

North West Training and Development Team

Regional School Nurse Network – Special Schools.

Minutes from meeting on: 16th January 2001.

Present:

Chair. Pat Byrne, School Health Lead – Halton and Chester Comm Trust
Janet Cobb, Primary Health Care facilitator, NWTDT.
Alison Sutch, School Nurse – Halton and Chester Comm Trust.
Janice Mortimer, Children’s Nurse, Ashfield Primary School?
Chris Rattigan, School Nurse Team Leader, Wigan & Leigh NHS Trust.
Jenny Bragetts, Wirral Hospital Trust, Elleray Park School.?
Janice Manning, Wirral Hospital Trust, Arrow Park Hospital.
Sioned Hilton, Children’s nurse, Kingsbury Special School, Skelmersdale.
Angela Halsey, Loyne Special School, Lancaster.
Pat Whetton, Sandgate School, Kendal.
Katherine Neequaye, School Nurse - Tameside & Glossop
Margaret Dorney, School Nurse manager – Tameside & Glossop.
Lesley Brownlow, School Nurse Manager – Alder Hey, Liverpool.
Mel Wilkinson, Alder Hey, Liverpool.
Jean Rollinson, Nurse Manager, Halliwell Children’s Centre, Bolton.
Sarah Murphy, School Nurse, Oldham NHS Trust.
Margaret Cartwright, School Nurse, Foxdenton School, Oldham NHS Trust.
Anne Weights, Springfield School, Kirkby.
Anne Shaw, Newfeild School, Blackburn.
Susan Dixon, White Ash School, Blackburn.
Elaine Huntingdon, School Nurse – Halton and Chester Comm Trust
Cathy Jones, School Nurse – Warrington.
Jane Doherty, School Nurse, Springfeild School, Kirkby.
Sue Bailey, Senior Nurse, Springfeild School, Crewe.
Claire Bell, Children’s Nures, Salford.
Sally Parker, Children’s Nurse, Salford.

Apologies:

Miriam Molley, Coppice School, Bamber bridge , Preston.
Kath Lowe. School Nurse – Wigan
Kath Fishwick, School Nurse – Wigan
Vivian Smyth, School Nurse – Wigan
Sheila Ainsworth, School Nurse – Preston.
Maria Farrar, Learning disability Nurse – Preston.
Theresa Smith, Learning disability Nurse – Preston.
Sue Wells, Children’s Nurse – Blackpool.
Lesley Burn, School Nurse – Chorley.
Margaret Cartwright., School Nurse Advisor – Oldham.
Sarah Murphy, School Nurse – Oldham.
Jan Norburn, Brentwood School.
Yvonne Mackereth, School nurse manager – Trafford.

Sue Johnston, School Nurse – Chester.
Christine Heshon, School Nurse – Chester.
Anne Clough, School Nurse – Cheshire.
Barbara Blacow, Blackpool.
Mary Orrell, School Nurse – Halton and Chester Comm Trust.
Sheila Ainsworth.
Sue Johnson.
Chris Heshon.
Joanne Berry, Southport.
Liz Finnigan, Carnforth.

Notes from the meeting:

- ◆ **Minutes of the last meeting.**
Minutes from 04/10/00 discussed and agreed as correct.

- ◆ **Guest Speaker. Lynne Ellwell - *Partners in Policy Making*.**

Lynne Elwell introduced '*Partners in policy making*'.
Partners in Policymaking is a leadership-training programme for disabled adults and parents of disabled children up to school leaving age.
Lynne works for the North West Training and Development Team organising and running the course.

Partners Development

The original Partners course was devised in 1987 under the direction of Colleen Wieck Ph.D, Director of the Minnesota Governors Planning Council of Development disabilities, and Ed Skarnulius Ph.D. of the Minnesota Department of Human Services. The World Institute on Disability adopted the Partners in Policymaking programme in recognition of its potential as a model for leadership training for parents of disabled children, and disabled adults.

