



“Moving On Together”

Learning Disabilities Forum

FORUM REPORT

V.1 5/11/06

DOCUMENT DESCRIPTION

The purpose of this document is to provide a summary report of the findings and recommendations of a learning disability forum held at The Riverside Centre, East Suffolk, on the Saturday morning of October 28th, 2006. The forum involved wide range of key local stakeholders with the aim to discuss and agree a programme of local action to help improve local solutions for people with learning difficulties and disabilities - against a back drop of a modernisation plan being overshadowed by significant county council budget, staff and service cuts.

1

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INDEX

FORUM ATTENDEES.....	3
APOLOGIES	3
BACKGROUND	3
FORUM AIMS	4
FORUM AGENDA	4
FORUM FRAMEWORK.....	4
DISCUSSION FINDINGS.....	6
RECOMMENDATIONS & WAY FORWARD	7
APPENDIX A: PARTICIPANTS	9
APPENDIX B: FACILITATOR.....	9
APPENDIX C: FORUM EVALUATION & FEEDBACK	10

Forum Attendees

25 participants attended the “Moving on Together” event, held at The Riverside Centre, East Suffolk, on the Saturday morning of October 28th, 2006, and they comprised:

- users of learning disability services,
- parent carers,
- relatives,
- statutory bodies,
- charities,
- private companies and
- social enterprises.

In addition, several organisations (Suffolk Carers, MENCAP & ACE) took the opportunity, free of charge, to promote themselves and their services at this event, including exhibition displays. Others handed out literature eg Get a Life!

A full list of attendees can be found the appendices, along with a pen-picture of Don Tricker, who acted as the facilitator.

The event was sponsored by PASTEL (Personal Development) Ltd.

Apologies

- Young Parent/Carers (prefer mid-week timing when sons/daughters are at school)
- Connexions
- JobCentrePlus

Background

This parent/carer driven event was for involved individuals and organisations - to improve local services for people with learning difficulties and disabilities living in rural East Suffolk.

The event was designed to address:

- confusion about all the talk of “more choices”, “parent involvement”, “person-centred planning” combined with Suffolk County Council’s reorganisation, “culture change” and major budget, staff and service cuts.

- the opportunity to meet with other local parent/carers/service users and with potential suppliers, to help investigate and develop more immediate local solutions.

Forum Aims

1. to exchange experiences and support each other with practical advice.
2. to explore and develop improved/new service solutions
3. to agree a programme of local action to help improve local solutions.

Forum Agenda

- 9.30 - 10.00 Registration (Coffee/Tea)
- 10.00 - 10.15 Welcome/Introduction – Don Tricker
- 10.15 - 10.45 Suffolk County Council Speaker - Anita Cameron
- 10.45 - 11.15 Questions & Answers
- 11.15 - 11.45 Discussion Groups (Coffee/ Tea)
- 11.45 - 12.15 Feedback from Discussion Groups
- 12.15 - 12.45 Agree Way Forward
- 12.45 - 13.00 Summary/Close – Don Tricker
- 13.00 - 13.30 Informal Chats

Forum Framework

Following introductions, the facilitator, Don Tricker, explained that the forum was loosely structured to allow interaction and adaptation to circumstances rather than a prescribed approach with formal presentations. The approach was to be informal with no “us” and “them”. There was no staging or use of technology – just face-to-face dialogue.

The event was not for a general moan and groan. If people wanted to complain about Suffolk County Council budget and service cuts they should contact their local elected county councillors

– their elected representatives, who were the decision-makers on policy, strategies and budget allocations, relating to the delivery (or not) of local services.

It was pointed out that both major political parties had spoken recently about transforming the culture of government from controlling to enabling and from directing to empowering. The question was being asked about not just what government can do, but what society can do - individuals, families, businesses, social enterprises and community organisations. This approach was being followed through to local government and local communities.

Major changes were underway locally as a result of Government policy and Suffolk County Council plans and financial issues.

This forum was an opportunity to better understand the statutory imperatives and the local needs and wants, combined with the challenge to explore the potential for working together locally to improve or provide new services to serve local people with learning difficulties and disabilities, and their parent/carers.

Anita Cameron, Assistant Director, Suffolk County Council's Adult Community Services then went on to speak on three major areas of the "modernisation" programme, Suffolk County Councils budgetary position and the newer forms of funding services for individuals.

Firstly, on a positive note, changes to local services were coming about following "The Children Act 2004 the programme Every Child Matters: Change for Children - aimed at transforming children's services , the Government's White Paper on adult services for people with learning disabilities Valuing People, and on the future direction of health and social care Our Health, Our Care, Our say. This was leading the development of "person-centred" plans giving greater individual choice and control of the services they and their parent/carer would like to see. This would place less reliance on placing individuals in "Day Centres" and see them more in the community joining in with others, as appropriate. A local consultation has taken place on these ideas and a wide range of views and ideas were expressed. This has led to the setting up of 12 Area Development Panels that include people with learning disabilities and family carers, and key partners. The panels will be informed about local resources and will be tasked with coming up with recommendations for local developments, and how best to use resources in that location.

