Development & Implementation Team

Carers' Conference

Conference Report

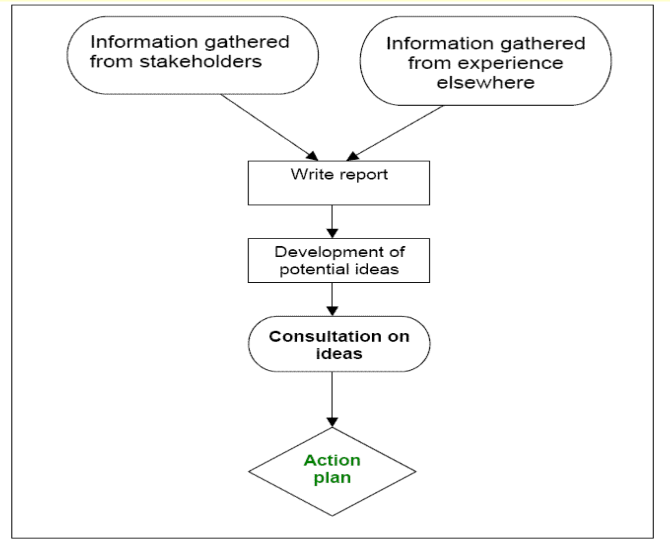
85 people attended the Carers' Conference on 8th February at Winchester House. Bill McKenzie and Councillor Cousins opened the event and welcomed everyone.

Sarah Mitchell (Director of Community Services) provided an overview of national policy and changes locally – she talked about how the council are going to work much closer together with health services. This will involve having shared 'back office' services, like Human Resources. This will mean a more efficient partnership

Julie Stevens from Wokingham talked about how they had developed their services. In summary, Wokingham District Council is selling their current Day Centre site (WROC). The reason they have opted for this is that the site is in a highly valued residential area. The money from the sale has funded a new purpose built community centre. The centre will be open access, with a café and rooms for community groups to hire. The process from consultation to build has taken nearly 7 years. In addition to this new build Wokingham are using two outreach centres in local communities. In Early Wokingham District Council have booked a room in the new community centre every day 9am – 5pm. The room varies depending on the activity and other bookings. Staff and service users were asked to volunteer to try out the Early centre. WROC kept open places for all the volunteers (both staff and service users) back at WROC during the pilot phase. This has successful taken off and staff and service users are happy with the new project with only one person opting to move back to WROC. They are looking at establishing a second community venue, however this is slower to get off the ground as they are trying to source a suitably accessible venue within a community setting, in partnership with local community groups.

Julie outlined the importance for people to get involved in the consultation and remain involved through the process. In Wokingham the only people now involved in the final stages of the build are those that are unhappy.

Laura Timms the Learning Disability Modernisation Coordinator briefly talked about what is happening on the Isle of Wight in terms of developing services. The process is:



Currently there have been three questionnaires developed and sent out to: Carers' of adults, Carers' of young people in transition and Staff. In addition consultation has been undertaken at St Georges school with the young people in transitions, in a pictorial format. The Carers' conference workshops are picking up on issues that have come out of the consultation and will also feed into the development of services. A group of service users are deciding on the format of consultation with adults who have a learning disability. Each centre has been asked to nominate or elect a representative, there are currently 5 service users on the group, there is a space for a non-service user and a service user from Riverside. The group have decided on the format of the consultation which will be a pictorial format facilitated by group members alongside the Advocacy Trust and small group discussions facilitated by Laura Timms.

The other work that Laura has been involved in is Benchmarking current services (using the Valuing People toolkit), running Drop in sessions at day centres, collating information from other places and is looking at modernisation agenda alongside In Control programme development.

From the Carers' questionnaire the following issues were raised in response to the question: What is the most important thing for us to remember when considering changes?

1) The needs of the individual
2) The difficulties of change
3) The needs of the family
4) Other – including communication, flexibility, diversity etc.

Martin Johnson talked about the new form of funding – In Control, which means people have an individual budget. **The presentation is attached as a separate document.**

Caroline Tomlinson talked about her experience of In Control with Joe her son who has an individual budget. Attached is a copy of her story, from the In Control website – www.in-control.org.

Joe's Story

Our first child, **Joseph Robert Tomlinson**, was born in October 1988.

