

Hampshire Self Advocacy Day






25th April 2009

Self Advocates in Hampshire speaking out

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Introduction

In 2004 the Hampshire Advocacy Regional Group (HARG) had a project to help self advocacy in Hampshire. It helped to organise a Self Advocacy day in Winchester. Many self advocates remember that day and said they wanted to meet together again.

In June 2008 HARG asked self advocacy groups what they wanted from a day. A questionnaire was sent out and eight groups gave us their ideas. Feedback from the questionnaires told us that people wanted a conference, on a Saturday and the issues important to them for workshops. Connect Advocacy volunteered to co ordinate the day and Speakeasy Advocacy, Choices Advocacy and Winchester Mencap representatives met and worked together from September to April to organise the day people wanted.

This report is to help share what the 88 self advocates from all over Hampshire said on the day. We have included lots of photographs to show what happened during the day and each workshop group has written about their workshop and what people said.

We have provided the contact telephone numbers for all the groups involved at the end of the report. So if you want more information, want to know what people with learning disabilities think about an issue or are interested in becoming a self advocate you can get in touch with your local group.

Welcome and opening the day

Stephen Hull from Connect Advocacy and Rodger Pike from Speakeasy Advocacy welcomed everyone to the day. They said **“This is your day to have your say.”** Just Us started the day off with their performance. They use music, rhythm and song to speak out together.



Speakeasy Advocacy
Report on the HARG Self Advocacy Day
25th April 09



Wicked and Wacky group took part in the Self Advocacy Day in Eastleigh on the 25th April 09. We ran a workshop called 'Our Health Matters,' and we began by showing our workshop rules. Some of us did a roleplay about going to the doctors, how they treat us now and how we should be treated.



Members of Speakeasy also attended the other workshops during the morning.

We had lunch in the restaurant, there was loads of food and it was very nice. A magician and a balloon model maker entertained us.



Everyone went into the big hall after lunch to present their work to a panel of people; some of them were from Hampshire County Council. Wicked and Wacky group read out all the feedback from the workshop and we asked the panel some questions.

OUR HEALTH 1
How things are now.....

- Ⓜ Explain things to me
- 👂 Listens to me
- 🕒 More time needed
- 👤 Doctor speaks to support worker not me - I'm independent!
- ? Didn't understand
- ✓ Did understand
- 👤 Carers help me stay healthy
- 👤 Doctors help me
- + Hospital ok
- 👤 Need help making appointments

OUR HEALTH 2
How things are now.....

- 👤 Ask me what's wrong
- ? Don't explain what is happening
- + Hospital good
- 👤 Don't talk to me like I have a disability + I'm a child - it upsets me!
- + Had to wait in hospital in pain - I wasn't allowed to move + had to stay overnight
- 👤 No respect
- 👤 Arrogant + don't listen
- 👤 Not listened to
- 👤 Nurses didn't care

