

# The HULON Herald

The Newsletter for the Hampshire ULO Network Group

Issue 5

April-May 2016

## Don't Miss!

- **The latest from HULON**
- **Close Encounters of the ULO Kind 1-  
Winchester Area Access for All Access Awards**
- **What's On**
- **Hollywood calling! The ULO team's epic  
blockbuster!**
- **Can robots be caregivers?**
- **Training Opportunities for User-Led Organisations**
- **FREE mentoring for YOUR ULO!**
- **and more!**



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**The Editor's Bit**  
**By Jennie Musson**



**Dear Reader**

Time and tide wait for no man, at least that's what Geoffrey Chaucer thought many moons ago, although in these more enlightened times I am sure we would all wish to be more inclusive and definitely include the female half of the population and possibly small furry mammals in this statement, although some might argue that including little furry critters might be a stage too far, no matter how cuddly they might be. Anyway, what I was trying to say was that time certainly is marching on this year for the ULO project.

As I type these words, our training package for ULOs is being put through the final stages of checking before its release in April. The pack comprises of a training video on starting up your own User-Led organisation and a written guide to obtaining funding—both **FREE** to user-led organisations and will be available on CD. If you would like to find out more about what it was like filming our own blockbuster, **please turn to my Blog, on page 7**. You will also be reassured to learn that no cute fluffy creatures or small children were harmed in the production of the training pack. Be sure to keep an eye on the News section of the SPECTRUM website and on the User Led Organisation Project page in Facebook where details of this will be announced—and, more importantly, how to get hold of a pack for **YOUR** organisation.

In this issue, we have the low-down from our Networking and Development Officer, Abdi, on what makes HULON tick, plus a very interesting article on whether robots could ever be caregivers, based on the Futures Debate at the Winchester Science Centre on 9th February 2016, which the SPECTRUM CEO, Ian Loynes took part in, as well as the usual features on training opportunities, What's On and pieces from Parability about their exciting new event, Parability Fest and Winchester Access for All's Accessibility Awards scheme - so plenty to get your teeth stuck into in this issue!

## HULON-What's It All About – by Abdi Elmi

### What HULON Members want from the Network?

Since I started my role as the Networking and Development officer for the ULO project at SPECTRUM, I have had several meetings with HULON members and have been asking them a number of questions that I prepared, including: what do you want from HULON? How would you measure the success of the project? What does sustainability mean for you? And what can you contribute to the network? What I gather is that HULON network members have similar aspirations and aims – despite their organisations being of various sizes and being structured in different ways and that is what brings them together. Here is what the Network members told me:

#### Voice

One thing that all network members want from HULON is for it to become an authentic collective voice for user-led organisations and community groups in Hampshire. They believe the best way to ensure that their voice heard in decision making bodies is to join forces in communities. This is particularly important in this time of austerity.

#### Peer Support

Another important area that network members want is for HULON to be a peer support network for user led organisations and community groups. This includes: sharing ideas, supporting each other during difficult times, mentoring each other and having events.

#### Information and Network

Members want HULON to be a valuable source of information. For the members, information consists of two elements, sharing information - whether that is opportunities such training and funding or raising issues, and distributing information -whether this is disseminating information in network meetings, taking each other's leaflets and having stalls at annual events for networking and showcasing services.

#### Diversity

All the members I met with agreed that the more the network is diverse in all its characteristics, the better and more sustainable it becomes. They also recognise that this is an area that needs more work and engagement with different communities.

#### Sustainability Depends on ...

Globally, we live in an era of sustainability. Therefore, not surprisingly one of the key aims of the user-led organisation project is to create sustainable user-led organisations in Hampshire. To find out what this means for HULON members I asked them how they measure sustainability. To HULON members, sustainability meant a fairly large network, consisting of committed members who willingly take responsibilities for tasks, building resilience and capacity of the smaller network members and having a reliable source of income/funding.

## **HULON's Mission Statement**

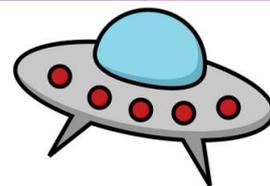
HULON's main aim is to build a strong collective voice and identity for all Hampshire based ULOs and user-led community groups from all diversity strands and communities.