The first Partners course in the UK was held in the Northwest in 1996. A further 2 courses have been held in the Northwest and there are now more than 100 Partners graduates.

The majority of Partners graduates are involved in many activities, setting up support groups, making presentations, delivering training to service staff and working with Social Services, Health Authorities and Education on numerous groups and committees.

A number have gone on to Further Education and employment.

In other areas of the UK, 20 people graduated from the South West Partners course in 1998, the first Partners course in Scotland commenced in October 1999 and Staffordshire and London both started Partners courses in January 2000.

My Personal Involvement – Lynne Elwell.

“My route to working with disabled people and their families has not been the traditional path.

It started when I compared and considered the quality of my disabled daughter's life to that of my other children, and found that it did not measure up very well.

Whilst it is impossible to know first-hand what it feels like to be segregated, labelled as being significantly different to others, or channelled into services set up around those differences, by spending time with other families and disabled adults I have acquired, second-hand, an idea of how difficult it can be to get service providers to listen.

People with learning disabilities are now increasingly being supported in ordinary houses, securing real jobs, attending college courses while children are having opportunities to attend mainstream school. These changes, are taking place only slowly, affecting some people only marginally and others not at all.

Many adults and children still lead most of their lives in special schools, day centres, hostels, hospitals or in families where they are lonely and isolated. I know that families still feel frustrated and distanced from the people who make decisions, on behalf of disabled people, and the impact that those decisions have on them”.

“We do not yet have an underlying belief in our systems that disabled people and their families have a useful perspective to bring to planning positive futures, yet experience shows us that when they are part of consultation, planning and training it has a great impact.

This will in turn help to bring those who rely on service support back into the heart of their communities.

‘Partners in Policymaking’ is an innovative leadership training programme for parents of children with disabilities and for adults with disabilities.

‘Partners’ is designed to educate and empower its participants to achieve systems change at the local and national levels. This is a unique training programme designed to encourage its participants to alter the future....

‘Partners’ is not about perpetuating the status quo of today's systems; it is about creating new possibilities”.

Partners in Policymaking™

Initially the course was set up to help parents of younger children with disabilities to avoid some of the difficulties they may have to face when working with the health, education and social services. The idea is to educate and inform parents/carers and people with disabilities so that they can access appropriate services, ask the right questions and work together with the agencies to ensure that they get the optimum support.

“It is a requirement of Health and Social Services that those who use services should be not only consulted but much more closely and actively involved in policymaking.

Users of services need **preparation** for this role. They need to think about what good practice is and also how they can contribute to policymaking.” Partners in Policymaking™

The course runs over a period of 8 months at no cost to the people on the course, funding is obtained from local authorities.

The training programme provides at least 128 hours of sequential instruction over eight weekends, once per month, from leaders in the field – both locally, nationally and

internationally - Partners learn histories, philosophies, and strategies for creating systemic change in disability services.

After the course groups remain in contact thus creating a network of informed parents who are able to work in partnership with agencies.

Who is *Partners in Policy making* aimed at?

The course has been developed in order to inform and educate parents who have children up to school leaving age, and adults with disabilities.

A typical mix of participants would be:

- Two thirds parents of pre school and school age children.
- One third self advocates.

Gender and different cultural backgrounds are taken in consideration when making selection.

Parents of children under five years of age are targeted in order to give them the information and skills to make informed decisions on behalf of their children, before they get directed into the systems that have traditionally segregated children with disabilities. Historically, systems and governments have dictated what people with disabilities receive, which may or may not be what is needed.

People with disabilities are often faced with: *“This is what we have, take it or leave it”*

The course uses the experience of enlightened parents and users of services, to help develop a new generation ready to play a much more active role in deciding the future lives of themselves and their children.

Course aims

The course aims to provide information and skills training so those people with disabilities and family members can speak for themselves.

