

# Health Stones

## UK Health and Learning Disability Network

For information, queries and to contribute to  
FPLD *health stones* contact Janet Cobb

[janet@jan-net.co.uk](mailto:janet@jan-net.co.uk)

or

[jcobb@learningdisabilities.org.uk](mailto:jcobb@learningdisabilities.org.uk)

### 1. Sexual Health Promotion Group

From Paul Hedges

[phedges2@hillington.gov.uk](mailto:phedges2@hillington.gov.uk)

I have recently taken up s post as a Community Learning Disability Nurse in the Learning Disability Health Team within the London Borough of Hillingdon. As part of my role I have been tasked to devise a Sexual Health Promotion Group for residents with LD who live in the borough, there is no provision at present & I hope to address this. I have already identified the potential target group and I am currently in the process of promoting the group to ascertain interest for the pilot.

With this in mind I was wondering if anyone had had experience of setting up such a group in their area, if so do they have and advice they can offer me to run the pilot successfully. I think I generally have a good grasp of what to offer and which direction to take the group but any support will be appreciated.

The other main aspect that I would appreciate advice on is the issue of capacity. The aim of the pilot is to offer the group to individuals with LD who live independently, may not access any services and are sexually active. My thoughts are that these people will not lack capacity when it comes to engaging in sexual activity but has anyone had experience of providing sexual health promotion services when this is not the case.

### 2. 22q deletion syndrome

Anonymous query please reply to [janet@jan-net.co.uk](mailto:janet@jan-net.co.uk)

Our team are currently supporting a young man with 22q deletion syndrome who also has learning disabilities . He has been presenting with hearing voices for a year or so now and he is failing to respond to antipsychotic medication. Has anyone else been in this situation with this condition? We have the 22qdeletion support group information but wondered if anyone in a clinical role has any suggestions?

### 3. Working Together with Parents Network SURVEY

Have extended the deadline on our WTPN survey in the hope that a few more of you will find time to complete it.

The link for your region is: <https://www.survey.bris.ac.uk/sps/wtpnpr>

If you could have a look and complete what you can, it would be very helpful. The information provided will contribute to the re-drafting of the Good Practice Guidance as well as providing information about your services for the forth-coming regional pages of the website.

#### 4. PLEASE HELP Parent Stories

If you have received this email it is because you told us you would like to be contacted about the Cerebra Centre Website Project (led by Prof Chris Oliver's team). This is an ESRC funded project to develop a website to ensure findings from research studies about genetic syndromes are communicated to families and professionals effectively. The project covers six syndrome groups including: Angelman, Prader-Willi, Fragile-X, Cornelia de Lange, Cri du Chat and Smith-Magenis syndromes.

When we consulted with parents and carers they told us that they like research findings to be presented in balance with parent accounts and stories. We invited parents to talk part in a story workshop to develop these parent accounts and, if possible, we hope you can give us feedback on these stories.

Please follow the link below where you will find some of the parent stories on the website of our funding body Cerebra. There is a link to a very short (5 questions) evaluation questionnaire on this page and we would be very grateful if you could help us by completing this about the stories so that we can further develop our resources.

URL for the videos:

<http://www.cerebra.org.uk/English/aboutus/AcademicChairs/birmingham/Pages/Parentstoryvideos.aspx>

URL for the short questionnaire

<https://www.surveymonkey.com/s/YL89DFB>

Dr Jane Waite

[j.e.waite@bham.ac.uk](mailto:j.e.waite@bham.ac.uk)

Research Fellow and Clinical Psychologist

The Centre for Neurodevelopmental Disorders

#### 5. Positive and Proactive Care: reducing restrictive interventions

<https://www.gov.uk/government/publications/positive-and-proactive-care-reducing-restrictive-interventions>

#### 6. Learning disability App from Lesley Montisci

A friend of mine has helped me produce a free downloadable app for health care professionals.

Hope it is of interest and help.

You can access it via the following link:

<https://play.google.com/store/search?q=learning%20disability%20montisci>  
[lesley@lesleymontisci.co.uk](mailto:lesley@lesleymontisci.co.uk)

#### 7. Working Effectively with People with Learning Disabilities and Offending Behaviours

The project team provides support for people with learning disabilities who have been convicted of a criminal offence or are deemed to be at risk of conviction. A number of approaches were used to understand the context of care, to engage the Community Learning Disability Teams in a process to create opportunities for change; and to capture the service user experiences of care to inform the development of an education package.