HULON exists to empower ULOs user-led community groups to come together to share experiences, develop ideas, and help each other, as well as supporting the development of new groups which share common values and principles. HULON enables ULOs to develop and engage with a range of influencing and co-production opportunities with statutory bodies, assisting them in welcoming, supporting and working better with ULOs in the future to build individual and collective sustainability.

## **HULON's Objectives**

- To become a progressive user-led organisations network committed to the empowerment and full inclusion of all user-led organisations and community groups, whilst promoting individual choice and control.
- To enable the collective and representative voice of ULOs to inform and encourage the work of our principle statutory partners.
- To aid the development and sustainability of all user-led organisations in Hampshire, and to become one-stop-shop for peer support, advocacy and advice for user-led organisations
- To create development opportunities for members to enable them to develop and become sustainable ULOs, and to collectively problem solve barriers to development and sustainability through working together, learning from each other and mutually co-operating in the best interest of all members.

**Close Encounters of the ULO Kind 1**  
**Winchester Area Access for All**  
**Awards**  
**By Keith Hatter**



Winchester Area Access for All (WAAFA) is a forum for highlighting difficulties in accessing shops, offices, public spaces and other facilities in the Winchester area, and, if possible, removing or preventing them.

As part of this aim, the Good Accessibility Scheme seeks to encourage shops and businesses to optimise their accessibility by carrying out audits by mystery and overt shoppers. Gold, Silver or Bronze awards are made to those businesses satisfying the relevant criteria.

At a ceremony in Abbey House on 7th March, The Right Worshipful, The Mayor of Winchester, Cllr Angela Clear, presented winners with certificates and badges. The badges can be displayed so that good practice is recognised and appreciated, to indicate that customers can enter the premises with confidence and so that non-winners might ask themselves whether it is possible to improve their accessibility.

As well as thanking Madam Mayor for hosting the ceremony, we would also like to express our appreciation of the volunteers who carried out the audits. This is a continuing project, and anyone who would be willing to help with future audits would be most welcome.

Further details can be obtained by e-mailing: [info@waafa.org.uk](mailto:info@waafa.org.uk) or calling 01962 -855016

## Move Over, Daniel Craig—here comes the ULO Team!

By Jennie Musson



Centre for  
Independent  
Living CIC

The ULO team have produced a training video for people who fancy setting up their own – prizes for the best guess –

- A) Cream cake farm
- B) Answer to “Britain’s (Not) Got Talent”
- C) User-led organisation
- D) Circus school
- E) Allotment growing peculiar shaped vegetables

No prizes for choosing “c”, by the way, which, incidentally, is the correct answer, which may be a “trifle” disappointing if you were hoping for “a” – get it? We chose a friendly and experienced film maker, Flexible Films, aka Sybil and Russ, ~~who drew the short straw~~ to work with us and ~~carefully~~ carefully recruited some of the members from the Hampshire User Led Organisation Network Group (HULON) to star in our very own blockbuster, sharing their experiences of how their own groups got started and even being “shot” in action at one of our HULON meetings. The three chosen were Rich le People, from Greenbuttercup, Rachel Harrison from Disabled People’s Voice Hampshire and last, but definitely not least, Lise Marron, from Capable Creatures. The film is part of a training package comprising of the video on how to set up your own user-led organisation and a written resource on obtaining funding. Both the film and the written resource will be issued as a 2 CD package and will be available on request from the end of April.

What I did not expect, however, when I first started looking round for filmmakers to work with, was to be roped into the filming process myself, and it was with considerable surprise (and dismay!) that I found my mouth opening and the word “Yes” coming out when asked if I would be happy to be one of the presenters for the film.

Horrible visions of me doing a Morecambe and Wise down the SPECTRUM corridors while being pursued by a massive yelling, camera-wielding pack of paparazzi flitted hideously across my mind, but there is no forcing the genie back into the bottle once it’s out, so there it was – no going back.

## **Move Over, Daniel Craig—here comes the ULO Team! - continued**

**By Jennie Musson**



Gerry Zarb, our Business Development and Policy Manager and Berni Vincent from SPECTRUM's Independent Living Team featured in the film as advisors, with Tony Brown from ADRC “upstairs” also sneaking in on the action.

