



**PCPLD Network**

Palliative Care for People with Learning Disabilities

## **TRUSTEE ANNUAL REPORT 2018/2019**

*Jason Davidson (Chair), Dr Irene Tuffrey-Wijne, Dr Annie Stewart (Secretary) and Steve Mitchell (Treasurer)*

### **Introduction**

In 2018, the PCPLD Network celebrated its 20<sup>th</sup> anniversary and also the 10<sup>th</sup> anniversary of the Linda McEnhill Award. We celebrated by holding one of our biggest and most successful conferences to date. The 20<sup>th</sup> anniversary conference was held in the award winning 'Friends House' on the Euston Rd, London. A very beautiful and appropriate venue we thought to invite all of our friends. We had an incredible line up of speakers who delivered some interesting and informative presentations. It was our afternoon speakers, the 'GRASSroots Group' who gained the most applause and recognition on the feedback surveys. It is clear that listening to someone with a learning disability talking about their own experiences, thoughts and reflections on death and dying is what's most powerful and memorable. We will make sure people with a learning disability continue to play a central role in future conferences. (To see the GRASSroots presentation, as well as several other presentations, see and we have since put their presentation online, along with several others, go to <https://www.pcpld.org/events-and-conferences/>)

Sticking to the theme of anniversaries. This year will be my 20<sup>th</sup> year as a member of the network and my 5<sup>th</sup> year as Chair of Trustees. As some of you know already I have made the difficult decision to step down from my role as Chair at our next AGM on Tuesday 9<sup>th</sup> April 2019 and I will also be leaving the specialist advisory group (SAG) on the same day. This decision has not been made lightly. Personally, I'm at a time of change and transition in my life which has included the death of both of my parents in the last two years. Professionally, doors are opening to new projects and potential career changes, so I've made the decision to transfer my energies and time into other areas of work, though still with a focus on improving end of life care for all. I will remain a lifelong member of the PCPLD Network because it's embedded in my heart and I will continue to sing its praises very loudly wherever the new paths take me.

Jason Davidson  
Chair

The following list summarises what our network Trustees and Specialist Advisory Group (SAG) has been up to over the last year:

- We continue to update and improve our website [www.pcpld.org](http://www.pcpld.org). This is a constant ongoing piece of work and is not without its challenges. Although this work has a financial cost to the Network, it is something we see as high priority and a great way for us to continue and expand on our core business in the future which is proving a place of specialist advice and resources, support for

all and widening the reach of the network. Our website is at the heart of the Network and continues to be well used and we are seeing an increase in hits from all over the world. Alice Parkinson stepped down from her role as communications lead and handed over to Claire Lam who manages not only the website for the Network but all of our social media. Claire's role is the only paid role in the PCPLD Network. We have seen a growth in our use of social media and we continue to plan to expand on our use of twitter and think more creatively about these and other forums in which we can continue our conversations and networking. Another way of communicating with people about our work is through video and we aim to do more of this in the future and we aim to make sure this is available via YouTube and other online forums.

- Amanda McKie continued in her role as *Area Coordinator Support* but like me will be leaving the specialist advisory group in April 2019 to pursue other areas of work. Amanda has been a key figure in the network for many years and her organisational skills, person centred approach, warmth, compassion and humour will be sorely missed by all. Amanda's departure will provide us with an opportunity to think more about how we can use our website and social media to support and coordinate those areas across the UK with strong local groups who have great practice to share.
- Looking to the future - The trustees and specialist advisory group will continue to work on our business strategy to plan the next 3 years. We will be having an awayday in April which will give us the opportunity to review our previous strategy and set some new objectives for the future. We know some of the key areas of our work like the development of our website and hosting national conferences, will continue to remain a priority for the PCPLD Network.

## Membership

We have always kept a simple, informal data base of members in the form of an email list. Membership of the Network is approx 270 people not only from the UK but from overseas. Membership of the PCPLD Network is free of charge and simple to do. You can register as a member via our website. Members are informed of events and items of interest through occasional emails.

## Conferences

Our conferences are one of the network's core functions and something we are all very proud of. They take a lot of planning and we are grateful to everyone who gets involved to make them as successful as they are. **Our next conference** will be in **Glasgow, Scotland in 2020!** Further details to be announced.

## Linda McEnhill Award 2018

The Linda McEnhill Award recognises excellence in end of life care for people with learning disabilities. It has been given annually since 2008, and has two categories.

- The category "new development or innovation in care" was won by St Christopher's Hospice Learning Disability Care Home Project, nominated by manager Julie Kinley. They developed a comprehensive programme aimed at improving access to timely healthcare (including palliative care), delivered to 60 learning disability homes in one London borough.
- The category "outstanding support to an individual with learning disabilities at the end of life" was won by 287 Dyke Road Staff Team in Hove, who are part of the Care Management Group (CMG) and were nominated by manager Michael Fullerton, for the team's wonderful care of a person with severe and

multiple disabilities who had lived in the home for many years. More information on the winners and runners-up can be found here: <https://www.pcpld.org/2018-winners/>.

The nominations this year were outstanding. There is clearly much excellent work going on, which is worth sharing. Together with Prof Irene Tuffrey-Wijne, who chairs the judging panel, we have looked back over the past 10 years of award winning practice and published our findings in an academic article (see here: <https://www.magonlinelibrary.com/doi/full/10.12968/ijpn.2018.24.12.598>)

We have decided that from now on, the Linda McEnhill Award will be given every two years (instead of annually). Nominations for the 2020 award will open in September 2019.

### **PCPLD NETWORK Financial report**

At the end of the last financial year (ending March 2018), PCPLD had a net cash balance of £4677. This included grants from both Awards for All towards the cost of the conference and Tesco via their 'blue token' scheme. The Tesco money was used to update the website. (Copies of the accounts to March 2018 will be available at the AGM). Those accounts were audited by Fiona Sykes, a retired Chartered Accountant, at no cost to the Network and have been filed with the Charity Commission.

As mentioned elsewhere in this report, the Network had a very successful conference and thanks to the grant from Awards for All, made a surplus on the event.

Presently we have a cash balance of £11,290 and the Trustees have prudently set aside £5,000 towards the 2020 conference in Glasgow.

As our year end does not end until the 31<sup>st</sup> March our accounts for the year are currently with our auditors.

March 5<sup>th</sup> 2019