
  - Eating disorder services: 20-35% of people with anorexia nervosa are autistic or have elevated autistic traits (5) and 44% of CYP with avoidant-restrictive food intake disorder had an autism diagnosis (6)
  - Gender identity clinics: Transgender and gender non-confirming people are 3-6 x more likely to be autistic (7)

# Autistic people have poorer health outcomes than non-autistic people

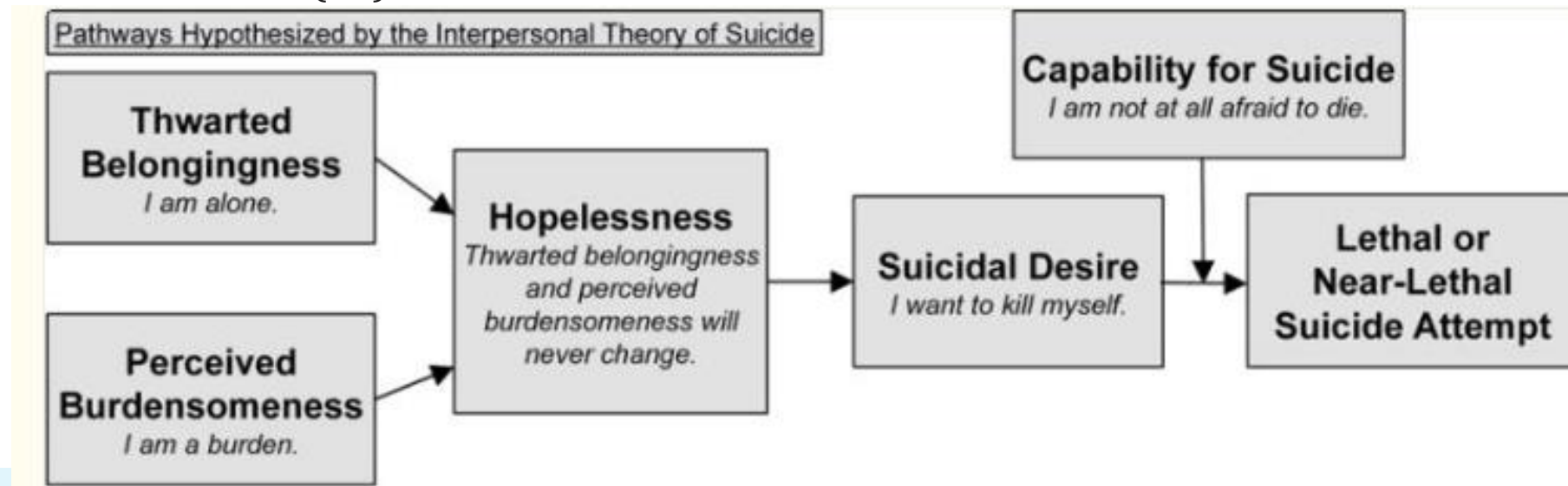
- Compared to non-autistic people, autistic people more likely to undergo mental health interventions that are not evidence-based (9)
- Higher risk of suicidal or self-injurious behaviour:
  - Autistic people are around 7 x more likely to die by suicide than non-autistic people (10,11)  
The risk is greater for autistic people without a co-occurring learning disability and autistic women (11)
  - Research conducted in England found that 66% autistic adults attending a specialist diagnostic clinic reported suicidal ideation and 35% reported suicide plans or attempts (12)
  - Approximately 42% of autistic people have engaged in self-injurious behaviours (13)
- Symptoms of anxiety and depression less likely to improve in autistic adults and more likely to deteriorate, following a course of NHS Talking Therapies (14)
  - 56.1% improved for autistic adults vs. 61.7% for non-autistic adults
  - 9.2% deterioration in autistic adults vs. 7.2% for non-autistic adults