<http://fons.org/library/report-details.aspx?nstd=16565>

**8. Developing an Inclusive Approach to Care Programme Approach Review Meetings**

<http://fons.org/library/report-details.aspx?nstd=6833>

**9. The Revolving Doors Checklist**

How Police and Crime Commissioners can improve responses to offenders with multiple and complex needs.

<http://www.revolving-doors.org.uk/documents/revolving-doors-checklist/>

**10. Improving the Care for Women with Learning Disabilities in Secure Mental Health Services**

<http://fons.org/library/report-details.aspx?nstd=5645>

**11. Actioning Health in Struell Lodge for People with Learning Disabilities**

<http://fons.org/library/report-details.aspx?nstd=5628>

**12. Right to 'ask' for personal health budgets begins**

<http://www.england.nhs.uk/2014/04/01/right-to-ask/>

**13. Helen Drewery: Circles of Support and Accountability**

<http://www.worksforfreedom.org/all-articles/item/950-helen-drewery-circles-of-support-and-accountability>

**14. Epilepsy Rescue Medication Training**

A new website [www.epilepsy-education.com](http://www.epilepsy-education.com) has been launched to provide training on administering emergency rescue medication.

Developed by medical experts in the field of epilepsy, this new resource should assist in ensuring people with epilepsy can receive emergency rescue medication in a safe and dignified manner.

**15. Making Hospitals Friendlier and Easier to Use for People with Learning Disabilities: a Project Looking at Service-Users' Perspectives**

<http://fons.org/library/report-details.aspx?nstd=5679>

**16. Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update.**

<https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

### **17. The revised Advocacy Quality Performance Mark**

Originally developed by Action for Advocacy (A4A), the QPM is a tool for providers of independent advocacy to show their commitment and ability to provide high quality advocacy services – essential for people to have their voices heard, to exercise choice and control and to live independently.

The QPM was reviewed by NDTi, who were asked by the Department of Health and the A4A Board to work in consultation with providers, users and commissioners of advocacy services to build on and update the work of Action for Advocacy, which sadly ceased operations in 2013.

For further information, please go to NDTi website: <http://www.ndti.org.uk/major-projects/current/advocacy-quality-performance-mark/>

or the newly launched Advocacy Quality Performance Mark website:  
<http://www.qualityadvocacy.org.uk/>

### **18. Developing an Inclusive Approach to Care Programme Approach Review Meetings**

<http://fons.org/library/report-details.aspx?nstdid=6833>

### **19. Positive and Safe: freedom from restrictive practices**

<https://socialcare.blog.gov.uk/2014/04/03/positive-and-safe-freedom-from-restrictive-practices/>

### **20. Postural Care Newsletter**

<http://us5.campaign-archive2.com/?u=b92f1c2239a2cf8ce0e952e68&id=3d144ff326&e=10d1e15494>

### **21. Sarah Clayton talks about Postural care**

[http://m.youtube.com/watch?v=BO\\_DwjqrEVI](http://m.youtube.com/watch?v=BO_DwjqrEVI)

### **22. Law Commissions' final report on the regulation of health and social professionals**

The Law Commissions of England and Wales, Scotland, and Northern Ireland have today published their final report and a draft Bill on the regulation of health and social care professionals.

This recommends that a UK-wide single statute be established for the regulation of health and social care professionals that would provide regulators with new powers and duties, and set them a clear main objective of protecting the public. If implemented, our recommended reforms, would:

- empower regulators to investigate proactively instances of suspected poor conduct and practice whenever such concerns come to their attention
- bring consistency to, and extend, the range of sanctions that can be imposed by regulators' fitness to practise panels, and
- for the first time, empower regulators to discipline or strike off professionals who are not able to communicate clearly in English.

Our reforms would also implement the recommendations of the public inquiry into the scandal at Mid-Staffordshire NHS Trust (the Francis report) that the regulators should have wider powers to investigate poor professional practice and to reconsider cases that have been closed following a mistake or error.

[http://lawcommission.justice.gov.uk/areas/Healthcare\\_professions.htm](http://lawcommission.justice.gov.uk/areas/Healthcare_professions.htm)

I would be very grateful if you could cascade this message to colleagues or others who might be interested.

