



## Cumbria Learning Disability and Autism Partnership Board Notes 25<sup>th</sup> of September 2018

### Who was there:

Cllr Peter Thornton  
Mark Humble

Lesley Miller  
John Paul Moffat

Vikki Ford-Powell  
Janette Buckland  
Dave Wheatcroft  
Wendy Turl  
Michelle Wood

Dr Rohss Chapman  
Cathy Mellstrom  
Louise Townson  
Pam Humphreys  
Elaine McGeen  
William Reay  
Laura Cawood  
James McGregor  
Chris Tolley  
Kleanth Labo  
Cath Moore  
James McGregor

Cabinet Member for Health and Care Services  
Cumbria County Council Senior Manager – Commissioning Learning Disability & Autism

Project Development and Volunteer Co-ordinator, C-Change Scotland (dates-n-mates)  
Executive Director dates-n-mates

North Cumbria CCG Senior Commissioning Manager Learning Disability & Autism  
Morecambe Bay CCG Senior Commissioning Manager Learning Disability & Autism  
CAAAS Clinical Director for Learning Disability and Autism services  
CPFT, Community Learning Disability Nurse  
CPFT, Community Learning Disability Nurse

Senior Leadership Team, People First Independent Advocacy  
Inclusion Officer, People First Independent Advocacy  
People First - Lead groups representative  
People First Independent Advocacy  
People First Independent Advocacy  
People First Independent Advocacy  
People First Independent Advocacy

<p>Helen Storey  Daniella Sheridan  Harry Winters  Dr. Gay Eastoe  Josephine Stabler  Joseph Robson  Dean Young  Lee Evans  Cathy Stubbs  Sue Beresford  Mike Neville</p> <p>Jane Davis  Julie Cameron  Gary Wilson  Lana Edwards</p> <p>Christina Bowman  Sheila Gregory  Emily Dodd</p>	<p>CEO, Triple A Project (All About Autism)  Autism Representative, Triple A Project (All About Autism)  Autism Representative, Triple A Project (All About Autism)  Autism Representative  Co-Chair of the Sellafield Site Autism Support Network  Co-Chair of the Sellafield Site Autism Support Network  NPAA Coordinator for Cumbria Constabulary  Operations Manager, Victim Support  Community Projects, AWAZ Cumbria  Assistant Principal, Beaumont College  Service Manager, Elysium Healthcare, Ann House</p> <p>Cumbria County Council, Social Worker- Learning Disability, Autism and Mental Health  Cumbria County Council, Transforming Care Project Lead  Cumbria County Council, County Manager Social Care North  Cumbria County Council, Commissioning Assistant</p> <p>Cumbria Downs Syndrome Support Group and Parent/Carer Forum Representative  Senior Manager, Carlisle Mencap  Thrown Overboard Media Co.</p>
<p><b><u>Apologies:</u></b></p> <p>Austin Dorrity  Julie Batsford  Mike Stanton  Shirley Murphy  Amanda Bland  Linda Turner  Lucy Simpson  Lynn Hamel</p>	<p>University of Cumbria  CCC Service Manager - HAWCS  National Autistic Society  Chair of Cumbria Parent/Carer Forum  Founder and Director, A Stitch Different, Barrow in Furness  CPFT, Community Learning Disability Nurse  Parent Representative  Expert by experience</p>

Welcome and introduction of the 2<sup>nd</sup> Partnership Board meeting with a theme of **Friends, Relationships and Loneliness**



Cllr Peter Thornton welcomed everyone to the second meeting of Partnership Board.

All who were in the room then introduced themselves.

Peter reminded everyone that the theme of the meeting was **Friends, Relationships and Loneliness**, and welcomed guest speakers from Dates-N-Mates, Scotland's national dating and friendship agency run by and for adults with a learning disability.

## Minutes of last meeting and the **Rules of the Board**



Mark Humble asked if anyone had any comments on last meeting's minutes. There were none recorded and the minutes were agreed. He then explained the order of the day and introduced the Rules of the Board.