# Autistic people experience barriers accessing care

- Autistic people report having referrals rejected on account of their autism diagnosis (15)
- Autistic people have reported that services are more likely to be tailored to autistic children and young people but not autistic adults (16)
- Accessing services can be overly complex and disjointed (15)
- Services may rely on methods of communication that are inaccessible for autistic people, such as phone communication (17)
- Lack of staff training or awareness around autism (15, 16)
- Reasonable adjustments to care are not consistently being offered (18)

# The Interpersonal Theory of Suicide (Joiner 2005)

“[Joiner \(2005\)](#) detailed several hypotheses regarding the emergence of suicidal desire and suicidal behaviours. Briefly, thwarted belongingness and perceived burdensomeness are theorized to comprise suicidal desire,<sup>1</sup> and the transition from passive to active suicidal desire occurs when individuals feel hopelessness about the mutability of both of these interpersonal and intrapersonal states. Nonfatal and fatal suicidal behaviours are theorized to emerge when active suicidal desire (i.e., the confluence of thwarted belongingness and perceived burdensomeness, and hopelessness about these feelings’ tractability) interacts with an elevated capability for suicide. Of note, the interpersonal theory predicts that these three constructs represent proximal predictors of suicidal behaviour and as such, may account for (i.e., statistically mediate) the relationship between various suicide risk factors and suicidal thoughts and behaviours.”(26)



# Understanding opportunities for suicide intervention

The bullet points below represent the stages of the Interpersonal Theory of Suicide. The opportunities for suicide intervention proposed by Dr Silvia Asensio are highlighted in green. (27) Additional suggestions are in blue:

- Feelings of “thwarted belonging” – early diagnosis/ autism hubs
- Perceived burdensomeness – roles in society/ support for families, Parent and Carer forums,
- Suicidal capability
- A lifetime exposure to painful and frightening experiences – early diagnosis/ education and training/ awareness, desensitisation therapies offered by ELFT, talking therapies
- Cognitive inflexibility (a reduced ability to solve problems in stressful or challenging situations) – clear planning and communication/ health passports, Reasonable Adjustments
- Perseverative suicidal thoughts and impulsive attempts without a plan – clear planning/ adapted Cognitive Behavioural Therapy, Dynamic Support Registers

# Dynamic Support Registers (DSR)

Dynamic Support Registers (DSR) aim to prevent unnecessary hospital admissions for people with a learning disability and autistic people. It is a list of people with Learning Disabilities and Autistic people, who are at risk of being admitted to mental health hospital.

Children on the Dynamic Support Register will receive Care (Education) and Treatment Reviews, known as C(E)TR. Adults will receive a Care and Treatment Review, known as a CTR.

These reviews identify the health and care needs of an individual, the severity of risk a person has of being admitted to hospital, and whether the person/ their family's crises can be managed in the community. The treatment reviews log the health care interventions intended to mitigate crises and to prevent hospital admissions. Escalation plans are developed if a person's mental health is at risk of deterioration.

National Guidance for Dynamic Support Registers can be found here: <https://www.england.nhs.uk/publication/dynamic-support-register-and-care-education-and-treatment-review-policy-and-guide/> (27)

Local Guidance for Dynamic Support Registers, and how to be self-referred into service can be found here: <https://bedfordshirelutonandmiltonkeynes.icb.nhs.uk/what-we-do/children-and-young-people-with-special-educational-needs-send/> (28)

# Communication is key

Good communication skills are critical to understanding the health and wellbeing of autistic people. It is also important to tailor your communication style to the needs of the individuals you support. Below are some resources to assist with honing your communication skills with Autistic people:

