

Editor's Musings



Welcome again to the second issue of North West Together. In this issue we have a diverse set of articles, including a look at issues around health, an interview with Karen Flood - the co-chair of the National Self Advocates Forum, a detailed look at where the Partners in Policymaking course came from and finally, to round-up this edition, a personal profile of Julie Stansfield, our director who will be going on maternity leave in August. We all wish her well with the joys of motherhood!

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Inclusion Conference

Between 7th and 10th November the NWTDT, in conjunction with Bolton Institute, the Valuing People Support Team, and IAS Services are hosting a four-day residential conference at Ribby Hall, Wrea Green near Blackpool called **The Continuing Struggle for Inclusive Education and Community Living.**

“For many years people around the country have been actively involved in increasing social inclusion and encouraging leadership which enables those who are excluded from our communities to engage with their families, friends and allies to make informed decisions about how they intend to live their own lives.

This Inclusion event is about building new alliances as well as building on long established relationships, creating a more powerful force to bring about real differences and meaningful inclusion to the lives of those individuals excluded from our schools, colleges, universities and communities.”

There will be a number of national and international speakers including

- A group of people, from Syracuse, New York, who are using Facilitated Communication (FCT)
- Richard Rieser
- Lynne Elwell
- John O' Brien
- Susannah Joyce
- Karen Flood
- Sophia Erskine
- Joe Whittaker
- Simon Duffy
- Micheline Mason
- Movable Feast drama group

Keynote presentations - The “Marsha Forrest” and “Herb Lovett” presentations

Workshops will include

- Direct Payments “In Control”
- The Right to Communication: Facilitated Communication and Training
- Making Inclusion happen in the classroom
- A Person Centred Attitude
- Politics of Inclusion
- Self-Leadership
- Changing Services to Inclusive Services

For further information and booking forms contact Karen Barton at the Bolton Institute on 01204 903 200, email: kb2@bolton.ac.uk

Inclusion is a battle cry, a parent's cry, a child's' cry to be welcomed, embraced, cherished, prized, loved as a gift, as a wonder, as a treasure.

Marsha Forrest



Marsha Forrest Herb Lovett

Partners in Policymaking

Congratulation to all the participants on the “Wigan Experience”, who are the latest graduates from the Partners in Policymaking leadership courses.



It is quite possible you have heard of Partners in Policymaking, but what is it?

Partners in Policymaking is a leadership training programme for disabled adults and parents of disabled children that was originally 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 course aims to provide information and skills training so that people with disabilities and family members can:

- create new possibilities for the future
- make informed decisions on what help, services and resources they need for themselves or their children
- support and guide other disabled people and families
- be aware of options and possibilities in different areas of people's lives so that they are knowledgeable about state of the are thinking and practice
- contribute to policymaking and implementation in wider service development, locally and nationally
- become real partners with the professionals and the policymakers

The first Partners course in the UK was held in the North West in 1996 directed by Lynne Elwell and Chris Gathercole, from the North West Training and Development Team. Over the last eight years the number of graduates in the North West has steadily increased and there are now more than 400 people who have completed leadership courses.

Sally Percival, a graduate of the North West 2003-04 partners had this to say about the course -
“When I first met Anne-Marie (a graduate from a 2002 course), she told me that Partners would ‘change my

life!’, and although I was looking forward to participating on the course I really did not believe it would change anything about my life. However here it is several months later and the Partners course is nearly over. As I look back it is without doubt that I was wrong, and Anne Marie was right! Partners has changed my life, not just because of the knowledge and new skills that I have gained, but it has significantly changed because of the people I have met and the inspiration, encouragement and friendship my fellow Partners have given me. With these friendships and the knowledge I now have it will be the building blocks that other partners in Cumbria and I will use to make the lives of all people in this county a better place to live!

We hope to take all that we have learnt at Partners in Policymaking directly to those who need it most, by means of workshops, leaflets and talks around the county. Our group intend to influence decision making at the highest level, we are in the process of forming a family forum to enable like minded people to get together to have a louder voice. We have already secured funding from Social services for direct payment workshops.

