



The National Network for Palliative Care of People with Learning Disabilities

CHAIR ANNUAL REPORT 2009

Introduction

The NNPCPLD is now 11 years old.

This last year has been a year of transition, with Linda McEnhill, our founding chair, stepping down in November 2008 after a very successful decade. It has been a daunting but exciting challenge to follow in her footsteps. During this year I have tried to get a feel for the NNPCPLD, and in particular for all the work that members are doing across the Network.

Change is set to continue, as our vice chair, Noëlle Blackman, is stepping down in November 2009. Noëlle launched the NNPCPLD together with Linda in 1998, and has been a hugely supportive and very active presence ever since. I would like to record early in this report my gratitude for all her hard work. It has been invaluable to have her continued support and service to the Network during this past year. A new vice chair will be elected at our 2009 AGM. Noëlle will continue in her role as representative for the London and Home Counties area.

I have been very impressed with the enthusiasm of so many members, and their commitment to improving the palliative care, end of life and bereavement experiences of people with learning disabilities. That commitment and enthusiasm is what keeps the NNPCPLD going.

Membership

We are a membership organisation. Membership fees were waived during our 10th anniversary year (2008). Fees were raised slightly in 2009: they now stand at £25 for individual members and £65 for group membership (3 members at the same address/organisation). Membership is free for the unwaged.

Members benefit from (1) linking in to area groups (area representatives are given the details of new members, so they can be invited to area meetings); (2) reduced fees at our national conferences, and (3) the newsletter.

Anyone is welcome to attend area meetings, but after one or two meetings, people are expected to become members if they wish to continue to benefit from these meetings.

By the end of October 2009, there were exactly 100 registered members.

Geographically, these members are not spread equally. One quarter of all members are located in London & Home Counties; another quarter in Yorkshire and the North West. Some areas of the UK have hardly any members at all.

Area groups

The area groups are a fundamental part of the NNPCPLD. They provide regional opportunities for networking, collaboration, and development of local 'best practice'. Each group is coordinated by an area representative (some areas have two representatives who share the role). Some groups have around three meetings a year; some have not been active during the past year; and some

are only just beginning, and have not yet held any meetings.

The area representatives are supported by the NNPCPLD, and meet once or twice a year for mutual support and exchange of ideas.

The following area representatives have stood down in 2008/2009:

Lynne Gibson (Northumberland)

Sue Medley (East Anglia)

Sally Radford (Hertfordshire)

Sue Read (Staffordshire)

Sue Smith (North West)

I would like to express my sincere thanks to them all for their work over the years.

The following area representatives are new, either taking over from existing representatives or starting/re-establishing an area group:

Carol Beaumont and Sharon Dewhurst (North West)

Maggie Coombes (Oxfordshire)

Louise Jenkins (Hertfordshire)

Rachel Lucas (Northumberland)

Josephine McCulloch (Scotland)

Dorry McLaughlin and Mary Bogue (Northern Ireland)

A warm welcome to all of them, and very best of luck in supporting the work of the NNPCPLD in their local areas.

We now have the following area groups and representatives:

Derbyshire (Debra Cooper)

Hertfordshire (Louise Jenkins)

London & Home Counties (Noëlle Blackman)

Northern Ireland (Dorry McLaughlin and Mary Bogue)

Northumberland (Rachel Lucas)

North West (Carol Beaumont and Sharon Dewhurst)

Oxfordshire (Maggie Coombes)

Scotland (Josephine McCulloch)

Staffordshire (situation vacant)

Wales (Stuart Todd)

Wiltshire (Amelia Jones)

Yorkshire (Amanda McKie)

Steering Group

The area representatives met together in London for our Steering Group Meeting on 17th February 2009. They will meet again in Glasgow on 9th November 2009.

The Steering Group includes :

Irene Tuffrey-Wijne (chair)

Noëlle Blackman (vice-chair)

Stuart Todd (treasurer)

Pat Charlesworth

Beverly Dawkins

Peggy Fray

David Oliver

In addition, all area representatives are also part of the NNPCPLD Steering Group.

Newsletter

The newsletter was re-launched in February 2009. The aim is to produce three issues a year, and so far, we have managed that! It has proved to be an effective means of communication with members and inspiring interest.

The newsletter is edited by myself. I have written most of the features, but there have been some contributions from other members. Any feedback, contributions or ideas for future issues will be most welcome!