- <https://www.autism.org.uk/advice-and-guidance/topics/communication/tips>
- [https://www.makaton.org/TMC/TMC/About Makaton/Help with autism and communication.aspx?gad\\_source=1&gclid=Cj0KCQiAo5u6BhDJARIsAAVoDWsdbAYVMX822QKzv6-2mmRA63PzrbNqVZdRHXjfNftQ2368DSEg42kaAs4GEALw\\_wcB](https://www.makaton.org/TMC/TMC/About%20Makaton/Help%20with%20autism%20and%20communication.aspx?gad_source=1&gclid=Cj0KCQiAo5u6BhDJARIsAAVoDWsdbAYVMX822QKzv6-2mmRA63PzrbNqVZdRHXjfNftQ2368DSEg42kaAs4GEALw_wcB)
- <https://www.ambitiousaboutautism.org.uk/sites/default/files/resources-and-downloads/top-tips-for-communicating-effectively-with-autistic-people.pdf>
- <https://www.nu.edu/blog/7-autism-behavior-and-communication-strategies/>
- [https://www.beyondautism.org.uk/about-autism/understanding-autism/engagement-and-communication/?gad\\_source=1&gclid=Cj0KCQiAo5u6BhDJARIsAAVoDWtm-43Ve3FLNF7ZbpumTMiTXos6J820pCFLuVAZZx6mado2uMcZ8GgaAn5XEALw\\_wcB](https://www.beyondautism.org.uk/about-autism/understanding-autism/engagement-and-communication/?gad_source=1&gclid=Cj0KCQiAo5u6BhDJARIsAAVoDWtm-43Ve3FLNF7ZbpumTMiTXos6J820pCFLuVAZZx6mado2uMcZ8GgaAn5XEALw_wcB)
- [https://www.mencap.org.uk/learning-disability-explained/learning-disability-and-conditions/autism-asd?gad\\_source=1&gclid=Cj0KCQiAo5u6BhDJARIsAAVoDWuiDG4crO\\_tNjPUEM9WBcVUVLjwJZZ1VJuvR2Fu35MCjeq53Mxj9IUaAuomEALw\\_wcB](https://www.mencap.org.uk/learning-disability-explained/learning-disability-and-conditions/autism-asd?gad_source=1&gclid=Cj0KCQiAo5u6BhDJARIsAAVoDWuiDG4crO_tNjPUEM9WBcVUVLjwJZZ1VJuvR2Fu35MCjeq53Mxj9IUaAuomEALw_wcB)



# Resources and training to support Autistic residents experiencing crises

- Mental Health Charity Autistica have developed a resource to help those working in mental health and crisis services, to support young autistic people experiencing a mental health crisis.

<https://www.autistica.org.uk/downloads/files/Crisis-resource-2020.pdf>

- Beyond Autism have developed an infographic explaining the behaviour cycle tools adapted from the 'crisis' or 'escalation' curve - <https://www.beyondautism.org.uk/blog/understanding-the-behaviour-cycle/>
- The UK government has written guidance regarding the identification and prevention of Autistic burnouts, which can be a cause of crisis which leads to suicide - <https://committees.parliament.uk/writtenevidence/117253/html/>
- Children and Young People Crisis Workforce Training - [AMBIT CYP Crisis Workforce Training | Anna Freud](#)
- Suicide awareness training for Autistic people - [ZSA – Autism](#)
- The National Autism Trainer programme - [National Autism Trainer Programme | NHS England | Workforce, training and education](#)



# Resources to support Autistic residents experiencing crises

In the UK, there are no specialised emergency hotlines for Autistic people. The staff working for the services below will have the appropriate skills and neurodiversity training to support Autistic people:

- 999 if it is an immediate emergency
- Call your GP surgery, or NHS 24 via 111
- [Samaritans](#) have a great website full of information, and their phone line is free and open 24/7: just call 116 123
- [Crisis Textline](#) – text 85258 if you are in the UK. You will be connected with a trained counsellor who will respond in real time.
- [Childline](#) can be called 24/7 on 0800 1111
- [Papyrus's Hopeline247](#) is for children and young people under the age of 35 and is available 24/7. You can call them on 0800 068 4141, or text them at 07860 039967, or email [pat@papyrus-uk.org](mailto:pat@papyrus-uk.org).

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