I know that we are all so enthusiastic and passionate about what we believe in that together we cannot fail to accomplish our goals.”

Increasingly there is a requirement on local authorities and health authorities that those who use services should not only be consulted but much more closely and actively involved in policymaking. Family leadership is also one of the five key priorities of the Valuing People support team and in many areas of the North West graduates of this course are working with service providers in real partnership to make positive change happen. This is reflected in some of the feedback that has been received regarding the course from services commissioners.

Some quotes:

"It bridged the divide between families and professionals"

"I now view parents and people with learning disabilities as colleagues"

"The Partners graduates now form the base of a formal strong support network"

"It's really useful to have people who have taken the time to understand the constraints and agendas we have to work with. Other carers are constantly destructive"

"If services really are to change in ways that mean they reflect the genuine wishes and aspirations of people with learning disabilities and their families, then it is crucial that those people are enabled to become full and active partners in policymaking, planning and development processes.

Programmes such as "Partners in Policymaking and Sharing the Challenge" are important and creative ways of helping this to happen. As I hear of innovative and creative service change across the country, I am struck by how often this is associated with the presence of someone who is a Partner in Policymaking graduate. We need more of them".

Rob Greig – National Director valuing people

The NWTDT is due to run their next Partners in Policymaking course starting January 2005, if you are interested in finding out further information then please contact Lynne Elwell, lynne.elwell@nwttdt.com or via the office on 01254 306850.

Native American Commandments

- Remain close to the great spirit
- Show great respect for your fellow beings
- Give assistance and kindness wherever needed
- Be truthful and honest at all times
- Do what you know to be right
- Look after the well being of mind and body.
- Treat the earth and all that dwell thereon with respect.
- Take full responsibility for your actions
- Dedicate a share of your efforts to the greater good
- Work together for the benefit of all people



Treat me right!

Mencap have recently started the "Treat me right!" campaign to highlight issues faced by people with learning disabilities when trying to use health services.

"Many people with a learning disability have poorer health than other people. A big reason for this is that people with a learning disability get poorer health services than other people. In the worst cases, this leads to people with a learning disability dying."

This report called Treat me right! looks at:

- the reasons many people with a learning disability have poorer health than other people
- people with a learning disability and their experiences of health services
- the changes Mencap wants to happen.

As part of the research Mencap asked 215 GPs (doctors) what kind of training they had been given about learning disability.

- 75% of doctors said they had been given no training to help them understand the health needs of someone with a learning disability.
- 90% felt that a patient's learning disability had made it more difficult for them to give a diagnosis (to say what was the cause of the health problem).
- 70% of GPs did not have accessible information in their surgeries.
- 80% of GPs who took part in the survey thought the Department of Health should provide medical students and practitioners (people like doctors and nurses) with more training.
- 66% of GPs thought the most useful type of training would be practical training involving people with a learning disability.

For further information visit the Mencap website at www.mencap.org.uk/treatmeright

National Self-Advocates Forum



NW Together caught up with Karen Flood, co-chair of the National Self-Advocates Forum to find out more about the workings of the forum. Karen was recently elected to the position along with Andy Docherty and they will serve a two year term.

The forum brings together self-advocates from all regions of the

country (two members from each region) as well as co-opted members from organisation such as Mencap, National People First and the Disability Rights Commission. The forum is also looking at co-opting two young people to make sure their issues and concerns are included.

We asked Karen about the aims of the forum –

“The forum is a strong group of individuals who make up a really good team. We are looking at how things can be improved in the lives of self advocates and to do this the we are going to set ourself some goals and concentrate on a handful of important issues –

- Young People
- Harassment
- Ethnicity
- Personal Safety

We also want to work more closely with regional organisation like the regional taskforce and Valuing People

regional advisors to look at some of these things.”

Karen would also like to see the forum do more to influence government policy; the problem in the past has been that short timescales and inaccessible documents have made true consultation difficult. Tricia Nicoll from the Valuing People Support Team is going to be doing some work with the forum around the best way to tackle these issues.

