

# PCPLD Network Annual Report 2019 – 2020



**CHAIR: IRENE TUFFREY-WIJNE**

## **TRUSTEES** (September 2020)

Annie Stewart (Secretary)  
Steve Mitchell (Treasurer)  
Gemma Allen  
Carol Gray  
Sarah Yardley

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# PCPLD Network

Palliative Care for People with Learning Disabilities

## Introduction

This has been a strange year for everyone, and the PCPLD Network is no exception. On behalf of the Trustees, I will share what has happened within the PCPLD Network since our last Annual Report (March 2019, [see here](#)).

It has been a pleasure and an honour to be the Chair over this past year, taking over from Jason Davidson and working with an inspiring group of Trustees and Specialist Advisors.

## Covid-19

The pandemic has affected people with learning disabilities and their families in ways we are only just beginning to understand. The issues we are concerned with (palliative care, dying, death, bereavement and learning disability) are difficult at the best of times, and even more so during times of social isolation, concerns about infection, and ensuring that everyone gets the best possible care and support when they are ill, dying or bereaved. We have added relevant Covid-19 resources to our webpage, [here](#).

Two key undertakings of the PCPLD Network, our 2020 Conference and the 2020 Linda McEnhill Award, have been affected by the pandemic – see details below.

## Linda McEnhill Award

This is an award scheme for exemplary practice in the end-of-life and bereavement support for people with learning disabilities. It was an annual award between 2008 and 2016, and biennial since 2016. We had opened nominations for the 2020 award, but closed it due to the pandemic. We felt that the people who might consider putting in a nomination, were likely to be occupied and under considerable pressure during the pandemic. We will re-open nominations in early 2021.

**Covid-19 has exposed the desperate need for this webinar.**

**The PCPLD Network have been shining a very bright light on the palliative care needs of people with learning disabilities for 20 years.**

**Jason Davidson,  
via Twitter**

## The 2020 PCPLD Network Conference

Our one-day conferences are always inspirational events. They provide wonderful opportunities for networking and hearing about the latest developments. We were looking forward to holding our 2020 conference in Cardiff on 16<sup>th</sup> September 2020, titled "End of life care for people with learning disabilities... Are we prepared?" Like everyone else, we had to cancel this event. We are hoping to be able to hold it in September 2021, but who knows!

In the meantime, we decided to host a short, free-of-charge **webinar** instead (on the planned date), inviting just the keynote speakers, Dr Kathryn Mannix and Baroness Ilora Finlay (as well as myself and several people with learning disabilities). We have been blown away by the interest in this. Whilst our conferences usually attract around 120 attendees, at the time of writing (late August), almost 1400 people have signed up for the webinar. This tells us that there is a real need and interest out there to connect, learn from each other, and focus attention on the end of life care needs of people with learning disabilities.

A huge thank you to Kingston University for supporting the technical aspect of the conference, and helping us host it on Microsoft Teams Live Events.

## Website and social media

The importance of communicating and networking online has grown steadily over the past decade, and exploded in recent months! The need for a dedicated and skilled website/email/social media manager has become urgent. For the first time in our 21 year history, we advertised and interviewed for a paid position (4 hours per week). We are delighted to have appointed Anastasiya Stravoleмова, who has lots of skills, ideas and enthusiasm.

## Membership

Membership of the PCPLD Network remains free. People can sign up by emailing [info@pcpld.org](mailto:info@pcpld.org). On 21 August 2020, we have 320 members.

## Trustees

We currently have six Trustees (see their names on the first page), who met 8 times since the last AGM, via telephone or video call. At the next AGM (16 September 2020), the



following trustees are retiring from office (as required by our constitution), and all of these will stand for re-election by members:

Irene Tuffrey-Wijne  
Annie Stewart  
Carol Gray  
Sarah Yardley

## Specialist Advisory Group

We are extremely fortunate to have an excellent group of people who act as a sounding board and give us their advice on all issues that arise. Since the last AGM, we have met a number of times; in recent months, this was via Zoom.

Current membership of this group is:

**Peter Allum** (representing people with learning disabilities; based in London)

**Pat Charlesworth** (representing people with learning disabilities; based in London)

**Kumar Cithambaram** (Lecturer at the School of Nursing & Midwifery, Queen's University Belfast)

**Jo Elverson** (Consultant in palliative medicine at St Oswald's Hospice, Newcastle)

**Louise Heatley** (retired support worker in the L'Arche London community for people with learning disabilities; now part-time teacher for children with special needs in Dorset)

**Louise Jenkins** (Strategic Lead Nurse, Hertfordshire Community Learning Disability Nursing Service)

**Gillian McGhee** (Team leader, Key Housing for people with learning disabilities, Clydebank. Winner of the Linda McEnhill Award 2013)

**Valerie Potter** (Consultant in palliative medicine at St Bartholomew's Hospital, London)

**Sharon Prowse** (senior manager at Freeways, a charity supporting people with learning disabilities in Bristol)

**Jean Willson** (representing family carers; based in London. Winner of the Linda McEnhill Award 2014)

We are keen to have as wide a range of experience and expertise on this group as possible, including both professional and personal experience. We are keen to increase the numbers of people with learning disabilities in this group, and will focus on this over the coming months.



**Patricia Charlesworth** and **Peter Allum**, our current Specialist Advisors with lived experience of learning disability.

We will be looking for more people with learning disabilities to join us over the coming year.

## Financial Report



This year, because of the cancelled conference (replaced by a free webinar), our income amounted to just £1 in total! We are looking into ways to obtain grant funding (and have applied to several potential funders), but in future, we will also have to consider ways to encourage donations to our charity, or charging for events. We want to keep our networking and learning events as accessible as possible, but we do need a certain amount of income to keep things going. We now have the new expenditure of our Website Manager. Current funds allow us to have her work with us for six months, but we are hoping to raise sufficient funds to extend this.

Our bank balance at the end of the financial year (31 March 2020) was £9,829.70. This included £720 of delegate fees received for the 2020 Conference, which was refunded in April 2020. We have ring-fenced £5,000 for the 2021 conference in Cardiff.

Expenditure was £1,021.55 (£673.85 for our website; £347.70 on meetings of the Trustees and Specialist Advisory Group). The accounts were externally audited and signed off by Ms Fiona Sykes on 3<sup>rd</sup> June 2020. Thank you to Steve Mitchell for his excellent work as our treasurer.

## Thank you

Finally, a huge thank you to everyone who has contributed to the work of the PCPLD Network over the past year, and especially to everyone working hard to ensuring that people with learning disabilities get the best possible deal at the end of life and in bereavement.

I will step down from my position as Chair on 16<sup>th</sup> September 2020, but am delighted to announce that the trustees have chosen Gemma Allen to take over from me as the next Chair – and that she has agreed! Gemma has the vision, skills and energy to take our work forward – especially important in this new world, with new ways of making connections and networking.

A handwritten signature in blue ink that reads 'I. Tuffrey-Wijne'.

**Professor Irene Tuffrey-Wijne**

1 September 2020



**Gemma Allen** is the Diversity and Inclusion Lead at The Mary Stevens Hospice in Stourbridge.

She will be our Chair from 16<sup>th</sup> September 2020.