Like many families we started to make the huge adjustments needed with the demands that such a small person brings. Our life was ordinary until 6 months later when Joseph contracted meningococcal meningitis.

To cut a long story short, after numerous assessments and examinations it was evident that Joseph had severe developmental delay and we entered a world we never knew existed - **Service Land**.

And so our journey changed. We were suddenly parachuted into a very strange and scary place. In this world of Service Land lots of other people became involved in our daily lives, constantly making recommendations to do this or do that. And all the time we seemed to have to ask for permission just to live an ordinary life.

But our life was certainly not ordinary. To function as a family we needed lots of support from other people, especially when Joseph's sister Rosie and his brother Jacob were born. Joseph, you see, finds it really difficult to sit still. He doesn't use words to communicate and his body doesn't always do the things he wants it to. In fact many people have said he is "extremely challenging."

So, as a family, we have needed help. But the help we received was what I call **conveyor belt**

care. This means that services put in help at the most crucial parts of the day based on their assessment of our needs. For example, home care was provided by the Local Authority to come into the home and assist with getting Joe bathed, dressed and eating his breakfast. Then there was more help again at tea time.

At first it worked okay. But as the service increased because of Joe's support needs we needed two people to assist him. In the end it began to feel that we were being invaded every morning and every tea time by an army of home care assistants. Due to rotas, rest days and everything else, the number of different people coming through our door had gone from two to over 40 in six months. This was totally unacceptable for Joe and very intrusive for us as a family. But all the time we felt that we had to be eternally grateful for the 'gift' of professional services – services that didn't really work.

Not only did Joe's home care not work but he was also being sent to a school that was over an hour's drive away. Joe wasn't happy there and his connection with his community was getting weaker by the day. And it was all at a phenomenal cost to the Education Department. Joseph didn't need specialist out of borough support. He just needed people to listen to what he was trying to say in his own unique way.

So when we heard about **in Control** we jumped at the chance of being involved. We had felt over the years that we were passive recipients of a service system that intruded in our lives and confused Joe. What he really needed was a person-centred approach to his support. In other words it was designed for Joe, by Joe - and the people who knew him best. He also needed to be recognised as an equal citizen, someone with rights who was entitled to his own life, someone who was prepared to take on some responsibilities too.

We started to help ourselves by organising a **circle of friends** for Joe. Basically the circle consisted of people who loved and cared about Joe and other people who were paid to be in his life. The social worker also came and used its meetings as a starting point for his assessment. At the circle meeting we discussed Joe's dreams and visions for the future, what his skills and gifts were, a step-by-step approach to how he was going to get there and who we needed to involve.

The social worker used the assessment to give Joe an allocation of money from Social Services and we considered a number of the other funding streams that might be available to Joe. In short we applied for funding from the Independent Living Fund and we maximised Joe's benefits. It is essential that the individual maximises their benefits, because, in order to get a life, you need money to spend – a disposable income.

This first phase of money enabled Joe to employ four Personal Assistants who work on a rotational basis and enable Joe to access ordinary social and leisure opportunities. (We need four because he needs two people at any one time to support him).

He now attends a gym, goes on the treadmill and swims in the pool. So he uses an ordinary facility, meets new people, has some important exercise which helps him to sleep. We get an excellent package from the local gym, Total Fitness - they allow any of his PAs to go with him. He visits a lot of the National Trust Parks as he is interested in history and likes to walk round the gardens. He loves fairs and fast rides. So Alton Towers is a great favourite, as well as Blackpool. He also likes to ride his bike, which is a specialised tandem. His PAs need the right range of skills to support him in his varied life style and we also need the flexibility from the PAs so that if we go away for a weekend the PAs can carry on working together as a team and can stop over at our house to support Joe round the clock.

The management for the staff works relatively easily. I do a monthly rota, the PAs fill in time sheets and they get paid on a monthly basis. I have a local company of accountants doing the PAYE and it all works quite smoothly. We have insurance for the PAs and have to deal with any staff management issues, which so far has worked fine for us all. Over the past few weeks we have started to break down the funding within the education system and have enabled Joe to attend the local college. We have considered how he can be in control of all of his week.

So, what do things look like now?

He goes to college 4 days a week funded by the Learning and Skills Council. He has his own PAs working with him within the college, and they are now paid by the college for this element of their work.