Conferences

The NNPCPLD aims to organise two conferences each year, in different locations across the UK. We organised two successful conferences during the past year.

The 10th Anniversary Conference was held in Gateshead on 3rd November 2008. It was an opportunity to look back, and to look forward to what is yet to come. It was clear throughout the day's conference just how far things have moved on during the past decade. The conference saw the launch of the annual Linda McEnhill Award (see below).

Our first Research Conference was held in Antrim on 24th March 2009. Over 100 delegates attended. A range of eminent researchers in the field of death, dying, bereavement and learning disability presented their work. It was a truly inspiring event, and an important opportunity for researchers in this area to get together. There are relatively few people who carry out research in this field, and therefore this was an important occasion for mutual support and sharing of ideas. It was also good for practitioners to hear about recent developments and new insights.

Our next conference will be held in Glasgow on 10th November 2009. We will hold our AGM during this conference.

Linda McEnhill Award

We launched the Linda McEnhill Award in November 2008. This award aims to recognise an individual or group who has made a positive difference to the end of life care for people with learning disabilities. The 2008 award was presented to Linda McEnhill herself.

Nominations for the 2009 award closed on 31st August 2009. The judges (made up of six members of the steering group representing a range of backgrounds and experiences) were impressed with the high number and standard of nominations received. The winner will be announced at our conference in Glasgow on 10th November 2009.

During the coming year, the NNPCPLD will support the dissemination of the important and exciting work that this award has uncovered – watch this space!

Change of name

The Steering Group has often talked in the past of the need to change our name. Not only is "The National Network for Palliative Care of People with Learning Disabilities", or "NNPCPLD" for short, rather cumbersome; it is also inaccurate, as there have been members outside the UK. Therefore, the word "National" will be dropped from our name. Members have been voting for their preferred new name. Voting will close, and the outcome announced, during our AGM on 10th November.

Financial report

In April 2009, I took over (from Linda McEnhill) the task of administering the organisation's finances, dealing with in- and outgoings, and keeping accounts.

Balance on 09/04/2009: £1,385.32

Balance on 02/10/2009: £2,986.07

Most of our income is through membership fees and conference fees.

Most of our expenditure is for steering group/area rep meetings (mostly travel cost, plus accommodation when the meeting is held the day before an NNPCPLD conference) and conference costs (venue hire, speakers' fees, speakers' travel and hotel costs).

It must be noted that the conference held in Antrim (March 2009) broke even.

The balance in October 2009 includes income from membership fees and some conference fees; but none of the expenditure for the November 2009 steering group meeting and conference is showing in the accounts yet.

A full financial statement of the accounts since April 2009, with breakdown of income and expenditure, will be sent to all members in December 2009.

Worryingly, one of the chequebooks got lost in the post, which I discovered when person(s) unknown tried to cash 15 cheques totalling over £84,000 ! Luckily, I spotted this just in time to save us from bankruptcy... Vigilance is everything!

The future

It is now time to begin thinking about the direction the NNPCPLD should take in the years ahead. These are exciting and crucial times. The health care needs of people with learning disabilities, including the care they receive at the end of life, has gained national prominence. There have been various reports and new legislation that brought these issues to the attention of practitioners and policy makers.

At the NNPCPLD, we have noticed an increasing interest from practitioners to collaborate and improve things for people with learning disabilities who need end of life care. To name but a few live issues: More practitioners are beginning to work on and ask about Care Pathways and advanced planning documents. There is also a growing concern about the needs of young adults with learning disabilities who have palliative care needs, and who are making the transition from children's to adult services.

Our challenge ahead will be to facilitate networking and sharing of information across counties and countries. We may well need to re-think the structures of the NNPCPLD in order to keep up with a changing landscape.

One of the priorities for the year ahead will be to set up a website for our organisation.

Conclusion

This has been a year of transition, taking stock, and new growth. I am acutely aware that it is the enthusiasm of our members that keeps our work going. Most of us who have a recognised role in the NNPCPLD (whether it is as a member of the steering group, or an area representative) have busy jobs, and carry out much of this work in their own time.

I hope that this report has given you enthusiasm to become (more) involved in our Network. This is very much a *network*. Everyone is most welcome to join us, and be inspired as well as inspiring!

Irene Tuffrey-Wijne

Chair

National Network for Palliative Care of People with Learning Disabilities

29th October 2009