Institution: Kingston University		
Unit of Assessment: 3 – Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Transforming policy and practice in palliative and end-of-life care of people with intellectual disabilities		
Period when the underpinning research was undertaken: 2012 – present		
Details of staff conducting the underpinning research from the submitting unit:		
Name: Irene Tuffrey-Wijne	**Role(s):** Professor of Intellectual Disability & Palliative Care	**Period employed by submitting HEI:** Dec 2012 – present
Period when the claimed impact occurred: 2014 – 2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

People with intellectual disabilities (IDs) are an ageing population with significant and under-recognised end-of-life care and bereavement needs. They experience serious healthcare inequalities and lack access to palliative care services. This has been exacerbated during the Covid-19 pandemic. Tuffrey-Wijne's pioneering research on end-of-life care, bereavement, and death-related communication for people with IDs has helped to reduce these inequalities through the following points of impact:

(1) Influenced national and international policy through health departments and organisations.
(2) Changed professional practice by conducting staff training in the UK and at least five other countries.
(3) Changed professional knowledge and understanding of end-of-life care for people with IDs.

2. Underpinning research

Intellectual disability (ID, also known in the UK as 'learning disability') affects 2% of the population. When people with IDs develop palliative care needs, the challenges for carers and professionals are enormous. However, their health care needs, particularly their end-of-life and palliative care needs, are often overlooked, poorly attended to, or not addressed.
Professor Irene Tuffrey-Wijne has pioneered research and development in this field, focusing on two main areas:

(1) Setting international standards and priorities for end-of-life care of people with IDs

In 2012, the European Association of Palliative Care (EAPC) invited Tuffrey-Wijne to establish and chair a taskforce on ID (unfunded). The EAPC is the principal palliative care organisation in Europe and provides a forum for all of those either working or with an interest in palliative care throughout Europe and beyond. Tuffrey-Wijne gathered 12 academic and clinical experts in the field from seven EU countries, who conducted a study to establish a Europe-wide consensus on universal palliative care quality goals for people with ID, regardless of social and geographical setting or national and cultural differences. The research focused on identifying 'best practice' examples, generating draft norms, and building a systematic consensus through the use of Delphi methods in four rounds involving 92 ID and/or palliative care clinicians from 15 European countries. Key findings included the following:

- People with ID do not have equal access to palliative care.
- Many of their needs are misunderstood or unmet.
- Good practice is currently dependent on the commitment of dedicated individuals, rather than on good policies, systems, or guidelines.

Tuffrey-Wijne was the main author of the resulting EU white paper (2015), titled "Consensus norms for palliative care of people with intellectual disabilities in Europe" **[R1]**. She then led a Nominal Group Technique study **[R2]**, involving 12 academics from 6 EU countries (funded by the Swiss National Science Foundation), which established Europe-wide research priorities around ID and end-of-life care. This led to the identification and publication of four important themes for international research.

Tuffrey-Wijne also conducted a study in the UK (unfunded) with the aim of identifying the key characteristics of 25 practice developments and case reports which won an annual national best-practice award for the end-of-life care of people with ID (2008-2018). The research used thematic content analysis of the written nominations for the award. The findings echo those of the European taskforce, with good practice being over-dependent on committed individuals within organisations. It also showed that care needs are highly individualised and that collaboration between services is essential **[R3]**.
Additionally, Tuffrey-Wijne carried out a mixed-methods study, funded by NIHR (GBP365,999), through a survey of clinical staff (n=990) and semi-structured interviews with clinical staff and with carers (n = 105), Tuffrey-Wijne identified the factors compromising patient safety and demonstrated that role confusion was a major barrier to effective carer involvement in hospital settings **[R4]**. She also proposed a new model to support role clarification.

Since 2020, Prof Tuffrey-Wijne has been leading a collaboration of researchers in 10 countries (across four continents), conducting a world-wide survey of end-of-life and palliative care provision based on the white paper, in the context of the Covid-19 pandemic.

(2) Breaking bad news, communicating about death, and making end-of-life decisions with people with IDs

Building on her ground-breaking research on "How to break bad news to people with ID", Tuffrey-Wijne's team investigated the **factors that affect the communication of death-related news** to people with ID by social and health care staff in two further studies, of which she was principal investigator and grant holder:
- An ID staff interview study (n = 20) funded by South West London Academic, Health and Social Care System (GBP9,987) in 2015 **[R5]**. This was followed by the development and implementation of a staff training course **[R5]**.
- Prof Tuffrey-Wijne led a team of researchers based at four universities across all countries in the UK to conduct a survey of staff working in ID residential and supported living settings (n = 690), funded by the Baily Thomas Charitable Fund (GBP61,064) in 2016-2018.