Tim Spencer-Lane | Law Commission  
Lawyer, Public Law Team  
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Email: [tim.spencer-lane@lawcommission.gsi.gov.uk](mailto:tim.spencer-lane@lawcommission.gsi.gov.uk)

### 23. Turning impediments into opportunities: Tim Chan at TEDxMelbourne

<http://youtu.be/Woy-XzC-UVs>

Tim Chan explains how he turned his own impediments into opportunities. At the age of three, he was diagnosed with severe autistic disorder and now, speaking in public for the first time, he tells of how he had to learn to communicate, with his mother's help, using an electronic voice-output machine. Tim recalls being a student with high needs who went through inclusive education, such as home programs and early intervention.

As a recent high school graduate, he hopes to keep advocating for those without a voice. He's had an article about his experiences published on ABC's RampUp—an online destination for discussion and debate about disability. He has done interviews on facilitated communication with The Age, 3CR Monday Breakfast and 7.30 Report.

Connect with Tim:

Tw: @I\_CAN\_Network

FB: [www.facebook.com/groups/icannetwork.au](http://www.facebook.com/groups/icannetwork.au)

Web: [www.icannetwork.com.au](http://www.icannetwork.com.au)

### 24. The latest issue of the Challenging Behaviour Foundation's newsletter **Challenge is out now.**

<http://www.challengingbehaviour.org.uk/cbf-articles/latest-news/spring-newsletter.html>

This time it's all about 'Circles of Support.'

What do we mean by a 'Circle of Support'? For this edition we've gathered perspectives from professionals and family carers on what a circle is and what it can achieve.

Our feature article focusses on the benefits a circle of support has brought to Pete Crane and his family in meeting his son Niki's needs. Pete and Helen Smith (who facilitates Niki's circle) describe the process of setting up the circle and some of the major benefits which make it 'a really wide network of support to draw upon'.

They also share the lighter side of circle meetings 'sometimes they end up being quite formal and sometimes it's more like a giggly party'. We hear from Kate Farmer who writes about the reasons behind setting up a Circle of Support for her daughter and there's a short introduction from the CBF about where to get more information and support setting up a circle.

In our front page article Mandy Neville shares what she has learnt over 20 years of developing circles of support as founder of the Circles Network and Vivien Cooper OBE, writes in her regular column about how circles of support both formal and informal have helped her 'make things happen'.

To sign up to get future newsletters by post, or if you'd like to be removed from this mailing list, give the office a call on 01634 838739 or email [info@theCBF.org.uk](mailto:info@theCBF.org.uk).

## 25. Dosh has today published it's banking guide: Making Banking Easier.

This follows our report last month on access to banking. Please find your free copy attached to this e-mail.

The guide aims to give people the information they need to understand banking, know what they should be getting and know how to ask for it.

It includes:

- Opening, changing and closing an account
- What should banks be doing?
- How can I get support with banking?
- How can I deal with problems?
- What do banking laws say?
- What do equality laws say? In particular, the Equality Act and Mental Capacity Act
- Links to further resources and helpful contacts

We hope that this guide will help people with a learning disability, other financially excluded and disabled people, their families, supporters and advocates to speak to banks and get the support and access they need.

Our report found that people with a learning disability were not always given different options to help them, for example an extended list of acceptable identity documents, a different type of account, or a signature stamp. This guide will help everyone to get past these problems by knowing what to say and what they should be getting, so that they can work together to find solutions.

Along with the full guide, there is a short help sheet for you to take with you on trips to the bank as a quick reminder. I have also attached this to the e-mail.

Please visit our <http://www.dosh.org/> to read more about Dosh and our banking report, as well as download the free report and guide. If you would like a paper copy of the guide or need any other format, please reply to this e-mail or call 0300 303 1288.

We hope you enjoy the guide and would like to know what you think of it. You can get in touch with us via e-mail or twitter [@DoshLtd](https://twitter.com/DoshLtd). Please do also share it with your colleagues, friends and anyone else you think it might help.

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## 26. Wheelie Good Idea update:

Our first container full of refurbished mobility aids left here last week and is currently on board the Amoliani somewhere north of Algeria. It is expected to arrive in Durban on the 12th April.

Good news indeed, and so we are concentrating on the next one...

With the aim of keeping this a truly community based project, we have turned to Crowdfunder to help us fund it.

