



PCPLD Network

Palliative Care for People with Learning Disabilities

NEWS

www.pcpld.org

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MEMBER SURVEY

As part of our new charitable status we are obliged to hold a minimum of information about our members.

As such we have produced a short survey for you all to please complete. The only information we are obliged to hold (in strictest confidence of course) is the names and contact details of members and the date they became members.

In addition we have included a number of other optional questions which we hope you will answer and will help us form a better picture of the what our membership needs from us.

We would be immensely grateful if you could complete the survey a link to which is [here](#).

For any other information do get in touch.

Many thanks!



LINDA MCENHILL AWARD 2017 & PCPLD CONFERENCE 2018

You may have been wondering what is happening with the Linda McEnhill Awards this year...

...well wonder no longer! As there is going to be no PCPLD conference in 2017 (this is to save resources for a special celebratory anniversary conference in 2018 - more details on this soon), there have been discussions as to how best to organise the 2017 Award.

The 2017 Award nominations are open slightly later than usual. **Nominations are open from now and will close on Friday 6th October 2017.** Applicants will be informed of the outcome by the 15th December 2017. Both the 2016 Award winners (Sarah Jane Price's team) and the 2017 Award winners will be invited to share their work at the 2018 Conference.

You can find

all the information you need about the Award, and how to nominate, including application forms on the PCPLD website here: <http://www.pcpld.org/linda-mcenhill-award/>

If you have any questions, please don't hesitate to contact our administrator Alice at info@pcpld.org.uk

New Trustees

As the PCPLD Network is now a registered charity, we are in the process of appointing new Trustees.

We are very happy to welcome Steve Mitchell as our new Treasurer Trustee. Steve has many years experience as a senior accountant (including auditing the PCPLD's accounts) and will (continue to) be a huge asset to the team.

If you or anyone you know might be interested in joining the team as a trustee, please do give it some thought. We are looking for people dedicated to improving palliative care in learning disability and we will be giving a presentation about our search for trustees with more information at the 2018 conference.

PCPLD Network collaborates with NHS England on new publication.

The PCPLD Network was invited by NHS England to collaborate on a new publication at the beginning of 2017. Irene Tuffrey-Wijne and Jason Davidson have been working closely with NHS England end of life care leads and learning disability leads to produce a publication which consists of resources and top tips for commissioners, service providers and health and social care staff.

Over the last seven months Irene and Jason, among others in our network have supported NHS England to pull together this publication which is now available - [click here to view it.](#)

Jason said: "We are thrilled to be working in partnership with NHS England but especially thrilled as throughout this work they have demonstrated their commitment to improving the end of life care experiences of people with a learning disability. We are hopeful that this guide will provide support and advice to those who commission services and all those who provide services."

FHSCE academic receives prestigious research award

Associate Professor Dr Irene Tuffrey-Wijne recently attended the 15th World Congress of the European Association for Palliative Care in Madrid where she was awarded the Postdoctoral Research Award for her work on palliative care for people with intellectual disabilities. The event was attended by almost 3,000 international peers, leaders in the field of palliative care and other research dignitaries. Irene was invited to give a plenary lecture, which she presented together with Amanda Cresswell, her co-researcher who has intellectual disabilities. Together, they highlighted the importance of involving people with intellectual disabilities in end-of-life research. It was extremely well received and praised as a conference highlight – a tweet about Irene and Amanda's presentation won a competition for best tweet summing up the essence of the congress!

At the congress, Irene also launched the EAPC Reference Group on Intellectual Disability (see <http://www.eapcnet.eu/Themes/SpecificGroups/IntellectualDisabilities/ReferenceGroup.aspx>), and presented another paper and two posters (one of which won a best poster award).



