

# Bulletin



National  
Family Carer  
Network

[www.familycarers.org.uk](http://www.familycarers.org.uk)

Tel: 07747 460727

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Welcome to this week's Bulletin from the National Family Carer Network. You are receiving this because you are members of our organisation. If you no longer wish to subscribe, please contact [info@familycarers.org.uk](mailto:info@familycarers.org.uk).

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NFCN is an umbrella organisation that aims to promote the voice and rights of family carers supporting a person with a LD. Its membership comprises both organisations and individuals but we cannot be responsible at any time for the views expressed by our members unless explicitly promoted by us.

# National

## 1. Research project: “Adaptation and Resiliency in Families of Children with Down Syndrome”

Marcia Van Riper, Professor, Chair of Family Health at the University of North Carolina is inviting parents of children with Down syndrome to take part in a research project. The purpose of the study is to learn about factors that influence how families respond following the birth of a child with Down syndrome. This study is part of a larger cross-cultural study which will be conducted in at least 8 to 10 countries (Brazil, Ireland, Italy, Japan, Korea, Netherlands, Portugal, United Kingdom, and United States). To date, over 600 parents have taken part in the study. If possible, they would like to collect data from 2,000-3,000 families.

**Who can participate?** Your child with Down syndrome can be of any age. If you have a spouse or partner, he or she is also eligible to participate.

**What will you be asked to do?** You will be asked to complete an online survey (this should take approximately 20-30 minutes) and if you would like, they will interview you. Generally the interview will be conducted by telephone or Skype. They expect the interview will take approximately 60-90 minutes. After you talk with the researchers and complete the online survey they may contact you a second time if they need to clarify any information with you.

The project has been approved by the institutional review board for human subjects research at the University of North Carolina at Chapel Hill. If you agree to take part, all information you give will be confidential. No one except the research team will have access to your information.

If you wish to be involved in this research, please email ( [vanriper@email.unc.edu](mailto:vanriper@email.unc.edu) ) . You also have the option of using one of the links below to access the survey directly (there is one link for mothers and one link for fathers – the surveys are exactly the same but if two people use the same computer to complete the survey, they need to use different links). If you agree to be interviewed, the researchers will arrange to do the interview at a time that is convenient for you.

Link for mothers: <https://www.surveymonkey.com/s/GZG7KW6>

Link for fathers: <https://www.surveymonkey.com/s/WBJL9ZF>

## 2. DWP PIP Assessment Guidance - updated

The [Department for Work and Pensions](#) has recently updated its guidance document for providers carrying out assessments for Personal Independence Payment.

You can read the updated document on our website [here](#).

### **3. The National Association of LINKs' Members Coroners' Rule 43 Project**

Every six months, the Ministry of Justice publishes a summary of Coroners' Rule 43 recommendations which have been made by local coroner's with the intention of preventing deaths and learning lessons from the cause of death.

The aim of [NALM's](#) project is to gather information about Rule 43 recommendations made in relation to deaths that occur during the process of health care, and to build local knowledge about causes of deaths in the NHS that result in inquests. The project aims to share recommendations made, and the action taken by the local NHS and related bodies:

To find out more please visit the Coroners' Rule 43 website [here](#).

### **4. Stop Hate Learning Disability Hate Crime New Helpline**

[Stop Hate UK](#) is a national organisation working to provide support to victims of Hate Crime, across the strands of Disability, Gender Identity, Race, Religion and Sexual Orientation. The independent charity has been operating the Stop Hate Line, a 24 hour helpline for Hate Crime victims and witnesses in some areas of the UK, since 2006.

Stop Hate UK has launched a new 24 hour helpline service, Stop Learning Disability Hate Crime, in England and Wales. The new service will be funded by the Ministry of Justice Victim and Witness Fund.

People in England and Wales who have experienced, witnessed or know someone who is experiencing Learning Disability Hate Crime can contact the Stop Learning Disability Hate Crime helpline on 0808 802 1155 for support and information. The helpline is open 24 hours a day, every day of the year. It is free to call the Stop Learning Disability Hate Crime helpline from landlines and most mobiles and the number won't show on a phone bill.

For further details, please visit the Stop Hate UK website [here](#).

### **5. Major Challenge to Healthwatch regulations in the House of Lords**

This week, [The National Association of LINKs Members](#) issued a press release regarding a motion attacking local Healthwatch regulations which was put to the House of Lords, in a major challenge to the government, on the effectiveness and freedom of its new health and social care watchdog.

You can read the full press release [here](#).

## 6. NICE Consultation

Care and Support Minister Norman Lamb has launched a 12 week consultation to establish a full set of NICE quality standards and guidance for social care.

The Department is seeking ideas from care users, their families and carers, service commissioners, care providers and front line staff to help decide on future topics for NICE guidance and standards.

The aim is to establish a full set of NICE quality standards and guidance in order to improve the quality of social care.

Some of the potential NICE standards for discussion in the consultation include:

- falls
- deprivation of liberty safeguards
- medicines management in home-based settings

The 12 week consultation ends on 26<sup>th</sup> April 2013.

You can find out more on the Department of Health website <http://www.dh.gov.uk/health/2013/02/nice-socialcare-2/>

You can also give your views via an online survey here: <http://consultations.dh.gov.uk/quality-and-safety/nice-future-quality-standards-2>

You can also read the topics for consultation, along with consultation questions on our website [here](#), which includes an easy read version.

## London

### 7. London Zoo Special Children's Day 2013

[London Zoo](#) will be hosting their annual 'Special Children's Day on 18th and 19th May 2013.

Special Children's Day is a unique annual event at ZSL London Zoo. With increased specialist facilities and number of staff, as well as special 'interactive events'. 3-18 year olds are charged £8.50 a ticket, one carer goes free with additional adults at £12.50.

To find out more call 0207 449 6551 or email [steve.marriott@zsl.org](mailto:steve.marriott@zsl.org).

## South East

### 8. QE2 Activity Centre & Hampshire Autistic Society Short Break Holidays and Day Activities 2013

[Hampshire Autistic Society](#) are pleased to offer ANYONE with an Autism Spectrum Condition and their families/carers an opportunity to take a 2 night residential break at the QE2 Centre based at Manor Farm Country Park, Bursledon, Southampton.

Short Breaks include overnight accommodation in a log cabin sleeping up to 8 people with a choice of activities which may include archery, zip wire, orienteering, crab fishing, canoeing, climbing, rope course and many more. (Subject to availability).

They are also offering Day Activities, ideal for those who wish to try this for the first time or who do not wish to stay overnight.

To find the dates of the above activities/breaks [click here](#) or call 02380 633951 to find out more.

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*If you would like to contribute to the newsletter, please submit articles in plain English of no more than 230 words to [info@familycarers.org.uk](mailto:info@familycarers.org.uk). We reserve the right to edit the articles to fit the newsletter whilst retaining the overall information. Due to the number of articles we receive we cannot guarantee inclusion of contributions.*