So where does Karen see the forum going over the next couple of years ?

“The main aim of the forum is to work to get people included in their communities, to have meaningful jobs and have fulfilling lives. Over the next few months the forum members will be working closely as a team to raise its profile, this will help us become more effective and influence policies so that we can work towards these aims.”

Network feedback

Modernising Day Services Network

This network is open to people who have an interest in the modernisation of day services, whether they are concerned with policy and strategy, or interested in making it happen at the front line. Participation is encouraged from Partnership Board members, modernisation leads, self-advocates, family members as well as managers and staff of day services.

Recent sessions have addressed issues such as:

- Modernisation Planning
- Feedback on Modernisation Plans and directions for the future
- Designing the workforce of the future

The title for the next session is ‘All Means All.’ We will be specifically focussing on people who have need for additional supports and who are often more likely to miss out on opportunities to lead fulfilling lives.

Not Consulting...

There is a strong case for moving away from traditional ways of consulting people who receive services and their family members and to achieve full and meaningful participation. We want to move towards people being at the centre of decision making

processes, for example Partnership Boards and their sub-groups.

Following its initial meeting in June, the next session will focus on ‘Developing a model for full participation’

Trainers Network

This network is open to anyone who has an interest in staff training and development, whether they are commissioners, providers of training, self-advocates or family members.

The network has addressed issues such as:

- The Learning Disability Award Framework and NVQ’s
- Self-advocates involvement in development and training
- Training in Person Centred Approaches and Person Centred Planning

The next session will be addressing two issues:

- The full participation of self-advocates in recruitment and selection processes
- Awareness training – what comes next?

For further information about these networks please contact Paul Clarke at paul.clarke@nwttdt.com or via the office on 01254 306850.

Meeting the Minister ... again



In the previous issue of NW Together, we reported that a small group of Partners in Policymaking graduates were invited to meet with Dr Stephen Ladyman in London earlier this year. The meeting although short, was enjoyable and everyone felt that the time was well spent. We were therefore very pleased to hear that Dr Ladyman had requested a second meeting with Partners during his visit to the north west for Carers week and this time we had an hour.

Although it was fairly short notice, as these opportunities tend to be, we managed to get ten Partners graduates and speakers to the meeting and had good representation from Rochdale, Oldham, Merseyside, Lancashire and Wigan.

Although there was no set agenda for the meeting we all felt that the issues important to us, as family members and self-advocates should be considered as part of the social care strategy for disabled adults. (For more information on the strategy see the website www.scie.org.uk).

Each person spent a couple of minutes talking about the things that particularly affected their lives, talking about the hope and aspirations for themselves and their children, the difficulties encountered in getting what they need and some solutions they have found. This was then followed by an open discussion.

The main themes discussed were:

- Health issues: including the need for good up to date equipment that is easier to get than at present.
- Direct payments: the many positive changes it has made in people's lives, the misunderstandings that still exist, and the time and difficulty in getting a direct payment.
- Day services: most people do not want to attend traditional day centres, the parents of teenagers who were present expressed their concerns that often day centres are the only or first option offered. The generation of children and young people growing up are more informed

and have high expectations for their futures. Planning to go to College, get involved with education and politics, they may need communication equipment or other support to achieve this.

Once again the importance of family leadership was discussed, with comments such as "Partners gave us the information and skills to make informed decisions", "we have an incredible network of support", The minister agreed, "there is nothing like Partners in Policymaking" and remarked on the warmth and the strength of Partners network. He hoped that everyone who has a relative who needs support across the UK could have what we have in the north west.

The meeting ended with Sophia, on behalf of the group, presenting the Minister with a brief report reaffirming our support and our aims for the future, a booklet describing the In Control project and a photograph of the latest group of partners graduates.



Canada guide dog in language row



A blind Canadian student barred from English classes because his guide dog only responds to commands in French has now been allowed to attend the course.