Both myself and Ian Loynes, the CEO of SPECTRUM were being filmed on the same day, so I had someone to ~~suffer with me~~ act alongside on the big day. Russ from Flexible Films has developed an autocue with a camera so cunningly concealed in it, we were convinced it was one of Baldrick's “cunning plans”, the idea being that when we read from the autocue, we were looking into the camera. I think Baldrick should be worried about losing his special Award Turnip for “The Most Cunning Plan”, dear readers, but if you don't tell him, we will also promise to keep quiet.....

We also discovered that there was a fine balance involved in running the speed of the autocue to match our different speaking speeds as my first attempt sounded like Minnie Mouse on helium and my second like Marvin the robot from “The Hitchhiker's Guide to the Galaxy”. However, this small issue, among others, was soon ironed out by Sybil and Russ and we found the whole thing was a very interesting experience, with the film-makers making the whole process as stress free as possible for us and we even ended up enjoying ourselves. No paparazzi, no stress and we are all definitely available should Hollywood come calling....\*

To see us in our full glory behind the scenes, click on

**<https://katch.me/SPECTRUMCIL>**

**And look for “Behind the scenes at @SPECTRUMCIL Video Shoot”**

And if your organisation or user-led group is interested in this FREE training pack, please contact: [ulo@spectrumcil.co.uk](mailto:ulo@spectrumcil.co.uk) **or phone 023 8020 2643 between Mondays and Wednesdays**

\* Fat hope – Editor



## **Mentoring and Advice service for User Led Organisations in Hampshire**



**If you are a User Led Organisation or community group in Hampshire our FREE Mentoring and Advice service can help you with:**

- **Setting up and getting constituted**
- **Organisational development, governance and management**
- **Support and advice on income generation opportunities and diversifying funding streams**
- **Service development**

**And much more...**

### **Some of the groups we have helped**

A small BAME community Group wanted help with organising and funding a multi cultural event. Our Mentoring support was able to help them to identify suitable funding sources, work out a detailed budget, and put together a funding application to the National Lottery which was successful. We also helped them with forming an organising committee and promoting the event.

A small ULO needed help with a funding application as the funders had asked a lot of additional questions particularly about the costs and they were unsure about how to answer these. Our Mentor's detailed knowledge of the sorts of information funding bodies require meant that we were able to help them understand why the funders were querying particular cost items, and to draft answers to send them. This resulted in all of the requested funding being approved.

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## **FREE Mentoring and Advice service for User Led Organisations in Hampshire continued**

A local ULO contacted us looking for help with developing a business plan for developing a new support service which they hoped would generate income to help the group to become more secure and sustainable. Our Mentoring support helped them to draw up a workable plan and budget. We also helped them do some basic market research to find out what other services were available locally and what would be a suitable rate to charge for their own service. They are now well on the way to getting this service up and running.

**If you think we might be able to help,  
or if you would like more information,  
please get in touch.**

**Email: [ulo@spectrumcil.co.uk](mailto:ulo@spectrumcil.co.uk)**

**Phone Abdi on 02380 202937**

**Website: [www.spectrumcil.co.uk](http://www.spectrumcil.co.uk)**

**This service is completely FREE to  
User Led Organisations in Hampshire**

# Can Robots be Caregivers?

By Ian Loynes



## **SPECTRUM's general stance:**

- Welcome any technology that enables user choice and control and Independent Living
- Concern that any move to robotic provision of care is likely to be driven by a cost saving agenda, rather than for quality of care or user preference.
- Disabled People are concerned that ethical and human rights aspects of this debate are not receiving enough consideration.
- Finally, the care recipients (users) of this brave new world are likely to be excluded from this conversation

## **I'd like to focus on the following issues, from the perspective of Disabled People:**

### **Pros:**

- Robots don't go sick, don't need holiday cover and don't cause HR problems – or could they!
- Intimate personal care can be embarrassing and undignified – robots to support toilet needs for example
- Robots could reduce certain risks – safeguarding, abuse, theft, language barriers
- Real opportunities to empower and enable the individual to compensate for some impairment barriers (communication aids, memory aids, visual aids, for me – exoskeletons!)
- It will happen (and already has – iPads, labour saving aids, communication aids)

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# Can Robots be Caregivers?