The course is intended to enable participants to:

- Be aware of options and possibilities in different areas of people’s lives so that they are as knowledgeable as the supposed ‘experts’ on state of the art thinking and practice.
- Contribute to policy-making making and implementation in wider service development, locally and nationally.
- Become real partners with the professionals and the policy makers.
- Have the confidence and competence to influence decisions about services and negotiate much more successfully when decisions are made about what is needed.
- Make **informed** decisions on what help, services and resources they need for themselves or their children.
- Support and guide other service users and carers.
- Contribute to the training of service purchasers, providers, planners and policy makers.

Course content

Topic areas of the course include:

History	The ways disabled people have been treated. History of services. Self-advocacy. Parent movements. Independent living movements.
Education	Quality and inclusive education. Outlines strategies for including Children with disabilities.
Whole Life Planning	Looking at and thinking about what children and adults with disabilities will need as they get older. Includes: <ul style="list-style-type: none"> - Person centred planning. - Circles of support. - Supported living. - Community building. - Exploring community resources
Employment	How people with disabilities, including those with substantial disabilities, can be enabled to do a job with appropriate training and support.
Policy development	How decisions on service provision get made and how to influence them.
Assistive Technology	How technology can help mobility, communication, self care and employment
Supported Living	What it takes to create a positive home environment for adults with disabilities
Advocacy	Developing a vision for the future and finding out about: <ul style="list-style-type: none"> - Relevant legislation. - How to change policies. - Meeting officials. - Use of the media. - Developing alliances. - Community organising. - Advocacy organisations

Lynne offered to come into schools to speak with groups of parents/carers about 'Partners in Policy Making'
She is contactable on 01254 821334.

E-mail: Lynne.partners@virgin.net

Or for more information on Partners in Policy Making and the work of the North west Training and Development Team go to:
www.nwtdt.u-net.com

Written information about Partners in Policymaking will be available at the next Meeting.

◆ **Sharing of best practice and looking at policies and procedures.**

After some discussion it was agreed that at the next meeting we would look at the policies and procedures related to Tracheotomy care and suction.
All authorities with policies and procedures relating to this will give a brief presentation about them, no more than 5mins.
If possible photocopies of any documents can be distributed.(Could individuals bringing documents to distribute ensure enough copies are available)

◆ **Role of the School Nurse working with children with disabilities.**

The meeting split off into small group to discuss and agree the core elements of this role.
(See list attached to minutes 04/10/00)

Shared underpinning values with other groups of professionals especially Learning Disability Nurses.

There was a lot of debate around this point, with many asking why 'especially Learning Disability Nurses'?

It was recognised that we all work with children with learning difficulties, however most members of the network are not registered learning disability nurses and have had little access to underpinning philosophies and values training.
See next item.

◆ **Underpinning Philosophies and Values.**

Most adult Learning Disability services have developed a very strong values base based on

John O'Brien's 5 accomplishments:

1. Making Choices.
2. Dignity and Respect – being treated with respect and having a valued social role.
3. Growing in competence – developing abilities.
4. Community presence – sharing ordinary places.
5. Relationships.

These values are transferable to other services and should form the basis of all services that are developed for people with disabilities, Children and Adults.

◆ **Information Circulated.**

- Once a Day
- Signposts for success
- The Healthy Way.
- Literature on various health Topics
- Water in Schools Campaign.

◆ **Agenda For Next Meeting**

- Guest Speaker – Joe Whitticker, Inclusive Education.
- Information on Inclusive Education.
- Information on Health Issues
- Tracheotomy care and suction.
- Role of School Nurse.
- Venues, dates and times.

◆ **Venue and Dates for next Meetings. (Note Change of Venue)**

Dates:

5th April 2pm to 4pm	3 rd Floor, Adamson House, Pomona Dock, Pomona Strand. Salford Email: NWTDT@compuserve.com Tel: 01942 607316
4th July. 2pm to 4pm	3 rd Floor, Adamson House, Pomona Dock, Pomona Strand. Salford. Email: NWTDT@compuserve.com Tel: 01942 607316

Janet Cobb. NWTDT.

3rd Floor,
Adamson House,
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Internet site for NWTDT: www.nwtdt.u-net.com