The University of New Brunswick has always insisted English must be the only language spoken during its five-week summer programme, but it had to reverse its previous ban on Mr Tessier's attendance after coming under strong public pressure over the extremely sensitive issue in the country which is officially bilingual.

He said he was entirely dependent on his dog and was worried that trying to teach him English commands could be confusing and even dangerous. I knew that I'd have to speak English to people. But I thought I could speak French to my guide dog."

You can make a difference

The government has recently published a guidance document entitled "You can make a difference, Improving hospital services for disabled people"

The guidance states:

"If you work in a hospital, however accessible the premises are, as a frontline member of staff you can make an important difference to the way services are delivered to disabled people, in terms of the quality of service disabled people receive and how successfully services meet their needs. Around a third of your service users – patients, their families and visitors – are disabled – that is, they have physical, sensory, learning or psychiatric impairments or other long term health conditions. Providing high quality health services can also play a crucial role in supporting disabled people in other areas of their lives, like helping them to stay in work and participate in family life and other activities. It is important to relate to the person in the context of their whole life and to enable them to participate in society, not to focus on treatment alone."

The full guidance and a summary document are available to download from the department of health website at www.dh.gov.uk/PolicyAndGuidance/EqualityAndDiversity



Green light for mental health

The Valuing People Support Team have produced a 'service improvement toolkit' aimed at mental health services for people with a learning disability.

Green light is a toolkit for improving mental health support services for people with learning disabilities. It paints a picture of what good mental health support services for people with learning disabilities look like, and gives a way of assessing how well your local services measure up to it.

The term 'mental health support services' is used because support for people with learning disabilities around their mental health is not the exclusive responsibility of just one service. People may get support from primary care services, mental health services, learning disability services, public and voluntary sector services, and others. This pack is about what all of those services can do to improve mental health support for people with learning disabilities.

To download the toolkit go to <http://www.valuingpeople.gov.uk/latestnews.htm>



Health networks round-up

There are a number of regional health networks that meet on a regular basis, below are some of the topics covered in recent meetings. If you want further information about any of these please contact Janet Cobb at janet.cobb@nwttdt.com.

Primary Care network - 9th June:

Presentation by Denise Szpuner & Malcolm Phillips from Preston PCT about a Pharmacy project that looks at prescribed medication to over 65 year olds and advises GPs and patients on improvements. The initiative is aimed at reducing the number of accidents and falls across population of older people because of inappropriate medicines.

Acute Hospital network - 21st April:

The meeting looked at the collective work done by the North West Group to identify the core elements of 'Acute Liaison Nurses' roles in General hospitals. Currently there are seven nurses acting in this capacity across the North West in a number of hospitals.

Childrens network - 20th May:

The meeting focused on the direction and remit of learning disability nurses in childrens services, and looked at information sharing and networking. Currently there are three NW childrens networks operating – there is the possibility that these networks may merge in the future.

UK Primary Healthcare network - 14th June at NPSA in London:

There were several themes at this event:
Debra Moore from the Valuing People Support Team talked about emerging findings from the 'Action for Health' frameworks
Meadhbh Hall talked about work going on around Read Coding in PCTs in Norfolk

NWTD 2004–2005 Meetings, Events & Training

Network Meetings	Dates
NW Primary Care & Learning Disability Network	11 th Aug, 19 th Oct, 8 th Dec
NW Acute Hospital & Learning Disability Network	14 th July, 13 th Oct,
UK Primary Healthcare Network	11 th Aug, 10 th Nov,
Short Term Support Network	6 th Oct,
NW Children's Network	21 st Oct,
Day Service Modernisation Network	6 th Dec,
Regional Trainers Network	10 th Sept, 24 th Nov, 10 th Feb
PCP Network	20 th Sept, 16 th Nov, 12 th Jan
Ethnicity & Cultural Diversity Regional Network	5 th Oct, 8 th Feb
Transitions Network	11 th Nov, 14 th March
Employment Network	TBC
NW Learning Disability Taskforce	26 th July, 25 th Oct
Health & Social Care leads meeting	23 rd /24 th Sept, 3 rd Dec, 3 rd /4 th Mar
NW Family Forum	21 st Oct
NW Self-Advocates Forum	TBC
Direct Payments Network	Oct 2004, Feb 2005
Not Consulting...	16 th Sept, 23 rd Nov, 15 th Mar
Housing Network	Oct 2004, Feb 2005