By Ian Loynes - continued



## **Cons:**

- May well be imposed on people – often the most vulnerable with least voice
- The care giver will often be the only person the user sees – social isolation is already the most common “unmet need”. – robots could make this worse. This would not be good for people who are already socially isolated or people with conditions actively benefit from interactions with others; ie Alzheimers.
- What is the motive? Likely to be seen as a “cheaper option” by local authorities looking to save money?

## **Ethical Considerations:**

In our experience, (i.e. telecare debate), ethical and human rights considerations often receive scant attention.

For instance:

- Who is responsible if the robot or software goes wrong or breaks or causes damage and/or death? – these events will happen.
- Who is in control? The care recipient, the local authority or the manufacturer?
- The main challenge in creating robotic care givers is the problem of programming a machine with a reliable set of ethics.
- A robot will have to make complicated decisions regarding its users on a daily basis (particularly for nursing care). Since its function will involve giving advice that will determine the health/welfare of human beings, it will need to have an ethical system that will allow it to properly carry out functions while treating users with respect.
- For example, if a robot is programmed to remind its users to take their medicine, it needs to know what to do if the user refuses. On one hand, refusing the medicine will harm the user. On the other hand, the user may be refusing for a number of legitimate reasons that the robot may not be aware of.

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## Can Robots be Caregivers?

By Ian Loynes - continued

For example, if the user feels ill after taking the medicine, then insisting on administering the medicine may turn out to be harmful.

- These scenarios are everyday situations that humans navigate with Ease. The human brain can assess a situation not only based on data that it directly receives through its senses, but it can also logically process other signs, such as the look of a person or the intonation of a response. If there is not enough data to make a decision, a human can figure out which questions to ask in order to receive more information.
- A key point for me is that many of the remote technologies in use of development today rely on being able to track people's movement and behaviours and, in practice, that can – and does – very easily lead to some serious breaches to people's rights to a private life as well as putting dignity and autonomy at serious risk. We are alarmed at how little attention providers seem to pay to these issues – in fact I'd go as far to say that in telecare they were mostly oblivious to the risks.
- The Health Select Committee also raises concerns about this issue. They emphasised that while technology can facilitate things like robotics and telecare, this has to be rebalanced against people's right to privacy. They recommended that privacy and confidentiality policies and protocols should be developed, implemented and audited when new technologies are introduced.
- They said that: It is essential that a balance between the use of technology and the continuation of human contact is an important element in any such judgement. Furthermore, evaluation needs to take account of the qualitative benefits for users and carers over time.
- I don't want to rain on robotics' parade – I really don't. Anything that can play a positive role should be welcomed.
- But, we do have to be realistic about what it can achieve and, more important still, we need to recognise that there are no quick fixes to the challenge of building a social care system capable of addressing the needs of an ageing population.
- Rather, we need a serious debate about the value we place on social care and the willingness – on the part of both the government and the public – to invest in social care as a positive public policy resource.

## Training Opportunities for User Led

### Organisations



#### Disability Awareness Training – Harbourside Training

**Date:** 5<sup>th</sup> May 2016

**Time:** 9.30am -1.00pm

**Venue:** Community Action Fareham

**Cost:** Voluntary Sector: £30

**Cost:** Statutory & Private Sector: £50

This course raises awareness of the barriers faced by Disabled People and helps to develop and understanding of how to overcome these.

This course will give you a greater understanding of the issues surrounding disability and provide you with practical advice and information on how to communicate with people with a disability. It provides the ideal opportunity to learn and ask questions in a safe environment.

The aim of this training is to help you be more confident in your day-to-day dealings with Disabled People.

**Book now at:**

<http://www.actionfareham.org.uk/index.php/support/training/course-details>

**Telephone :** 01329 223155

**or email:** [bookings@farehamaction.org.uk](mailto:bookings@farehamaction.org.uk)

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## **Training Opportunities for User-Led Organisations – continued**



### **How to be an Effective Employer – FREE training!**

Most people come to Direct Payments having never employed anyone before and it can seem daunting.

This event will help you to understand what your employment responsibilities are, will build your confidence and provide knowledge about what support is available to help you become a responsible employer.

### **An invitation...**

Independent Lives, in partnership with Hampshire County Council, is running free “How to be an Effective Employer” workshops.

