EVALUATING A TAILORED MODEL OF PALLIATIVE CARE FOR PEOPLE WITH INTELLECTUAL DISABILITY

Maryann Barrington [1], Tawanwart Thipayawat [1], Maria Heaton [2], Linda Sheahan [2], Rachael Cvejic [1], Julian Trollor [1], Suzanne Sheppard-Law [2], Gemma McErlean [2], Janelle Weise [3], Rebecca Koncz [1] , Simone Reppermund [4], Rebecca Strutt [2]

1. National Centre of Excellence in Intellectual Disability Health, Faculty of Medicine & Health, UNSW Sydney, Sydney, NSW, Australia
2. South Eastern Sydney Local Health District, Sydney, NSW, Australia
3. Faculty of Medicine & Health, University of Sydney, Sydney, NSW, Australia
4. Centre for Healthy Brain Ageing, Faculty of Medicine & Health, UNSW Sydney, Sydney, NSW, Australia

KEYWORDS

Intellectual disability; model of care; inclusive healthcare

EXECUTIVE SUMMARY (100 words maximum)

South Eastern Sydney Local Health District implemented a tailored model of care to address fragmented pathways and late access to palliative care for people with intellectual disability. A co-designed, mixed-methods evaluation examined impacts on person-centred care and communication and coordination. The model improved coordination across services and strengthened palliative care literacy among support networks, facilitating more proactive and planned care. However, persistent system constraints, including fragmented cross-sector responsibility and limited community supports, continued to shape care delivery. These findings highlight that while local service innovation can improve care, broader system reform is required to achieve equitable palliative care outcomes.

INTRODUCTION

People with intellectual disability experience significant inequities in palliative care, including late access, unmet support needs, and poorer end-of-life outcomes. These reflect systemic challenges across health and disability sectors: limited workforce confidence, communication barriers, fragmented services, and limited involvement of people with intellectual disability in care planning. In community and supported accommodation settings, support staff often lack the training and clinical support needed to recognise and respond to deterioration. Within South Eastern Sydney Local Health District (SESLHD), local data identified delayed engagement with palliative care and reliance on crisis-driven pathways. In response, SESLHD implemented an Intellectual Disability Palliative Care Model of Care (MoC), embedding a specialist Clinical Nurse Consultant to support coordination, build workforce capability, and facilitate person-centred care planning across hospital and community settings. This paper presents an ongoing mixed-methods evaluation of the MoC, examining its impact on care coordination, workforce capability, and person-centred care.

HIGHLIGHTS

1. Model facilitated proactive care planning for people with intellectual disability
2. Palliative care literacy improved among support workers and families
3. Strengthened coordination across health and disability services
4. System limitations continue to constrain equitable palliative care delivery

METHODOLOGY/ PROCESS

Study design. A sequential explanatory mixed methods design is used to evaluate an Intellectual Disability Palliative Care Model of Care (MoC) implemented within South Eastern Sydney Local Health District (SESLHD). The study combines quantitative service-level data with qualitative interviews to examine changes in care coordination, person-centred care, and workforce capability following implementation of the MoC.

Setting and participants. The study is conducted across hospital and community palliative care services within SESLHD. Participants include people with intellectual disability receiving care through the MoC, their

support networks (family and paid support workers), and healthcare professionals involved in their care. Proxy participation is used where required to support inclusion.

Model of care. The MoC centres on a specialist Clinical Nurse Consultant embedded within palliative care services. Key components include care coordination, multidisciplinary collaboration, workforce education, and structured, person-centred care planning across hospital and community settings.

Data collection. Quantitative data include administrative service data and clinician-reported indicators related to care processes, such as care planning, coordination activities, and service engagement. Data is examined for changes quarerly over 12 months. Qualitative data are being collected through semi-structured interviews.

Data analysis and integration. Quantitative and qualitative data are co-analysed with researchers with intellectual disability and integrated to assess the impact of the MoC. Quantitative findings will be used to describe patterns of service delivery and care processes, while qualitative data provide insight into how the model influences care experiences and coordination across settings. Cross-case analysis is used to identify common themes, including improvements in care delivery and ongoing challenges in implementation. At the time of analysis, qualitative findings reflect interviews with 17 support networks and 8 healthcare professionals (see Table 1 for demographic information).

RESULTS/ OUTCOMES

Findings. Preliminary findings demonstrate that the MoC improved multiple aspects of care delivery, particularly care coordination, workforce capability, and person-centred care. Table 2 provides an overview key improvements and challenges identified by healthcare professionals and support networks. Below we outline 5 emerging themes.