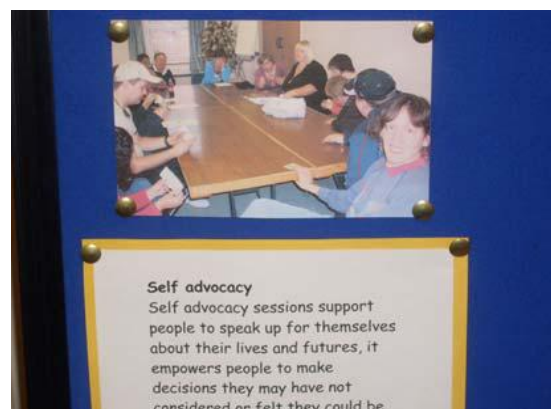
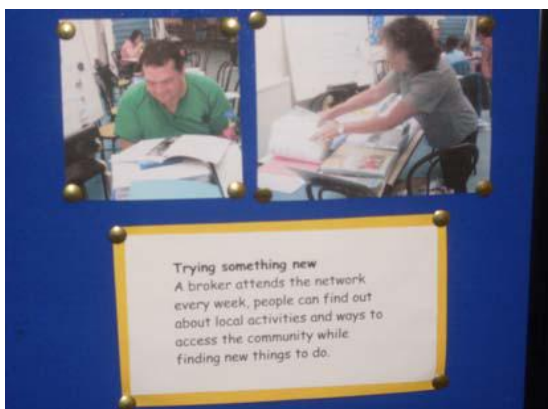
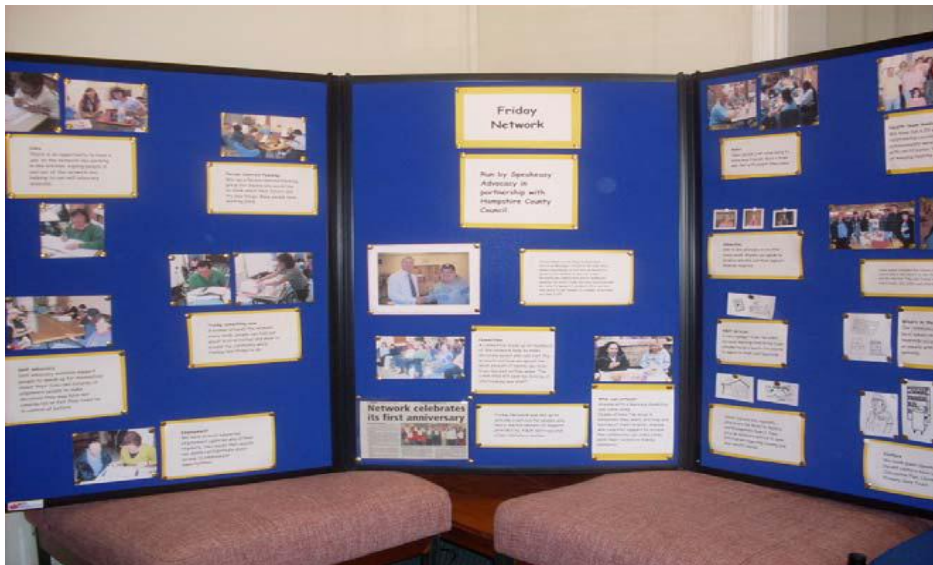
OUR HEALTH 1
How we want things to be.....

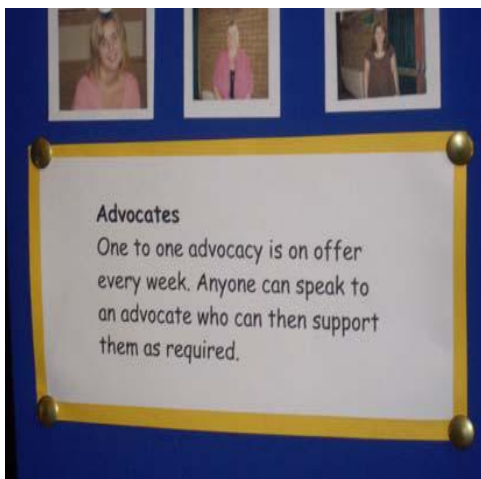
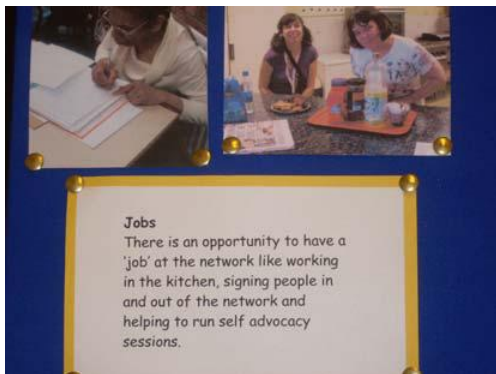
- 👂 We should be listened to
- 👤 All the information about our treatment
- 👤 More staff in community
- 📅 More appointments
- 👤 Speak to me - I'm the patient!
- 👤 More female staff
- 👤 Let me say my part of view
- 👤 Training for staff from us!
- 🗣️ Speak slowly + easy words
- 📺 Information easy to understand with pictures
- 🕒 More time - longer appointments
- 📺 Rules for working with us - let us speak + don't interrupt
- 😊 Be nice to me

OUR HEALTH 2
How we want things to be.....