No more taxis and escorts to get to college. Instead, he catches the bus like other young people. His PA's come to the house and support him from here to college. The walk to and from the bus stops sets him up for a calmer day in college. This is funded by the LEA.

After college he goes on to the gym which is funded from his original social and leisure resource allocation from ILF and SSD.

On his fifth day - when he's not in college - he does voluntary work. This has only just started and we are trying out a few different things. The support for this is currently being paid for by the LEA until Social Services do a reassessment.

His weekends and evenings are the same as they were and support is paid for by ILF and SSD.

It sounds complicated but in the whole scheme of things it isn't. In comparison to the difficulties around the support in our lives before Joe was in control, it is so much better for the whole family. Joe has consistency with the people supporting him through his whole week - people he has chosen. The support is flexible and works around what Joe needs to do. So if he has a dental appointment he just fits it into his life – like the rest of us - instead of his Dad or I having to take a half day off work to travel over an hour each way to pick him up! There are also many times when Joe doesn't have paid support and we are really happy as a family to support him at this time. This is so much easier than before because he has been active and has had a fulfilling day.

So, how will it move on in the future? We are setting up a trust as Joe turns 18 and the trust will manage the staff team and will have the legal responsibility for managing the finances. The trust will be people who love and care about Joe, and it will be developed so it is sustainable, as we, his parents, get older.

After all I never wanted to be his care manager, his accountant or his director of services. All I ever wanted to be is Joe's mum, doing things that mums do for their growing children – like doing the washing! Bring it on!

Afternoon workshops:

The afternoon workshops focused on issues carers' had raised in their questionnaires – developing services, drop-ins, respite, holidays, transport, carer support etc. Attached are the notes from those sessions, with ideas about how developments should be made and bullet points of the discussions held.

In Control Workshop – issues / discussion points (Martin Johnson, Caroline Tomlinson and Elizabeth Martin)

Questions

- *Can we afford this?*
  There is no extra money available, and not everyone will get loads of cash! We need to change the system

- *Who will get an individual budget?*
  The council will be asking for volunteers, people wont be forced onto one, we also need councillor support to make it happen on a wider scale

- *What if Government changes in 5 years time?*
  The eligibility Criteria will still be there.

- *How would it apply to a person in Residential Care?*
  With and IB you may choose to live in Residential after your assessment, you may have change to buy other support. You cannot have a Direct Payment in residential care yet.

- *Will people move out of Residential?*
  If the care package is sufficient to enable that and they want too, it's their choice.

- *When will it start?*
  Pilot group is happening with young people in transition, also been undertaking some mapping work on one care managers' caseload.

- *Do you think everyone will need a broker?*
  Cautious due to brokerage issues need to be reliable.

- *Where do you find trained people?*
  Money fuels the market - people need to have the right support skills, carer recruitment can be flexible. People need help to manage the budget

- *Are your points static?*
  You still have an annual review – if needs change you are entitled to a review.

- *Who has the money?*
  The budget is the individuals to spend, so the Council has to give up control.

Examples:

- One young man from West Sussex saved his IB (by reducing his care) to enable him to purchase a house.

- Look at Gavin from Oldham's story on the In Control website.

- A family in Wigan were getting respite more and more. They got an IB and when the family bought caravan, the individual with an IB paid site fees and stayed there with carers.

Issues:

- Shortage of respite care.

- Need to look at the needs of older people who have Learning Disabilities.

- The move from current Day Care arrangements to Individual budgets will involve a long transition period, the council is looking at recommissioning. Day care services will need to look at their provision, how it can be individually purchased and how it fits with In Control – Laura is working on this. In Woking, they have drop-in's, people decide on the day as to what they want to do. Mencap have developed a costed menu. The cost per unit of day services is £33 per half day and £66 per full day, people may opt to use this money in leisure facilities instead.

- Older Carers may need more help to do this, and some felt scared.

- Fix what needs fixing not everything

- We must have choices – things to do and buy that people want

Workshop – Ideal Services / Drop In (Jan Gavin)

Staff / care.

- Let people with learning disabilities choose their own carers
- More staff, more 1:1
- Medina centre – choose their own keyworkers – great idea.