People First and Triple A have told us that the 3 most important issues for them are:

1. Loneliness and Relationships (25<sup>th</sup> of September 2018)
2. Hate Crime (22<sup>nd</sup> of January 2019)
3. Transport (27<sup>th</sup> of March 2019)



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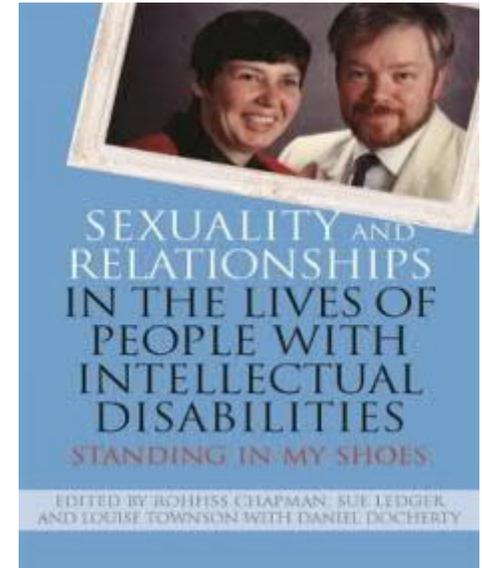
Dr Rohhss Chapman and Lou Townson introduced **Friends, Relationships and Loneliness** theme



Dr Rohhss Chapman and Lou Townson of People First introduced their book **Sexuality and Relationships in the Lives of People with Intellectual Disabilities – Standing in my Shoes.**

Rohhss and Lou explained how they wrote the book and what it covered.

It tracks stories of different people and their experiences and explains how sexuality has been managed and controlled in different countries. It explores a range of issues such as rights, resilience, protection, sexual oppression and the lack of privacy for those living in care institutions. Co-edited and with contributions by people with intellectual disabilities and allies, this unique book offers an authentic account of the challenges people face and what society needs to do to respect people's rights. The content also addresses risk aversion, which seems to be one of the major stumbling blocks in allowing people to form meaningful relationships.



**We watched a video on Loneliness & Relationships - “Relate, connect and listen”**



This was a video by People First and shared one person's wishes, hopes and dreams.

John Dias, a representative from People First was interviewed about his thoughts on how it felt being lonely and the challenges, barriers he had faced in trying to form relationships in Carlisle.

We shared our thoughts and feelings after watching this video.



## What people thought

- The video made me feel a real sense of loss when living your life without love.
- One of the major challenges is how to support people having relationships? We base everything around managing risks but forget about good health.
- Different types of love and relationships need to be recognised and allowed to be developed. It isn't always about a sexual relationship. Companionship, brotherly/sisterly love, loving family relationships are very important to support and promote.
- Popular culture drives expectations. It very often seems that it is ok for an older man to have a relationship with a younger woman and yet it is not ok for an older woman to have a relationship with a younger man.
- Sometimes people's expectations of finding a partner are too high.
- There needs to be an element of better education of how to form relationships, how to hold onto them and how to cope if things don't go as expected.
- We need to break down barriers of society's negative views of people with a learning disability and/or autism being interested in having a sexual relationship.
- We need to promote people's self-esteem and self-belief that they can be loved and they deserve to hear those words: "I love you!"

Dr Rohhss Chapman summarised with an open question addressed to all present:

**What do we need to do and what changes do we need to make to enable people to start living their lives?**

### **ACTION: Form a Task Group on Friends, Relationships and Loneliness**

This will be a dedicated Task Group set up to review the feedback we aim to collect from people in Cumbria regarding loneliness and relationships. The Group will identify additional issues and gaps in where people can make friends and develop relationships, and plan to make things better.

Those who would like to join this Task Group or would like further information are invited to contact us on [partnershipboard@cumbria.gov.uk](mailto:partnershipboard@cumbria.gov.uk) and to be added to circulation list.

It is thought that the Task Group will meet every ten weeks, or more frequently as the work gains momentum.

Helen Storey of **Triple A Project (All About Autism)** told us about what they do



Triple A works towards helping to reduce inequalities and challenges faced by autistic individuals.

Helen Storey, Chief Executive Officer told us about

- the **Navigator Programme**, which focusses on helping people through the probation process;
- **Positive Pals** – where people come together and meet to make pals from all over the county;
- **Discovery Panels**, which focus on explaining to autistic people how to understand their autism better and thus promote coping strategies.