Events	Dates
Inclusion Conference (4 day conference)	7 th – 10 th Nov
Housing Strategy Events (3 sessions)	Autumn 2004
Employment Events	Autumn 2004
Direct Payments Events	9 th Sept, 9 th Dec
To Boldly Go... (1 day events)	17 th Jan, 20 th Jan

Training	Dates
Day Service Modernisation Skills for Best Practice (GM & Cheshire) (4 sessions)	First session 27 th September
Day Service Modernisation Skills for Best Practice (Lancs & Cumbria) (4 day course)	First session 28 th September
Day Service Modernisation Skills for Best Practice (Merseyside) (4 day course)	First session 30 th September
Managing Change (NW Course) (8 day course)	First session 18 th Nov
Delivering the Vision (5 day course)	First session 4 th Nov
Inclusive positive action for all communities (2 day event)	11 th &12 th Oct, 13 th &14 th Dec, 10 th &11 th Jan, 21 st &22 nd Mar
Partners in Policymaking	Jan 2005

**Getting to know you, The 60 seconds challenge –
Julie Stansfield, Director, NWTDT**



In March 2003 Julie was appointed the Team Manager. Her background includes working in a Local District Service managing and developing change.

Who has been the biggest influence on your work life?

Have to say 2 main people!
Janey Bolton who was institutionalised against her wishes from the age of 21 till she was 63 years of age. Her story, history and survival instigated my passion for inclusion, justice and civil rights. The other great influence from this - Marsha Forrest.

What is your most treasured possession?

Cards from my grandmas

What is your greatest extravagance?

Gifts/treats for family and friends

Which words or phrases do you most over-use?

“Phone the police!!”

What do you most value in your friends?

Being there for me genuinely and unconditionally, as I would do for them.

What is your motto or word that mean a lot to you?

“What’s the most important thing in the world tis people tis people tis people”

What is your favourite cheese?

BRIE!!! And I cant have it at the moment boo hoo!!

What is your favourite piece of music?

Tchaikovsky - sleeping beauty
Delibes – the flower duet

What is your favourite film?

Pride and Prejudice

What book are you reading at the moment?

And baby makes three!!

Do you have a surprising or unusual hobby or skill?

I’m a diver and I can pull a great monkey face.

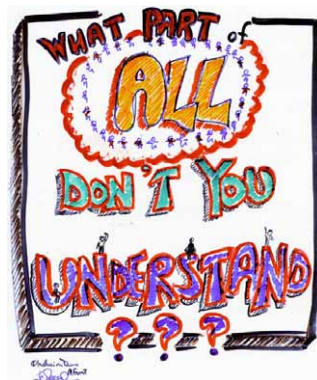
We are all colleagues together in a very important mission.

Ultimately our goal can be nothing less than total transformation of our culture.

Only when the most vulnerable of us is valued and appreciated for his or her gifts will everyone be safe and supported to be a fulfilled person.

Inclusion is in the journey, not in the goal. Each step of the journey is as important as the ultimate destination.

Judith Snow



Aunty Margaret’s Quaker Oat Biscuits

- 8oz Plain Flour
- 8oz Oats (either porridge or Jumbo)
- 5oz sugar
- 4oz Lard
- 4 oz Margarine
- 1 teaspoon bicarbonate of soda
- 1 tablespoon vinegar
- 3 tablespoons milk



Mix all the ingredients together, roll them out and cut with biscuit cutter.
Bake in a fairly hot oven until golden.

Wonderful on their own, or with Lancashire cheese.

If you have any comments or suggestions for future issues then please let me know.

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