- 👤 Ask ~~me~~ me
- 😊 Make me feel welcome so I relax
- 🏠 See doctor at home
- 🗣️ Speak politely
- 👂 Listen to me
- 📺 More information + someone to explain what is happening
- 👤 Treat me like an adult
- 👤 Be independent
- 👤 More training + experience - by universities and us!
- 🗣️ Explain things to us
- 🕒 More time
- 📺 Give us information on tape
- 👤 Named nurse in all hospitals that can help

Members of the Friday Network had a display stand which showed all the things that people take part in on a Friday.





Some things people from Speakeasy said about the day include:

“I bought myself a drink from the bar”

“There was music from a band at the end”

“The whole day was really good and we would like to do it all again soon”



Winchester & District Mencap

Workshops 25 April 2009 – “My Community”

Over the two workshops 43 people attended and came from all areas of the county.

People accessed a range of services in their community but these were not consistent in each locality. For example “Twice weekly drop ins” in Winchester are very popular to meet friends, find out information, have a chat and arrange to do other things together.

What’s not so good?

Transport:

No buses in and around Stubbington

Have to pay before 9.30am (some areas only and not consistent across the county)

New Town centre development - preferred old buildings

No training in how to get to places - get lots and lots of traffic

Catching buses can be stressful, number on front, not at side when you get on, not sure if correct bus. Having to wait for buses, not always bus shelters, not enough buses

Some drivers are helpful

No support to get the right bus

Dial a ride is expensive

No transport in the evenings – have to get taxis which is expensive

Have to spend £100 per month on taxis to get out to do things in the community

Walk during the summer but cannot do that in winter when it is dark, cold and not safe

Lack of public transport on a Sunday, feel alone have to stay in.

Rude bus drivers

Things to do in the Day

Bored, not enough to do

Only college one or two sessions a week – used to do a lot more at college

Some people are not friendly

Lifts at new venue too small and too busy

Sports Centre – expensive

No Night Club

Art Class near where I live, but have to pay a lot to go, plus taxi to get there and back

Roads busy, not enough pedestrian crossings, not enough lights when it is dark

Not enough shops close to where I live

No evening activities where I live (Swanwick)

Snooker Club is upstairs – difficult to access

Finding out what is on the cinema is not easy – need easy to read advertising of things to do

Supported Living

Did not choose who I live with

Not enough staff to support me with what I would like to do

Do not eat together, we have to cook and have meals separately

What would you like?

Transport

Helpful bus drivers

Easy to read bus signs, numbers on side of bus to make sure you get on correct bus

Bus pass you can use at any time, and to take a support worker with you "Free" across "district" boundaries

Support to use buses/trains

Companion Pass to be included on bus pass of person with LD so that support worker would not be able to access bus without the disabled person.

Voluntary transport in the evenings to go to my clubs/activities instead of having to pay for a taxi

Things to do in the Day

Drop in meeting place to meet people

Local information about what's on

Do more things with people like me (LD)

Leisure Centre – sometimes need support to access

Support to access ordinary Sports Club

Go to a Night Club

Like to choose what I want to do

Some college courses good – Towards Independence – Health and Safety (Portsmouth)

Like to do cooking course – meals for one or two as I live on my own

Town centre under cover so don't get wet (Basingstoke)

Paid work not always voluntary work

Go out and make new friends

More evening activities

Make friends with someone to go to cinema/bowling with (Befriending scheme)

Support to go to “mainstream” college course – Art, Flower Arranging etc.

Supported Living

Choose who I live with

Would like to move out

Be able to cook with my house mates

Have people in for a meal

Need support when I need it, as cannot go out when I want to if other people in house do not want to go out as well

My Community Key Issues

Housing

- Some people like where they live
- Very few had a choice of where they live
- Want to move from living with my family – waiting and waiting
- Would like to buy my own house, instead of living in a flat on an estate
- Live in place where there are no buses in the evenings would like to move

Question to Panel

Why can't we have a choice of where we live and who we live with?

