



PCPLD Network

Palliative Care for People with Learning Disabilities



ANNUAL REPORT 2020-2021

Palliative Care for People with Learning Disabilities Network

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Introduction

This year has been marked by the uncertainties, challenges and the devastating impact of the COVID-19 pandemic. It has affected our PCPLD Network community, our colleagues working in health and social sectors, people who are most clinically vulnerable and those who have felt lonely and isolated.

Whilst it was a privilege to take over from interim Chair, Professor Irene Tuffrey-Wijne in September 2020, it hasn't been the easiest of years to lead a small charity. We have seen a significant change in the way that we source our income, after the cancellation of our 2020 Conference. However, PCPLD Network responded by successful collaborations with individuals and organisations, developing and leading the way in online educational webinars that were delivered to thousands of health and social care professionals and family carers.

We navigated change, explored different ways to generate income and adapted to new ways of working. We passionately and loudly campaigned for people with learning

disabilities, including the voices of people with lived experience and highlighted blanket DNACPR decisions and COVID-19 vaccines, hitting the BBC News headlines with our friends from the GRASSroots group.

This was only possible due to the determination, time, reassurance and courage of the Board of Trustees and Specialist Advisory Group. The PCPLD community is quite something and the support of our members this year has gone above and beyond. Together, we are ensuring that people with learning disabilities live well until they die, with equitable palliative and end of life care, including bereavement support.

There is much to celebrate and continue to build on in the coming year and I am delighted to share our Annual Report 2020-21 on behalf of the Board of Trustees.



Gemma Allen
Chair of PCPLD Network
August 2021

Trustees and Specialist Advisory Group

The Board of Trustees consist of six individuals, mainly from health and social care backgrounds. We have met this year on zoom and communicated regularly via email. Trustees make the overall decisions for PCPLD Network and are supported by the Specialist Advisory Group.

PCPLD Trustees:

- Gemma Allen (Chair)
- Dr Annie Stewart (Secretary)
- Steve Mitchell (Treasurer)
- Dr Sarah Yardley
- Professor Irene Tuffrey-Wijne
- Carol Gray

As required by PCPLD Network constitution, Gemma Allen and Steve Mitchell will retire from office and stand for re-election at the next AGM on 16th September 2021.

We are extremely fortunate to have sixteen individuals with a wealth of experience and knowledge about palliative care and/or learning disability on our Specialist Advisory Group. Since September 2020, the Specialist Advisory Group have met twice on zoom as a group, in addition to smaller meetings for work task groups.

Current Specialist Advisory Group:

- Pat Charlesworth (representing people with learning disabilities)
- Peter Allum (representing people with learning disabilities)
- James Benfield (representing people with learning disabilities)
- James Elmsworth (representing people with learning disabilities)
- Dr Jo Elverson (Consultant in Palliative Medicine, St Oswald's Hospice)
- Dr Valerie Potter (Consultant in Palliative Medicine, St Bartholomew's Hospital)
- Louise Jenkins (Strategic Lead Nurse, Hertfordshire Community Learning Disability Nursing Service)
- Louise Heatley (Retired support worker. Works in special educational needs)
- Kumar Cithambaram (Lecturer at School of Nursing and Midwifery, Queen's University)
- Sharon Prowse (Senor Manager, Freeway Bristol)
- Catherine Wood (Chief Executive Office. Representing family carers)
- Sian Mair Owen (Independent advisor in autism, learning disabilities and inclusion. Representing family carers)
- Jean Wilson (Representing family carers)

Webinars and conferences

In September 2020, we took the plunge of hosting online education events, moving our conference online with support from PCPLD Network Website Manager, Anastasiya Stravolemova, and the IT team at Kingston and St Georges University. This event attracted an audience of 1,700 people and was later viewed 1,800 times on YouTube. Feedback suggested the need for PCPLD Network to host regular webinars, so we formed a small working group to organise and deliver regular webinars. The team behind these events are Professor Irene Tuffrey-Wijne, Gemma Allen and Anastasiya Stravolemova, with additional support from Louise Jenkins and Sharon Prowse.

8 online education events have been delivered by PCPLD Network, with over 9,000 people attending!

PCPLD Network usual face-to-face conference is our only source of income and therefore the decision to alter the format of the 2020 conference was not taken lightly by the Board of Trustees. However, inspired by our previous events, we decided to run a full day online conference on 16th September 2021. We have planned a phenomenal programme with keynote speakers including

Professor Mark Taubert, Dr Katherine Mannix, Dr Jo Elverson and David Harling. A call for abstracts received an inspiring response of papers submitted that have allocated space within the agenda. It's not too late to book a place for our Annual Conference and you can do so [here](#).

Planning online events is time consuming and we could not do it without the dedication of the planning team and speakers. I would like to express my personal gratitude to everyone involved or who has participated this last year.

'The PCPLD Network are pioneers in raising the voices of people with a learning disability and educating those who are supporting them. I am learning so much from their inclusive webinars and passion for people with a learning disability to be recognised for the worth and value they hold. They confront the injustice and discrimination faced by people with a learning disability at the end of their lives (and during) with power and patience. An incredible example of how to campaign, share best practice and truly advocate for learning disabilities.'