1. **Shift to proactive, planned care.** The model supported a shift from reactive, crisis-driven care to more proactive and planned care. Participants described earlier engagement with palliative care, improved symptom management, and greater capacity to support people in community settings rather than relying on hospital-based care.
2. **Centralised coordination across services.** The Clinical Nurse Consultant role functioned as a central coordination point across health services, disability providers, and families, reducing fragmentation and improving continuity of care. Both healthcare professionals and support networks highlighted the value of a consistent, knowledgeable contact to navigate complex care pathways.
3. **Strengthened capability across the care network.** Targeted education and support improved palliative care capability across the care network, increasing confidence among healthcare professionals, support workers, and families in managing symptoms and supporting decision-making.
4. **More inclusive, person-centred care**. Care was experienced as more inclusive and person-centred, with improved communication, greater involvement of families and support networks, and more accessible approaches to care planning.
5. **Persistent system-level constraints**. Despite these improvements, participants consistently identified ongoing system-level challenges. Fragmentation across health and disability sectors, variable workforce capability, and unclear coordination responsibility continued to shape care delivery. Families and support networks remained key care navigators, often doing so with limited structural support.

CONCLUSION

The MoC improved coordination, workforce capability, and person-centred care for people with intellectual disability, supporting earlier engagement and more proactive, community-based care. The Clinical Nurse Consultant role was central to these gains, providing coordination, education, and continuity across services. However, persistent system constraints, including fragmented responsibility across health and disability sectors, variable workforce capability, and reliance on families for care navigation, continue to shape care delivery. These findings demonstrate that while local service innovation can improve care, broader reform is required. Next steps will prioritise inclusive participation methods to centre the perspectives of people with intellectual disability.

Table 1

Participant Demographics

Demographic	**HCP (n = 8)**
Gender	
Female	6
Male	2
Age	
Average	43.63 years
Standard Deviation	6.21 years
Professional Practice	
Medical	3
Nursing & Allied Health	5
Palliative Care Experience	
Average	15.63 years
Standard Deviation	8.16 years
Intellectual Disability Health Experience	
Average	11.38 years
Standard Deviation	5.71 years
Demographic	**SN (n = 17)**
Gender	
Female	12
Male	5
Age	
Average	51 years
Standard Deviation	19.05 years
Type of Support	
Informal Support	10
Formal Support	7
Experience Providing Support	
Average	25.71 years
Standard Deviation	21.97 years

Note. HCP = healthcare professional. SN = support network (informal and formal). Informal support networks are unpaid supporters such as friends and family. Most informal supporters were parents and siblings. Formal support networks are paid supporters such as disability service professionals. Please note we have avoided reporting specific roles of participants, as the limited geographical context increases risk of participant identification. Similarly, we have combined categories where cell sizes are low.

Table 2

A summary of the main facilitators and barriers within the ID PC MoC and key findings relating to HCPs and SNs perspectives of the MoC

Theme	**Main barriers reported**	**What improved (model contribution)**	**HCP perspectives**	**SN perspectives of the model**
Proactive, planned care	Late recognition of palliative needs. Reliance on crisis pathways.	Earlier engagement and anticipatory care planning. Providision of community-based support.	Greater ability to plan ahead and intervene earlier.	Reduced uncertainty and improved ability to support at home.
Coordination across services	Fragmentation across health and disability sectors creating unclear responsibility.	CNC as central contact has improved communication and continuity across settings.	Easier navigation of complex systems and improved collaboration.	"Go-to" person reduced stress and there is less chasing services.
Workforce capability	Variable workforce skills and high turnover in community settings.	There is greater education and training, support for decision-making, and shared knowledge.	Increased confidence in delivering palliative care.	Greater confidence in managing care and understanding needs.
Person-centred care	Time constraints and system-driven processes limiting flexibility.	Accessible communication and inclusion in care planning. The model facilitates advocacy.	Improved communication and shared decision-making.	Reflected that both they and the person they supported were heard, supported, and included in decisions.
System constraints	Cross-sector fragmentation and policy limitations drive some ED visits. There is overreliance on informal coordination by support networks.	(*not directly addressed by MoC*)	Recognition of limits of service-level change.	Ongoing burden of navigating care and coordinating services.

Note. HCP = healthcare professional. SN = support network (informal and formal). Informal support networks are unpaid supporters such as friends and family. Formal support networks are paid supporters such as disability service professionals.