Transport

- Social transport
- Leisure transport – more of it!
- Own minibuses
- More drivers and escorts
- Minibuses are available – handicentre, riverside centre
- Need a central pool of volunteer drivers
- Regional development – more outreach day opportunities
- Some regional activities to minimise the need for transport
- Could we share current facilities – Carisbrooke high school, Sandown high
- Finding opportunities with areas i.e. freshwater. Small regional facilities
- Less travel and waiting time required

Drop in Centre

- Should be open 8am – 10pm everyday
- In towns / churches
- Could extend John's club
- Should cover the whole island
- No new build
- More than one centre needed, in different locations
- Nowhere to go between St Georges and sports training at 5pm at Carisbrooke high school – drop in centre could provide this
- Could citizen's advice be used?
- Vary the venue.

Sports

- Purpose built facility on IOW?
- Finding coaches is an issue
- Need to find volunteers to support people who have learning disabilities
- Education of students
- Could tap into Millennium volunteers / student volunteers

- Run taster days / weeks
- Use existing sports facilities
- Educate the coaches
- More clubs arranged to use existing provisions and transport – special Olympics does this and is excellent
- Make sure special needs are encouraged with their sports and put on their Olympics
- Educating the next generation to accept people who have learning disabilities
- Make best use of available resources
- Should promote health
- Performing arts, keep fit classes, use IOW college

Holidays

- Could there be a younger age range e.g. 18 – 25
- Not too expensive, not too far away or not necessarily with mum + dad!

Socialisation

- Not too expensive
- More facilities for young people
- Centred on people – all people
- Paid staff to help
- Brokers
- Information sharing
- Volunteers (including young people with learning disabilities volunteering)
- Raising awareness and sharing skills

Other ideas!

- Housing adaptations for living accommodation
- More facilities for HSN to do what they want
- Get people with learning disabilities involved in chamber of commerce
- Involvement of rotary clubs, round table, we are all part of total community

Workshop – Dream service / Drop In (Pat Ready)

What's working:

- Services can and do respond to needs
- Wealth of talent ready to provide new things
- People are learning new things
- Giving her an opportunity to mix with her peers
- Meadowbrook - deals with behaviour problems

What's not working:

People's thoughts	Discussion on what might help deal

	Attitudes need to change in community
Emergency cover during statutory breaks for carers	Need info on emergency help (practical things e.g. hoist repair) to be in directory
Government policy – no joined up thinking	
College – too many courses repeated each year, little change	IB will show demand Learning aims must be meaningful an achievable (more realistic in day service)
College - not individually tailored to persons needs, people with greater ability are more valued that those with less ability	IB will show demand Learning aims must be meaningful an achievable (more realistic in day service)

Dream Service:

People who should be trained and experienced, are as important as physical accessibility.

If in building, there needs to be lots of interaction with the general public.

All young people will want to do voluntary work as part of their learning.

Not a group apart, but a part of the community.

Maintain friendships all over island.

Flexibility in location.

Workshop – Respite / Carers Support (Sue Bennett)

This was a small group, where respite was discussed. The respite care offered through Westminster House is very good, appreciated by the parents and enjoyed by the service users who look forward to the monthly weekend stays as an opportunity to meet with friends. The downside is the inflexibility of the booking system for anything that is not an emergency and therefore the need for parents to plan their social lives at least 3 months in advance.

There was a long discussion about guilt - parents seem to find it difficult to have time for themselves, particularly to take holidays on their own if their sons/daughters are not also having a holiday experience. Holidays used to be organised by the Medina Centre and other groups but this apparently no longer happens. Carers were not aware of the range of support available to them such as advice on benefits, accessing alternative therapies and the Carers Emergency Alert Card.

There was a discussion about the fact that the carer support service through Two Counties was suspended when the care worker went on holiday.

Closing comments:

The workshop feedback was summarised. Thanks were extended to everyone who had helped in planning, brought a stall for the showcase over lunchtime, spoken or facilitated workshops.

At the Carers' Forum and the Learning Disability Partnership Board an action plan will be discussed.

On The LDPB website you can download the what next folder for carers' which has information in that people highlighted through the day would be useful. www.iwight.com/council/ldpb/

If you have any comments about the day or would like to suggest topics for future forums and meetings, please contact either Bill McKenzie (Tel: 752764), Chair of Carers' Forum. The next Carers' Forums are on 19th March, 21st May, 16th July all from 12 – 2pm at the Riverside Centre.