Independent Autism Reviewer for Northern Ireland

Current state of palliative care services

In your view what is the current state of palliative care services in Northern Ireland?

Don't know

Do you think there is an understanding by the public of what palliative care is? If no, what are the main barriers to the public understanding palliative care?

No

In respect of autism there is very limited specific research. The cultural issues of death within the autism community has is not well documented.

Additionally, there is longstanding and systemic misunderstanding of autism within healthcare provision.

Access to services

Are palliative care services equally accessible to all who need them?

Not sure

From your experience where are the gaps in the provision of service?

Research in other healthcare area have unequivocally found gaps in the provision of services for autistic individuals - it is not anticipated that this is any different for palliative care.

Do you believe barriers exist that prevent equitable access to these services? If yes, please provide examples in the box provided.

Yes

There is systemic misunderstanding of autism particularly within healthcare. Research in other healthcare areas confirms that there are significant barrier to access for autistic individuals - it can be predicted that there are similar barriers to access to equitable palliative care.

What additional services could/should be provided?

Understanding, acceptance and respect for the autistic experience and identity is the bedrock and starting point for equitable services within palliative care. Most effective adaptions and accommodations are low / no cost. However, investment in research and innovation in the delivery of effective and equitable palliative care for NI's autistic population is critical.

Integration of Services

How well are palliative care services integrated across the health system, through primary, secondary and specialist care?

In respect of autism within the NI context - unknown

Should palliative care be a regional service? Please outline your reasons in the box provided.

Yes

NI is a small jurisdiction. A regional service is only preferable if it can provide a consistent service to the whole of NI's population.

What can be done to improve integration?

Good practice (across current Trusts as well as international best practice) must be delivered NI wide.

Best Practice

Do you have any examples of good practice or pilots in palliative care that are meeting the needs of patients and families/carers? If so, is this best practice happening widely across Northern Ireland?

Within UK there is limited good practice models / pilots specific to autism. There is however, an emerging body of good practice which in due course, alongside international best practice could helpfully inform palliative care practices in NI.

Do you think that families receive sufficient support when accessing services? Please outline your reasons in the box provided.

Not sure whilst I have not been able to engage with families, it is likely that within the context of autism that families do not receive sufficient support when accessing palliative care services

Funding and Strategy

Do you think the current funding for palliative care is sufficient? Please outline your reasons in the box provided.

Not sure

Is the current model for the funding of hospices, including hospice at home/community care/rapid response support, sustainable and sufficient to meet needs now and in the future? Please outline your reasons in the box provided.

No

Given the limited research and guidance in respect of autism and palliative care versus the growing knowledge about NI's autistic population it is unlikely that funding is adequate.

Is there a need for a new Palliative Care Strategy for Northern Ireland? If yes, what should it include? If no, why not? Please outline your reasons in the box provided

Yes

Any such strategy should ensure that best practice regarding autism and learning disability is woven into it

Any other comments

I have submitted a report to the committee, which I hope provides some broad guidance.

REPORT TO THE HEALTH COMMITTEE INQUIRY

‘REVIEW OF ACCESS TO PALLIATIVE CARE SERVICES – ORGANISATIONS / HEALTH PROFESSIONALS’

Defining Autism.

Autism is a natural and intrinsic variation of human neurology which presents across all ages, stages and walks of life.

Current diagnostic classification defines autism as *“Persistent deficits in social communication and social interaction…Restricted, repetitive patterns behaviours, interest, or activities…”* [1] However, this description can often lead to a deficit-based view that overlooks the unique ways in which autistic individuals process the world.

Dr. Peter Vermeulen's scientifically grounded ‘predictive brain theory’ offers a compelling alternative. [2] He frames autism, not as a flaw, but as a difference in how the brain processes information.

The autistic brain operates by creating rigid, detailed models of the world, heavily relying on predictions.

Unlike neurotypical [3] brains, which adapt flexibly to new information, autistic brains may struggle to adjust to unexpected stimuli or ambiguity. This often leads to heightened sensitivity and difficulty interpreting the world around them.

Predictive brain theory and processing, is a widely discussed concept in cognitive neuroscience, perception, and developmental psychology, and has garnered significant attention among neuroscientists. Dr Vermeulen’s empathic perspective highlights the unique cognitive strengths of many autistic individuals without disregarding the challenges they face in navigating a world that is volatile, uncertain, complex, and ambiguous.

By shifting the focus away from deficits, we gain a better understanding of behaviours like insistence on sameness or difficulty with change, which can be seen as responses to a different way of interpreting the world.

Understanding autism through this lens is crucial when developing effective support systems, in particular health and social care systems.

By creating structured, predictable environments, reducing sensory overload, and providing clear, consistent social cues, we can better accommodate the unique cognitive styles of autistic individuals.