Transport

- Bus passes – some areas restricted cannot use before 9.30am so have to pay to get to college
- Buses don't have numbers on the side, so not sure if I am on correct bus
- I can go free but my support worker has to pay to come back if we go outside the district
- Buses not enough in rural areas and in the evenings
- No voluntary community transport in some places after 5pm
- Taxis are expensive – some areas give tokens to help with cost but not everywhere

Question to Panel

Why do different areas have different rules? – it should be the same no matter where I live in Hampshire

What I do in the day

- Work – not enough paid work (Southampton only)
- In same voluntary work for years – no move on or training

Question to Panel

When will I be able to have a paid job?

What I do in the day

- Sports Clubs – expensive not always accessible
- Cinemas/Theatre do not have accessible programmes - do not know what is on, so don't go

Question to Panel

Community mainstream providers need to produce their information in a format I can read/understand – I could be a good customer – When will this happen?

What is Good

- Groups – need more and to be able to get to them cheaply and easily
- Drop in café in local community- be same as everyone else – meet friends, but not everywhere

Question to Panel

When will the same services be available everywhere in Hampshire?

What is not so good – lack of support to do the things I want to do

- Supported living – not enough support when I want it, no choice and cannot go out late – bed by 9pm
- Living with Mum and Dad - can I get support to do things without Mum and Dad

Question to Panel

Just because I need support to do things in my community I either do not get support or not enough support or when I want it. When will I be in control of my life?

Other Things

- Night Club – been once, but need support - cost to pay for support – can we have one just for people like us?
- Leisure Centres need to be more welcoming to us with understanding staff – special sessions to begin with
- Bus Drivers – some are helpful but some need some training – we could do this
- Bus numbers need to be on the side of bus as well as on the front; would also help older people or people with some sight loss
- Not enough to do in the evening - especially living out of towns, as not evening/weekend transport
- Some community things still not accessible – e.g. snooker club upstairs
- Bus timetables not easy to understand
- Information – easy read for all services



The Support We Want – Connect Advocacy

We wanted to look at the difference between Person Centred approaches and a non Person Centred approach. Also, does having a Person Centred Plan make a difference to the support we get?

So how did we do this?



Our role play was a group of people living in a residential home. It was their shopping day but due to staff sickness there was an agency worker supporting residents to do this. Four Self Advocates used their own experiences of being supported to go shopping in the role play.

Act 1

The home manager informed the agency staff member that shopping had to be done with all individuals today. The manager gave people no choice and directed them to get shoes and coats because they would all be going to Tesco to do shopping. Each person tried to say where they wanted to shop, but this was not listened to.



Act 2

The home manager told the agency staff member that people wanted to go shopping and everyone wanted different things. The home manager said people have their own Person Centred Plan that say how they like to be supported with their shopping. The support worker asked permission to read the Person Centred Plans regarding shopping preferences so she would know how best to support each person. Each individual was given a choice of shop and time they wanted to go.



The Self Advocates taking part in the workshop recognised the difference between the acts. The group then talked about their own experiences.

The group also talked about support they want and the support they didn't want. People said how support staff can be person centred.