Helen also told us about the training programmes offered through Triple A.



Daniella, Autism Representatives then told us about what she does at Triple A and how it feels being part of Triple A's "family".  
"I do Admin at Triple A. It's about relating to people with autism and feeling that we are all in the same boat. I don't feel like I am an odd one out. Life seems easier around people who understand and who are on the same page with you. Positive Pals really helps with combatting loneliness. Please look at our website and ask us questions today."



Helen sent in a presentation which supported her talk at the Partnership Board.

Triple A's website can be found through this link:

<http://tripleaproject.org.uk/>

Contact details are available through the website and at the end slide of the enclosed presentation.

**Presentation:**



Triple A Partnership Board Presentation

Cathy Mellstrom from People First introduced **Feedback from the Learning Disability Cumbria Lead Groups**



Cathy Mellstrom together with Pam (North Cumbria), William (West Cumbria) and Ella (South Cumbria) gave their feedback from the self-advocacy groups.

Their presentation asked these questions:

- Where and how you meet people?
- What barriers are there in forming relationships?
- How loneliness makes you feel?
- Ideas for Cumbria about changing things for the better



Cathy said the main barriers to forming positive relationships being:

- Not always feeling safe and lacking trust
- Objecting to relationships from families, staff and community
- Family and carers being overprotective
- Difficulty around communicating with people and sometimes feeling inadequate
- Being annoyed and confused and a result of feeling lonely.



All three groups came to the same conclusion that loneliness can sometimes even lead to self-harming physically and mentally. We need to help people form relationships so that they can lead better lives.

**What can and what should be done?**

- Talking to people
- Speed dating
- Walking
- Social media without fear

**Presentation:**



People First Relationships and I

Lesley Miller and John Paul Moffat from **dates-n-mates** told us about their work in Scotland



**dates-n-mates is Scotland's national dating and friendship agency run by and for adults with a learning disability.**

Lesley and John Paul told us about how their membership works and that their work is not just about getting out of the house and providing events and activities, but is also about supporting members in finding love and relationships.

They shared with us their success stories, awards and accolades. They also told us what people have said about them.

The main challenges to date dates-n-mates faced have been about:

- Reaching people in rural areas
- Transport
- Training in how to form positive relationships and building up self-esteem
- Overprotective parents and carers
- Supporting people with emotional downs when things go wrong,

but they do have a positive attitude throughout and have a view that “To get your prince, you have to kiss a few frogs in the process!”

[https://dates-n-mates.co.uk/glasgow/wp-content/uploads/2018/06/dnm\\_Spring\\_Summer\\_newsletter\\_online.pdf](https://dates-n-mates.co.uk/glasgow/wp-content/uploads/2018/06/dnm_Spring_Summer_newsletter_online.pdf)



Their ultimate aim is to become “redundant” at the end of the journey people take with dates-n-mates. Once their confidence has been built up and they have gained skills in forming friendships and dating, people are able to do it themselves – independently.

**Presentation:**



d-n-m Presentation  
- September 2018.ppt

**CLOSE**



Mark Humble thanked all for attending the meeting and sharing their experience and thoughts on **Friends, Relationships and Loneliness**. It is clear that we need to do some work in introducing some support for individuals, groups to form relationships and fight loneliness.

Our first step will be to identify and form a Task Group and look at “what’s already out there” in Cumbria, raise further interest in getting involved in this work and look at funding to introduce models similar to that of date-n-mates.

During our January and March meetings we will be shaping the work of the Board further and as well as priorities and themes we will also start discussing in detail the Board’s:

- Governance (How we do things)
- Terms of Reference (Why we do things)
- Forming Task Groups and how they will feed their work into the Board meeting
- Promoting and influencing decision making in partnership with People First, Triple A, Cumbria’s Clinical Commissioning Groups, voluntary organisations, the Police and others.

**Next meeting date:**

**22<sup>nd</sup> of January 2019**



Please join us at Cumbria House, 117 Botchergate, Carlisle, CA1 1RD

We will be talking about **HATE and MATE CRIME**