---

[1] American Psychiatric Association: Desk Reference to the Diagnostic Criteria From DSM-5-TR

[2] Peter Vermeulen, Autism and the predictive brain: absolute thinking in a relative world (Routledge, 2023)

[3] ‘Neurotypical’ refers to individuals whose cognitive development aligns with societal expectations and typical patterns of functioning

Why consider the 'Autism Perspective'?

> *When we make the world more accessible for one group,*
> *we often end up making it better for everyone.* [4]

- An increasing shift towards better understanding of autism and its occurrence within our population has the unforeseen, and welcome, advantage of illustrating the value of inclusive design and policies for the whole of society - the *"Kerb Cut Effect"*. [5]

- There is also a financial advantage to the 'autism perspective'. A growing and persuasive body of evidence demonstrates that investment in systems, policies, and services designed to support autistic individuals deliver broader societal benefits – often reported as the *"Autism Dividend"*.[6]

- The Covid-19 pandemic exposed severe health inequalities for individuals with autism and learning disabilities. When adjusted for age the death rate for people with learning disabilities *was "over six times"* higher than the general population.[7] There is a high degree of consensus that existing inequalities, pre-dating the pandemic, played an important role in this. [8]

  The most disturbing illustration of this was the confusion over 'Do Not Attempt CPR' (DNACPR) guidance - the LeDeR review of the deaths of people with learning disabilities from Covid-19 found that in several cases 'learning disabilities' were given as the rationale for a DNACPR decision. [9]

  It is therefore critical that within the design, provision and monitoring of <u>all</u> healthcare provision that the need to value autistic lives is explicitly stated.

- Finally, the existing scope of guidance specific to autism and palliative care is limited across all age groups. The Committee's Inquiry therefore presents an opportunity to have significant input into palliative care for Northern Ireland's autistic population.

---

[4] Oxford Review Briefings, People & Organisational Research – Curb cut Effect – Definition and Explanation Curb cut effect - Definition and Explanation accessed Jan 2025

[5] *"The Kerb Cut Effect"* – originating from the pavement modifications initially designed for those with physical disabilities. Dropped kerbs soon proved useful for others - parents pushing prams, cyclists, and delivery workers. See Angela Glover Blackwell,The Curb-Cut Effect. Stanford Social Innovation Review, 2016

[6] National Autism Project – The Autism Dividend – National Autistic Taskforce and comprehensive-submission-Australian-Autism-Alliance-Senate-Inquiry-into-Autism-Aug-2020.pdf

[7] Dan Scorer, Head of Policy at Mencap's oral evidence taken before the Health and Social Care Committee on 9 February 2021, HC (2019–2021) 1195, Q10

[8] Coronavirus: Lessons Learned to date Report paragraph 315

[9] The Learning Disabilities Mortality Review Programme, Deaths of people with learning disabilities from COVID-19, 2020

A Framework for Effective, Equitable and High-Quality Palliative Care for NI's Autistic Population:

- Respects and Promotes Autonomy
- Supports Effective Communication
- Person-Centred
- Tackles Environmental and Other Stressors
- Is Rights-Based and Respectful
- Removes Barriers to Access High Quality and Dignified Care
- Promotes a Positive and Accepting Approach to Autistic Identity and Difference
- Recognises and Challenges Discrimination
- Ensures Better Transitions
- Ongoing, Practical and Relevant Training for Everyone Involved in Palliative Care
- Embeds Continuous Evaluation, Monitoring and Research into the Effectiveness of Service Provision

Spotlight on Palliative Care through the Lens of Autism.

To align with Northern Ireland's Autism legislation[10] and the Autism Strategy[11] it is critical that a whole person, whole life approach is considered in the context of autism and palliative care.

Given the relative infancy of my role, and that engagement with the autistic community has not been possible in respect of this specific issue, I intend to report broadly on key areas only. I trust that this input will still be of value to the Inquiry.

- **Autistic distress** – this often arises from unmet needs, such as discomfort, pain, changes in routine, sensory overwhelm, or social misunderstandings. This distress can manifest in behaviours like meltdowns, shutdowns, increased anxiety, irritability, or withdrawal. Distress is not innate to autism or a particular autistic individual, but rather an expression of their unmet need,[12] and is often linked to environmental factors or the support they receive. Identifying and addressing these underlying causes is crucial to reducing or preventing distress.

- **Pain and symptom management** - autistic people often experience pain differently from non-autistic individuals. Understanding these differences is crucial for effective pain management and ensuring

---

[10] www.legislation.gov.uk/nia/2011/27/contents

[11] Autism Strategy 2023-2028 | Department of Health

[12] MacDonald, A (2018) Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs | Scottish Government

that autistic individuals receive appropriate care without being misunderstood – this is an area in which close collaboration with family and carers is vital.