Want We Want

Freedom

**Friendly
staff**

Independence

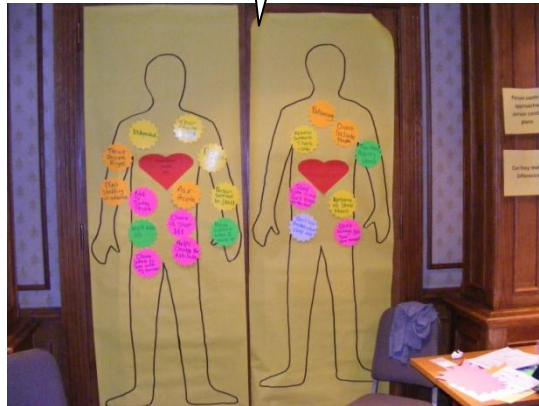
**Pleasant staff
who talk to
people**

Be polite

Patience

**Respect
us**

**Not to judge
people**



**Help to
change the
attitude**

**Person
Centred
staff**

**Always
someone
there**

**Work
with**

Choice

**Allow people
to give own
opinions**

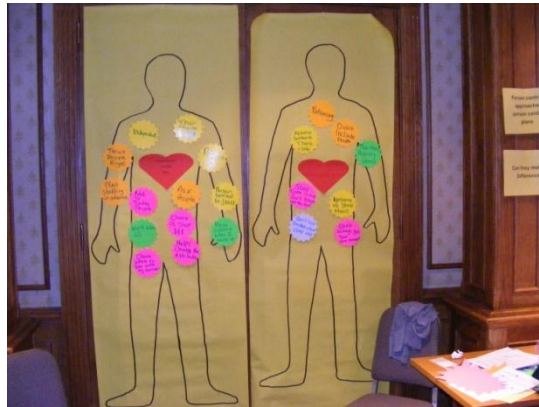
**Have support
in advance**

What We Don't Want

**Nuisance of
staff hours –
can't stay out
until 10pm**

**Can't always
get your care
manager**

**Staff who
speak with an
aggressive
attitude**



**To have
limited or
no choice**

**It's our home –
we should do
what we want**



The group thought about the questions they would like to ask the question time panel in the afternoon.

The questions people wanted to ask were:

Do you include people who use your services on interview panels?

We know staff want to get it right! We want to help them.

What experience have you got?

Are you paid too much?

What training do staff get? – To work with us

We would like all our support to be trained in Person Centred approaches. How can this happen?

Can we choose the people who support us? – participating in interviews

Is there funding for Person Centred planning?



Lunch

Good food and lots of getting together with other Hampshire Self Advocates to talk about what's happening locally for them.





Question Time

Thank you to all the people who joined the panel to answer questions from the workshops.



Danny Barker from In Touch, Jo Pointer from the Valuing People Team, Councillor Felicity Hindson, Charles Hodgson (Chair), Jo Hooper from Hampshire NHS, Dr. Kevin O`Shea from Hampshire Partnership Trust and Lucy Butler from Hampshire County Council Adult Services.

The panel members all listened and gave answers about how the services they represent are working to make what they do person centred and what people want.

“ I thought in the Question Time the panel answered our questions and they were good things they said,” Self Advocate.

Music and dancing to end the day.



Music by Firestone Rock Band got people dancing and celebrating the end of a day sharing ideas and issues.



Thank you

The Self Advocacy Day could not have taken place with the help and work given by many people.

- The planning group
- The Self Advocacy group members leading workshops
- The Question Time panel members
- The invited guests who shared the day
- The team at the Hilton Hotel for their first class service
- The LIGS helping to pay for the day
- FRB for their music www.firestonerockband.com

What people said about the day?

Evaluation sheets were handed out at the end of the day. We asked people what was good, OK and not so good.



The hotel 95% said



Good



Health workshop 85% said



Community workshop 100%



Support workshop 95% said





Question Time 95% said



100% of people said

“ We want to meet like this again”

People who came to the day also said:

“The people that served us were fantastic. I would like to go back there next year,” Self Advocate.

“I liked acting about staff working with me to do things I want. Staff often can` t help me when I want,” Self Advocate.

“I live with my family and sometimes I need help to tell them things,” Self Advocate.

“It was interesting. People are having trouble using buses because certain buses don` t show up and some people can` t get on the bus with their bus passes. I hope they can settle this problem,” Self Advocate.

“I think it was really good. People understood the acting about staff and a lot of people did speak out,” Self Advocate.

“I want to send you many congratulations on organising such a very successful event and my warmest thanks for including me and making me so welcome,” Councillor Felicity Hindson.

“ It was great to see so many advocacy organisations working together,” Jo Pointer.

“ A fantastic day”, Lucy Butler

Contact Self Advocates

Everybody said how great it was to get together to let everyone know what they have to say. If you want to find out more about what people with learning disabilities think or would like to join a local self advocacy group, please get in touch.

Andover Advocacy Alliance	01264 336380
Choices Advocacy	02380 337735
Connect Advocacy	01329 848649
East Hampshire Advocacy	01730 233345
Eastleigh Advocacy	02380 363304
Just Advocacy	01252 322204
Speakeasy Advocacy	01256 328080
Winchester Advocacy	01962848023
Winchester Mencap	01962 848074

HARG

02380 715679