We need £5,000 to buy and ship our next container. Over £100,000 worth of equipment went into the last one, so its a great return and each piece of kit really can change a life.

You can find more information about the Wheelie Good Idea on our website:

<http://www.clynyfw.co.uk/wheelie.htm>

If you would like to help, please go to the Crowdfunder link below and work your magic. And please share this link and tell your friends and contacts. Hundreds of people in South Africa, Mozambique and Abercych would really appreciate it!

If you would like more info, please let us know.

<http://www.crowdfunder.co.uk/Wheelie-Good-Idea>

## **27. GLASGOW PCPLD Network conference**

The annual conference of the Palliative Care for People with Learning Disabilities Network will take place on 26th November in Glasgow.

The theme is "End of life care planning for people with learning disabilities".

<http://www.pcpld.org/events-and-conferences/>

## **28. LONDON Decision Making for Adults and Keeping Safe National Family Carers Network events**

NHS England, London have commissioned the National Family Carers Network to run 3 events for family carers on the MCA and safeguarding.

Booking forms at <http://www.familycarers.org.uk/default.aspx?page=25633>

*London South region event*

Wednesday 23rd April - London South Bank University - Clarence Centre (nearest tube Elephant and Castle). <http://www.lsbu.ac.uk/>

*Central and North East London region event*

Thursday 24th April - NCVO building (nearest tube Kings Cross).

<http://www.ncvo.org.uk>

*NW London region event*

Monday 28th April - Friends House (nearest tube Euston).

<http://www.friendshouse.co.uk/>

Please arrive at 10.00am for registration. All events are 10.30am to 3.00pm.

## **29. BIRMINGHAM and LEEDS events Making it real – for everyone**

*Booking forms download at*

<http://www.thinklocalactpersonal.org.uk/News/PersonalisationNewsItem/?cid=10021>

A personalised response to Winterbourne View

Making it real for everyone events to be held in Birmingham on the 12th June and Leeds on the 2nd July.

Jurys Inn, Birmingham

12th June 2014

9.30 am – 4.00 pm

Park Plaza, Leeds

2nd July 2014

9.30 am – 4.00 pm



**30. LONDON Thursday 10th April 2014, London South Bank University**

Assessing Risk for Sex offenders with intellectual disability - the ARMIDILO-S

Due to popular demand Danshell have reopened the bookings for this event.

They have an extra 20 places released. Don't miss out! Book through the following link:

<http://danshellevents.co.uk/index.php/events/20-armidilo1004>

**31. LONDON Epilepsy Society and London South Bank University (LSBU) present: 'The changing landscape of the epilepsies' conference Friday 24 October 2014**

At London South Bank University

The UK's leading medical charity for epilepsy and London's largest Faculty of Health and Social Care come together again to deliver their second joint conference for healthcare professionals with an interest in epilepsy.

*This conference is free to attend, so early booking is essential to secure a place.*

Find out more: [www.epilepsysociety.org.uk/epilepsylandscape](http://www.epilepsysociety.org.uk/epilepsylandscape)

Book now online: <http://www.lsbu.ac.uk/whats-on/epilepsy>

This conference will:

- enhance your understanding of the landscape of individual rare diseases in epilepsy;
- assist you in developing person-centred risk management strategies;
- demonstrate strategies for developing and delivering epilepsy service improvement; and
- offer excellent opportunities for networking with other healthcare professionals within epilepsy services.

Sessions will cover:

- The changing landscape of the epilepsies: the importance of identifying different epilepsies – Professor Ley Sander, Epilepsy Society.
- The genetic causes of epilepsy: what we are learning from research – Professor Sanjay Sisodiya, Epilepsy Society.
- Differential diagnosis: non-epileptic seizures/dissociative seizures – Brent Elliott, Epilepsy Society.
- The uses and benefits of therapeutic drug monitoring – Professor Philip Patsalos, Epilepsy Society.
- Service improvement for better outcomes – Juliet Ashton, Epilepsy Society.
- Epilepsy and learning disability: risk management and capacity – Jennifer Davidson and Julie Joyner, Epilepsy Society.
- Supporting evidence for benefit claimants – Alban Hawksworth, Independent benefits advisor.
- The value of the pharmacist in the multidisciplinary team - Trudy Thomas, Medway School of Pharmacy.