- **Reasonable Adjustments** – a 2024 article in the BMJ[13] highlights that people with an intellectual disability were almost two times as likely to die from an avoidable cause of death[14] compared to the general population. Timely reasonable adjustments can significantly reduce the risk of avoidable deaths and are often low or no cost, for example, adopting an individual's preferred communication method or allowing more time for processing information. This is another area where family and carers can play a pivotal role.

- **Planning** - amidst the pressures of day-to-day life no one is keen to stop and contemplate death or dying. However, conversations surrounding palliative care and death should not wait for the diagnosis of a life-limiting illness or the transition into hospice care. Predictability for the autistic brain reduces uncertainty, which in turn reduces anxiety. The consistent use of strategies such as the 'P.L.A.T.O.' principles[15] creates clear and reassuring predictability for autistic individuals. [**P**eople, **L**ocation, **A**ctivity, **T**ime, **O**rganisation].

- **Effective Communication** – for autistic people *"nothing is self-explanatory"* and *"nothing is obvious"*.[16] Clarity in *what* is communicated and *how* it is communicated reduces the anxiety that often leads to autistic distress. Death is a complicated, abstract concept [17] and concrete straightforward language supported by visualisation (infographics, diagrams, videos) can help the autistic brain to process information. Sequential and graduated explanations to build knowledge incrementally and provide context are preferred. Using 'positive' explanations that state *what is going to happen* (instead of what is not), aids clarity and deeper understanding.

- **Transitions** – palliative care is often described as a *"hidden transition",* as a diagnosis of life-limiting illness forces the individual to acknowledge a whole new set of assumptions about their future.[18] Palliative care for autistic individuals must centre around clear communication about the diagnosis and

---

[13] Ding J, Keagan- Bull R, Tuffrey- Wijne I. Editorial: It is up to healthcare professional to talk to us in a way that we understand: informed consent processes in people with an intellectual disability. BMJ Qual Saf doi:10.1136/ bmjqs-2023-016830

[14] Avoidable mortality includes deaths that resulted from conditions or diseases which could have been avoided with current, effective methods of prevention and/or treatment

[15] Peter Vermeulen & Koby Vanroy, *What Really Works for Children with AUTISM* (Future Horizons, 2024)

[16] Ibid

[17] And this can present particular challenges for autistic people who need unambiguous language and may find uncertain futures difficult to understand

[18] National Autistic Society, Jill Ferguson Palliative and end of life care for autistic people Professional Practice Guidance, 18 May, 2016

future care options. For example, visual aids, social stories and simple language to explain what is happening, what will change, and how the environment will be adjusted if critical.

- **Collaboration** – while further research and development are needed into supporting carers and professionals in end-of-life care planning conversations, there is no doubt that collaboration can deliver optimal palliative end-of-life care.[19] Collaboration ensures personalised care that addresses both the medical and sensory needs of the individual, while also ensuring clear, consistent communication with family and caregivers. Best practice involves early, ongoing discussions about end-of-life care, using accessible communication methods to ensure continuity of care. For example, when transitioning an autistic individual into hospice care, insights into the individual's preferred routines and communication styles from family and carers are critical to enable palliative care teams to deliver effective pain and symptom management strategies.

Can Change be Implemented Within Current Budgetary Constraints?

Improving palliative care for autistic people in Northern Ireland can be begin with low / no cost accommodations and adaptions to existing practice:

- Low-cost training that builds upon existing resources
- Individualised care plans created collaboratively with the individual, their family, or carers
- Use of visual aids, communication boards, or apps to enhance understanding for non-verbal or minimally verbal autistic individuals
- Identify and designate quiet areas within healthcare facilities to reduce sensory overload
- Accommodate family members or carers within palliative care settings who provide stability and comfort for the individual and ensure continuity of care
- Use social stories to prepare individuals for procedures or changes in routine
- Proactively discuss end-of-life preferences and needs in a patient-centred and accessible manner
- Involve caregivers and family members in care discussions, recognising their unique understanding of the individual's needs
- Create support networks for caregivers to share experiences and resources
- Engage autistic individuals and their families in evaluating services, offering feedback for improvements

---

[19] Research and development are needed into supporting intellectual disability staff in end-of-life care planning conversations. Collaboration between intellectual disability staff and palliative care services may facilitate timely end-of-life care planning and thus optimal palliative end-of-life care

- Work with autism charities / the Community & Voluntary sector to co-develop and implement initiatives. Involve trained volunteers to provide companionship or assist in activities that suit the patient's needs
- Incorporate autism-friendly practices into palliative care policies and guidelines at a minimal cost by reviewing existing protocols and integrating best practice.

These changes focus on creating a compassionate, tailored approach that respects the unique needs of autistic individuals in palliative care, ensuring dignity and comfort at every stage of life.