These studies demonstrated that:

a) Death, dying, and bereavement are highly prevalent within ID services;
b) ID staff often do not know how to support people with ID in cases of bereavements or end-of-life decisions.

This can lead to the exclusion of people with ID from being educated on death, thereby increasing the risk of a complicated grief process and adding significant stress on the staff. Current practice also prevents **meaningful involvement in end-of-life decision making**. In relation to this, Tuffrey-Wijne, who qualified as a nurse in Amsterdam, has been involved with three studies carried out in the Netherlands, through:

- Supervision and consultancy on a series of studies on end-of-life decision making processes from the perspectives of ID physicians, nurses, and family carers (2007-2013)
- Consultancy on a study developing a tool for shared end-of-life decision making (2018-2021)

Leading an investigation of the legal practices of euthanasia and assisted suicide involving people with ID in the Netherlands **[R6]**.

3. References to the research

R1 – **Tuffrey-Wijne I**, McLaughlin D. *Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe: EAPC White Paper*. London/Milan: European Association for Palliative Care (EAPC); 2015.

- *Associated academic paper:* **Tuffrey-Wijne I**, McLaughlin D, Curfs L, et al. Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of Palliative Care (EAPC). *Palliat Med.* 2015;30(5):446-455. DOI: 10.1177/0269216315600993 REF2ID: 03-196-563

R2 – **Tuffrey-Wijne I**, Wicki M, Heslop P, et al. Developing research priorities for palliative care of people with intellectual disabilities in Europe: a consultation process using nominal group technique. *BMC Palliat Care*. 2016;15(36). DOI: 10.1186/s12904-016-0108-5 REF2ID: 03-109-327

R3 – **Tuffrey-Wijne I**, Davidson J. Excellence in palliative and end-of-life care provision for people with intellectual disability *Int J Palliat Nurs*. 2018;24(12):598-610 DOI: 10.12968/ijpn.2018.24.12.598 REF2ID: 03-199-570

R4 – **Tuffrey-Wijne I**, Giatras N, Goulding L, Abraham E, Fenwick L, Edwards C, et al. Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study. *Health Serv Deliv Res* 2013;1(13). DOI: 10.3310/hsdr01130

R5 – **Tuffrey-Wijne I**, Rose T. Investigating the factors that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services: An interview study. *J Intellect Disabil Res*. 2017;61(8):727-736. DOI:10.1111/jir.12375

R6 – **Tuffrey-Wijne I**, Curfs L, Finlay I, Hollins S. Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012 – 2016). *BMC Med Ethics*. 2018;19(17):1-21 DOI: 10.1186/s12910-018-0257-6 REF2ID: 03-198-552

Evidence of the Quality of the Research
Prof Tuffrey-Wijne won the 2017 EAPC Postdoctoral Researcher award, which recognises the best palliative care researchers in Europe.
In 2020, she was nominated and selected by St Christopher's Hospice as one of 24 "Pioneering Nurses in Palliative Care" worldwide.

4. Details of the impact

Tuffrey-Wijne's impact rests on a portfolio of research that demonstrates the inequities in end-of-life care for people with intellectual disabilities (IDs). This has led to changes in culture, policy, and practice related to the palliative care of people with IDs at an international level. The research, including the scoping of EU-wide norms and research priorities, presents the first guidance for clinical practice, policy and research related to palliative care for people with ID It has established a consensus on and set a benchmark for changes in policy and practice. The EU white paper **[R1]** now underpins policy, practice, and staff development across Europe, with impact claimed in the following areas:

(1) Influencing national and international policy

UK: Tuffrey-Wijne's research **[R4]** is extensively quoted in the National Health Service (NHS) England document "Delivering high quality end of life care for people who have a learning disability" **[S1]**, with three referenced quotes, a link to the Breaking Bad News website, and a citation. This document provides national guidance for commissioners, service providers, and

health/social care staff. The National Clinical Director for End of Life Care, NHS England, has stated that Tuffrey-Wijne's research was the major source of the evidence base from which the guide was developed, that the workshop she facilitated directly led to the publication of these NHS England guidelines, and that they '*could not have achieved this work without Dr Tuffrey-Wijne's participation*' **[S2]**.

Netherlands: As the Netherlands is the only country in the world with specialised ID physicians, the national organisation of Dutch ID physicians has initiated a project to investigate the extent to which they can implement EU norms. Their guidance '*relied heavily on the 13 norms in EAPC White Paper*' **[R1]**, and that '*research* **[R6]** *led by Prof.Tuffrey-Wijne has been a significant influence on the development of policy and practice*' **[S3]**.

Outside the EU: The white paper **[R1]** underpins the concept paper commissioned by the Department of Health and Human Services of Victoria, Australia, to inform their implementation strategy for the public health approach to end-of-life care of people with ID in the state of Victoria **[S4]**.