### **Topics include:**

- Getting it right from the beginning  
(know your budget, costs and responsibilities)
- Recruiting a Personal Assistant
- Induction, Staff Management and Supervision

### **Wednesday 20<sup>th</sup> April 10:00 to 14:30**

Andover Wellington Centre, (Andover and District Mencap),  
Winchester Road, Andover, Hampshire SP10 2EG

### **Tuesday 17<sup>th</sup> May 10:00 to 14:30**

Wells Place Centre, Allington Room, Eastleigh, Hampshire SO50  
5LJ

**Please phone 01903 219482 for dates in June and October!**

For further enquiries please contact Independent Lives

Tel: **01903 219482** and/or

Email: [advice@independentlives.org](mailto:advice@independentlives.org)

## Training Opportunities for User Led Organisations-continued



### **Disability Rights UK—Disability Confidence Course**

**Places now available on our next course!**

We are holding our next open Disability Confidence Course on **Monday 27th June**. Book now to secure your place.

The course is aimed at anyone who works with disabled people, either as an employer or as a staff member who interacts with disabled clients or customers. We very much welcome disabled people who work in these environments and the course content and location is designed to be accessible.

The course runs from 10am until 4pm, with lunch and refreshments provided. Course content will cover a range of topics and include sections on the Equality Act, the various theoretical models of disability and a number of case studies about employment and reasonable adjustments.

The course is being held at our offices in London, at CAN Mezzanine, 49-51 East Road, N1 6AH. Attendance costs £99 + VAT per person.

To request a sign up form, please contact Natasha Fagelman at [natasha.fagelman@disabilityrightsuk.org](mailto:natasha.fagelman@disabilityrightsuk.org)



## What's on



**GO LD Go Social Events** for people with Learning Difficulties is held every **4th Wednesday of each month from 7pm to 9pm**. The group decide together what they would like to do the following month. Events can be discos, karaoke evenings, dinner and pub night out, bowling, theatre, Sprinkles trip and more!

For more information go to:

<http://learningdisabilitieswinchester.org.uk/whats-on/go-social/>

- Or call 01962 873608 for more details.

### Hampshire Festival of the Mind 2016

May 7<sup>th</sup> Festival Launch Event at Portsmouth Cathedral, sponsored by the Cathedral Innovation Centre – **FREE!**

The day will include a wide range of stalls from local community groups, agencies and social enterprises with information about activities, events and services which promote good mental health and wellbeing. There'll be exhibitions of art, fashion and sculpture, and exciting interactive creative activities for adults and children, as well as refreshments from popular on-site pop up cafe, Lily & Lime.

There is an exciting programme of events during the day.

Click on the link below for more information and to book your **FREE** workshop spaces in nearby Becket Hall:

<http://goodmentalhealth.org.uk/event/hampshire-festival-of-the-mind-2016/>

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# Time for Tea

A peer support group for people with mental health problems

Come along and meet other people, as well as receive support with your mental health. Share ideas and meet new friends.



- Basic benefits housing advice available
- Tea and Coffee provided

Meetings third Thursday of every month  
2:00pm to 3:30pm

Located at:  
Spectrum, Unity 12  
9-19 Rose Road  
Southampton  
SO14 6TE



For more info contact:

Berni Vincent (Spectrum)  
023-8020-2931

Luke Basford (Solent Mind)  
07919-991578

Solent Mind: Registered charity number 1081116

# LIVING *your way*

We are experts in Assistive Technology and can provide a range of services including:

- Advice or demonstrations on using Assistive Technology at home, at work or in school or college
- Training in the use of AT equipment

There is a huge range of Assistive Technology available and we can nearly always find a solution that is just right for you. Appointments can be made with an AT Advisor who will discuss your needs and what resources you might already have (Disabled Students Allowance, Access to Work for example, Individual budgets), and identify what AT solutions would be most suitable. We will then give you a written report detailing our recommendations and detailing all the information you need to obtain the equipment you want.

**For more information and to book your place, contact us on...**

**Tel: 023 8020 2941 | email: [yourway@dnamatters.co.uk](mailto:yourway@dnamatters.co.uk)**



**Don't be a Stranger-get in touch!**



Call 023 8020 2643



Email [ulo@spectrumcil.co.uk](mailto:ulo@spectrumcil.co.uk)



**<https://www.facebook.com/pages/User-Led-Organisation-Project>**



**Hampshire ULO Network Forum:**

**<https://www.facebook.com/groups/1659594594293677/>**