A Final Thought – Autonomy [20].

> *"Autistic people often express the wish for greater autonomy –*
> *more choice in the opportunities available to them and*
> *greater control over decisions that affect their lives."*[21]

Autistic children, young people and adults must have a stronger voice in the decisions and direction of their lives – especially those with the highest support needs and, often, least autonomy. [22]

The protection of service users' autonomy must be a core priority within the delivery of any service [23], and this is no less true within the context of palliative care.

End of life and palliative care is a difficult area, but we must ensure that any discomfort we may feel does not overshadow the development of self-advocacy and the individual right to say 'no'. There must an unwavering right to dignity and choice.

Respect for the right to full and honest information about one's own life, including when the person might react adversely [24] is a basic human right.

A **good service for autistic adults** is one in which their rights to be adults and have control of their own lives are deeply respected. A **good service for autistic children** is one in which their right to be treated in age / developmentally appropriate ways is respected and promoted.[25]

---

[20] Autonomy is a person's control over their own life.
[21] P.19 National Autism Project, The Autism Dividend (2017)
[22] RC791_NAT_Guide_to_Quality_Online.pdf
[23] Rule 3 Milton, D et al (2016) TEN RULES for ensuring people with learning disabilities and those who are on the autism spectrum develop 'challenging behaviour' … and maybe what to do about it. Hove: Pavillion. See also 7.1.3 MacDonald, A (2018) Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs. Scottish Government
[24] General Data Protection Regulation Chapter 3
[25] RC791_NAT_Guide_to_Quality_Online.pdf

APPENDIX A

Palliative Care

The Health Committee defines palliative care as; [26]

- *An approach aimed at improving the quality of life for patients, both adults and children, as well as their families who are dealing with life-threatening illnesses. It works to prevent and relieve suffering through the early identification, proper assessment, and treatment of pain and other issues, whether physical, emotional, psychosocial, or spiritual.*
- *Palliative care goes beyond managing physical symptoms; it takes a holistic team-based approach to support both patients and their caregivers. This includes addressing practical concerns and offering bereavement counselling. It provides a support system to help patients live as fully and actively as possible until the end of life.*
- *Palliative care is recognized as part of the human right to health and should be delivered through person-centred, integrated health services that respect the unique needs and preferences of each individual at the time(s) when such care and support is needed.*

The Inquiry

The Committee is holding an inquiry into palliative care services in Northern Ireland. The Committee wants to; [27]

- *Develop its understanding of the current provision of palliative care and hospice care;*
- *Find out more about the challenges in the provision of, and access to, this type of care; and*
- *Learn more about excellence in palliative and hospice care by identifying examples of best practice.*

The objectives of the inquiry are; [28]

1. *Evaluate Current Provision*
2. *Funding Mechanisms*
3. *Accessibility and Equity*
4. *Coordination and Integration*
5. *Challenges and Barriers*

---

[26] Survey
[27] Ibid
[28] Ibid

6. *Future Needs*
7. *Support for patients and families*

APPENDIX B

The Independent Autism Reviewer

Appointed by Minister Nesbitt, I began my role as Northern Ireland's first Independent Autism Reviewer on September 2, 2024, for a five-year term. This role operates independently of all Northern Ireland government departments.

As a statutory 'scrutiny mechanism,' the Autism Reviewer's responsibilities and functions are defined under sections 3C and 3D of the Autism Act (Northern Ireland) 2011.[29] My work involves targeted examination of decisions[30] across all government departments.

Given the early stages of my appointment, I have not yet had the opportunity to consult with the autistic community or assess the current Northern Ireland Autism Framework in respect of access to palliative care.

This report, therefore, focuses on defining what good palliative care for autistic people should look like, while highlighting the broader benefits of an inclusive approach with palliative care.

As we learn more about autism and stigma is increasingly challenged, it is evident that the number of autistic individuals across Northern Ireland, is likely to be higher than official statistics suggest. Knowing, learning and understanding more about our population is very welcome and we should not be alarmed or concerned by reports of the 'rising prevalence' of autism - it is a natural part of human diversity.

---

[29] Autism Act (Northern Ireland) 2011

[30] **'decisions'** for these purposes refer to prospective decisions, those decisions at planning stage, decisions taken and decisions that have already been implemented in respect of autism.

APPENDIX C

Useful resources / further reading

- The 'Dapple Project' aims to ensure people with learning disabilities have access to high quality palliative and end of life care, Palliative care, Learning disability services, end of life care, Dapple Project | end of life care for People with a LEarning disability.

- The National Autistic Society Palliative and end of life care for autistic people Jill Ferguson (18 May, 2016)

- Palliative Care of People with Learning Disabilities Home - PCPLD Network