(2) Changing professional practice

In 2019 Tuffrey-Wijne's team was asked by Open Future Learning, a USA-based company, which provides online training for ID staff worldwide, to produce a module on "Breaking Bad News" (June 2019) and "End-of-life care" (September 2020). As of December 2020, 2760 professionals have completed these continuing professional development (CPD) modules **[S5]**.

Dimensions UK and Macintyre Care (two ID service providers supporting around 7,500 people with ID across the UK) are currently developing new end-of-life care policies, support, and guidance materials [S6] that are entirely based on Tuffrey-Wijne's research (particularly the Baily Thomas Charitable Fund survey) and white paper **[R1]**.

The new NHS long-term plan has prioritised the needs of people with ID, and their right to a quality standard of care. Tuffrey-Wijne's research **[R5]** is cited in the National Quality Board's 'An improvement resource for learning disability services' **[S7]**, which supports NHS trusts in meeting the Learning Disability Improvement Standards. Speaking at the second reading of the 'Access to Palliative Care Bill' in the House of Lords, Baroness Hollins brought together the NHS long-term plan, the European white paper **[S1]**, and '*Professor Tuffrey-Wijne's research programme at Kingston University and St George's*' **[S8]**. Her argument was in favour of the bill - which supports access to high quality care and end-of-life provision for those with IDs.

Tuffrey-Wijne's research, as quoted from her Marie Curie lecture in the House of Lords, forms the rationale for the 'Masonic Charitable Foundation Hospice Grants – Widening Access Programme', run in partnership with Hospice UK. In 2019-2020, seven organisations were awarded funding totalling GBP152,367 to improve access to end-of-life care for people with IDs **[S9]**. The programme also advocates the use of the Breaking Bad News course as a means of education.

(3) Changing professional knowledge and understanding of End-of-Life care for people with IDs

Tuffrey-Wijne's commitment to disseminating her findings to a wide range of stakeholders in many different formats is raising awareness and changing perceptions among staff, carers, managers and policy makers.

Tuffrey-Wijne's research outputs have reached end users, including support workers, family carers and people with IDs themselves, through books and materials in lay language, as well as picture books for people with IDs. For example, Tuffrey-Wijne helped to write "Jenny's Diary", a resource to help people with IDs and dementia to understand their own illness. This booklet, produced with funding from the Alzheimer's Society **[S10]**, won the Alliance Scotland 2017 Self-Management Resource of the Year. It has been promoted by Dementia Training Australia as a

resource to assist practitioners and end-users, and is available for free downloads in Dutch, English, French, German, Italian, Mandarin, Norwegian.

Tuffrey-Wijne has driven the development of resources to support people with ID and their families, carers, and professionals during the Covid-19 pandemic, which has disproportionally affected people with ID. Based on her knowledge and expertise of communicating difficult issues, end-of-life, and bereavement support, she has developed pictorial resources, podcasts, and popular webinars. Her guide "Jack plans ahead for coronavirus" was her September 2020 webinar. "End of life care for people with LD" was attended live by 1,400 people (mostly health/social care professionals) and two months later, the recording has had a further 1,300 views on YouTube. The 79 survey respondents came from 13 different nations, including India and New Zealand; 78% said that webinar would influence their practice. Examples included a care professional taking inspiration for 'developing a toolkit', and a borough strategic lead praised the 'really useful resource ideas' as the reason for engaging with their local hospice and palliative care provider as they review their end-of-life care procedures **[S11]**.

5. Sources to corroborate the impact

S1 – NHS England & Palliative Care for People with Learning Difficulties Network (2017): Delivering high quality end of life care for people who have a learning disability: Resources and tips for commissioners, service providers and health and social care staff.
(p 9, 10, 18, 29, 30)

S2 – Testimonial from National Clinical Director for End of Life Care, NHS England

S3 – Testimonial from Head of Dept of Primary and Community Care (ai) and Head of Dept for Intellectual Disabilities and Health, Radboud University Medical Centre, Netherlands

S4 – Concept paper for Department of Health and Human Services of Victoria

S5 – Figures for 'End of life care' and 'Breaking bad news' CPD modules. Open Future Learning company data, via email.

S6 – Testimonial letter from Clinical Director, Dimensions UK

S7 – National Quality Board: An improvement resource for learning disability services, 2018

S8 – House of Lords debate on Access to Palliative Care Bill, June 2019

S9 – Masonic Charitable Foundation Hospice Grants 2019/20 - Widening Access Programme,

S10 – Alzheimer's Society Website Article

S11 – Webinar attendee feedback report. Kingston University. Dec 2020