Podcasts

Another new experience for PCPLD Network is podcasting! Whilst this remains in its early stages you can hear our current available podcasts by visiting PCPLD Network Soundcloud account. Again, thank you to everyone who contributed time and effort into these podcasts.

Membership

Our last Annual Report announced that as of 21st August 2020, PCPLD Network had 320 registered members. I am delighted to say that this has increased over the last year and there are now 1763 members. Membership is free and you can register by visiting: www.pcpld.org

Funding

PCPLD Network were successful in two grant applications from The National Lottery and Baily Thomas Trust. This enabled the employment of part time Website Manager, Anastasiya Stravolemova, who is instrumental in the delivery of online events, managing membership and general administration. PCPLD Network have an Amazon Smile account and a Text donate system. If you would like to fundraise on our behalf, or donate, we would really value your support.

Please see our financial report for further information on PCPLD finances.

Awards

For the first time, PCPLD Network have been nominated for three national awards! In June 2021, we were awarded joint winners of The University Alliance Awards for 'Innovation in Education' in partnership with Kingston and St Georges University.



We were nominated for 'THE' Awards and will learn if we have been shortlisted during September.

Lastly, PCPLD Network were shortlisted for The National Diversity Awards 2021! Winners will be announced at an awards ceremony next year. A huge thank you to everyone who voted for us!



COVID-19

The COVID-19 pandemic highlighted several inequalities for people with learning disabilities, including inappropriate blanket DNACPR decisions and COVID-19 vaccination. Two key moments from PCPLD Network were the webinar's 'Do Not Resuscitate? DNACPR and people with learning disabilities and an emergency webinar 'People with learning disabilities and COVID-19 vaccinations.

In addition to this, PCPLD Network passionately campaigned for people with learning disabilities. A Public Health England report, published in November 2020, stated people with learning disabilities were six times more likely to die from COVID-19. This prompted PCPLD Network to release a call for immediate action, insisting people with learning disabilities, family members and staff received regular testing and that when a vaccine was available, people with learning disabilities would be prioritised. On January 24th 2021 PCPLD Network and GRASSroots group made BBC News headlines, calling for people with learning disabilities to receive priority vaccines. This led to the Joint Committee on Vaccination and Immunisation (JCVI) advising the government that every person on the GP

learning disability register to be prioritised for vaccination.



PCPLD Writing Group

A PCPLD Network writing group was formed following a request from Royal College of General Practice journal to write a paper on end-of-life care and learning disabilities. Dr Jo Elverson is leading the writing group who have also been in conversations to work with Royal College of General Practitioners and Marie Curie Daffodil Standards. The writing group members are Dr Jo Elverson, Dr Valerie Potter, Dr Sarah Yardley, Gemma Allen, Kumar Cithambaram and Louise Jenkins.

Congratulations!

Our Trustee Professor Irene Tuffrey-Wijne was awarded one of the thirty worldwide St Christopher's Hospice Pioneering Nurses of the year in 2020! Congratulations!

Linda McEnhill Award

The Linda McEnhill Award is a biennial award that showcases excellent practice in palliative and end of life care, including bereavement support, for people with learning disabilities.

Due to the pandemic, we postponed the 2020 awards, instead opening nominations earlier this year in preparation for the award ceremony on 16th September 2021. The nominations were remarkable, and it was a pleasure to be part of the panel, alongside judging panel chair Professor Irene Tuffrey-Wijne, Dr Annie Stewart, Dr Sarah Yardley, Carol Gray, Pat Charlesworth, Peter Allum, Jean Wilson and Louise Heatley.

We are delighted that the awards will be presented by guest host, BBC News and BBC Watchdog presenter Nikki Fox. Tickets can be booked [here](#).

Business Strategy

An away day for the Board of Trustees and Specialist Advisory Group to update our business strategy was postponed in 2020 and 2021. We are planning a new date in Spring 2022, to review the previous business strategy (2017-2020) and the opportunity to discuss the charity aims and objectives for the next three years.

Financial Report

(Year ending 31st March 2021)

The income for the year was £13,393 (£1 in 2019/20) which included two grants:

- Lottery Community Fund £8,832
- Baily Thomas Fund £3,000

Both grants were awarded so that we could appoint a person to help develop our website, a series of webinars and podcasts. Over the course of the year, the webinars & podcasts attracted many thousands of people, not only in the UK but overseas.

The rest of the income came from either direct donations or donations received following webinars.

Expenses totaled £10,481 (£1022 in 2019/20) during the year of which £6510 was the cost of our self-employed Website Manager. We were also able to charge the cost of a Photosymbols License, Zoom subscription and IT equipment to the Lottery Community Fund Grant.

At the end of the year, we carried forward £12,740 into 2021/2022 which included the £3000 from the Baily Thomas Grant (this was fully utilised by July 2021).

S Mitchell
Treasurer
August 2021