Reporting back from the March 'Last Days of Life (Learning Disability (LDoL) study and conference

- *Dr Stuart Todd*

Findings from the study led by researchers from the University of South Wales and involving other UK academics were launched at a conference in Cardiff. The conference, attended by over 120 participants from around the UK and beyond, was organised with the support of the Network and also sought to promote the Network within Wales with a view to building support. The 18 month study looked at 99% (220) deaths in a representative sample of the some 13,000 people with learning disabilities living in UK learning disability services. The findings highlighted: the relationship between ageing and risk of death; the lower than anticipated levels of expected deaths in this population; the distinct nature of deaths of people with Downs syndrome; and the majority of people living within these services were also supported to die within them. However, there was evidence that dying at home happened less frequently for people living in small scale settings supported by a small number of staff. In addition, the data also suggested that at the end of their lives many people with learning disabilities may not be living in LD services and being supported in generic care homes. This is a sector of provision that many people do not think of when thinking about end of life care and people with learning disabilities. A small steering group for the Network in Wales has been established and hopefully plans for its development finalised by the end of the year. We would like to thank here the Baily Thomas Charitable Trust for their support, equally, the time, commitment and support given to us from participating services across was crucial to the success of the study. If you have questions please contact Dr. Stuart Todd stuart.todd@southwales.ac.uk

TALKING ABOUT DYING SURVEY

A team of researchers from universities in London (Irene Tuffrey-Wijne), South Wales (Stuart Todd and Jane Bernal), Glasgow (Janet Finlayson) and Ulster (Laurence Taggart) have launched the UK-wide Talking About Dying Survey. They are planning to send it to independent providers of residential and supported living services for people with learning disabilities. The aim is to find out how many people with learning disabilities are affected by death and bereavement, and to what extent staff are communicating with them about death. This will help to plan staff support within learning disability services.

If you would like to find out more, or if you think your organisation might be interested in taking part, contact Claire Lam (research assistant) on tad@sgul.kingston.ac.uk



AGEING WITH A LEARNING DISABILITY

- conference report by Allison O'Donnell

Some of the Scottish members recently attended a one day conference at Edinburgh Napier University in relation to Aging and older adults with Learning Disabilities. The Conference was facilitated by NES and Chaired by Professor Michael Brown.

The day focused on Professor Mary McCarron and her Research Team from Trinity College Dublin presented their findings from the first ever Longitudinal Comparative Study on Ageing in Persons with Intellectual Disability (IDS-TILDA) to be conducted in Ireland or internationally.

Mary McCarron, PhD RNID, RGN, BNS. F.T.C.D is Dean of the Faculty of Health Sciences, and Chair of Ageing and Intellectual Disability at Trinity College Dublin and she is the founder and Principal Investigator for the first ever Longitudinal Comparative Study on Ageing in Persons with Intellectual Disability (IDS-TILDA) to be conducted in Ireland or internationally.

The varied programme had participants considered research around ageing and physical health; mental health; challenging behaviour; loneliness ;medication and Polypharmacy as well as Down Syndrome and Dementia

Her award winning approaches on environmental design and technology sustaining and improving quality of life for people across the continuum of dementia, was the focus of the final presentation of the day and despite it being the end of the day and the week participants were reluctant to leave and were keen to hear more.

This was a very enriching and engaging conference and gave participants a lot to consider in relation to practice on their journeys home.

FUTURE EVENTS

19th September - DAA Seldom Heard Groups campaign launch. Venue: Royal College of Nursing, London
www.dementiaaction.org.uk

6th October - closing date for nominations for the Linda McEnhill Award

12th October - 4pm: PCPLD Network AGM (venue: St George's University, London SW17 0RE). If no quorum is reached at this meeting, a second AGM will be held on 13th October at 10am. Members will be sent further details nearer the time.

12th October - Improving Lives: Autism & Learning Difficulties in Manchester. For full details please click [here](#).

ACADEMIC ARTICLES OF INTEREST IN 2017 - *click on the title to view the article*

[Pain and pain assessment in people with intellectual disability: Issues and challenges in practice](#)

[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](#)

["I'm still here": Exploring what matters to people with intellectual disability during advance care planning.](#)

[Mortality in people with intellectual disabilities in England.](#)

[Communicating about death and dying: Developing training for staff working in services for people with intellectual disabilities](#)