However, secondly, these moves were somewhat overshadowed by the county's need to keep within the funds allocated by the government. This has meant that the County Council has had to introduce a savings programme, including some reductions in budgets for services. It is therefore important to make sure, through the Area Panels, that we are making the best use of the resources we have.

And finally, in order to further control and choice for service users, new funding approaches were being introduced eg Direct Payments and individual budgets.

NB: The Saxmundham Area Panel covers the parishes of:

Aldeburgh
Earl Soham
Framlingham
Fressingfield

Hacheston
Hoxne
Leiston
Peasenhall
Saxmundham
Snape
Stradbroke & Laxfield
Walberswiick & Wenhaston
Wickham Market
Worlingworth
Yoxford

There are three neighbouring area development panels for Beccles & Bungay, Stowmarket and Woodbridge.

Discussion Findings

The participants were then divided into 4 teams, working at separate tables, to discuss and agree possible solutions to the 5 following issues:

1. Local needs of service users & parent/carers
2. Local services that existed that were good
3. Local services that existed that were poor
4. Services that did not exist in the area
In order to come up with
5. Suggestions for local individuals/organisations to work together to improve local service offerings.

The teams reported back in a plenary session and the following was noted:

The groups had no shortage of things to talk about and became quite animated. In the 30 minutes permitted the 4 groups had, not unexpectedly, been drawn down different paths and had not all covered all the points which, in fairness, would need more time to explore fully. However, while individual comments were noted there was also a general consensus on the way forward.

Some of the individual comments related to:

- The need for a wider choice of available service user training/leisure/sports options
- The need to cut down the need to travel across/out of county for facilities
- Encourage rural satellite operations of Ipswich options (eg CSV Media, Papworth training)
- The need for a local user befriending scheme.
- Woodbridge Packaging/A12 Packing services work well, but there was a need for more choice of work, including working outside/meeting general public.
- The need for better transition advice/guidance. The new transition teams had not delivered yet.

Existing Service User resources/ facilities noted were:

- Saxmundham Resource Centre (SCC)
- A12 Industries (SCC)
- Lincoln Avenue Respite (SCC)
- The Library (SCC)
- LearningThroughLeisure (charity)
- PASTEL (social enterprise)
- The Willows/MIND (charity)
- Workers Education Association (charity)
- Causeway
- Mingle Club
- WRVS
- The Salvation Army
- “Wardens” (Sizewell)
- The Cut - Halesworth (charity)

General

- It was noted that there were “pockets of good things going on” but they all existed in isolation of one another. There is no co-ordination of a coherent package being promoted.
- Let service users decide what they’d like to do / how they want to socialise
- Feeling that Younger Parent/Carers were generally unaware/ not focussed on the tougher realities coming to them when their sons/daughters became Adult Service Users.
- More/Wider choice of respite care options.
- More/Wider choice of living accommodation for future adult service users.
- More/Wider choice of community transport for service users (vital in rural area!)

Recommendations & Way Forward

There were 4 “big” ideas to build on the “Moving on Together” forum.

1. **Form local service user/parent/carer support groups** (to map onto 12 SCC panel areas) – a local geographical gathering of carers and service users of all ages and perspectives - informal social meetings over coffee to share knowledge, experiences and suggestions for self help/advice, one-to-one support, social interaction, friendship groups. These would be independent and driven by carers/users. They could be financially supported eg venue fees/refreshments by related organisations eg Suffolk County Council and/or MENCAP and/or Suffolk Carers. Professional/related Organisation speakers by invitation.
2. **Conduct a mapping audit of local carers & users with local facilities & services.** This could be executed in conjunction with SCC.

3. **Encourage more consolidated/accessible support information/advice service** – feast or famine – one umbrella website with powerful search engine eg an improved/enhanced Suffolk County Council “Infolink” - information – electronic/up-to-date, including advice/pointing service to specialist organisations/websites.
4. **Investigate possibility of creating an outdoor/ community inclusive user service** eg gardening service working in the community/ community café.

The first recommendation was the “biggest” which would also help drive/support the other three, as well as pick up on the other issues raised in this report.

It would now be for the carers/users who had attended the forum, or colleagues, to take the idea forward and liaise with other carers/users to fix another date/time/venue and sort the funding necessary (with SCC?) to proceed (£30 per 2-hour session with coffee/biscuits?).

Appendix A: Participants

- Judy Clark (O.T Technician, Learning Disabilities, S.M.H.P)
- Richard Griffiths (Parent/Carer)
- Ann Griffiths (Parent/Carer)
- Cathy Banks (Suffolk Family Carers)
- Phil Robbins (Parent/Carer/SCAMPS/SPCN/NAS)
- Ruth Bailey (ACE)
- Ann Griffiths (Grand Parent/Carer)
- Sharon Terry (MENCAP Suffolk day Services, Halesworth)
- Teresa Drake (MENCAP Community Development Officer)
- Paul Bailey (United Response)
- James Perks (Byways)
- Antoinette Tricker (Parent/Carer/PASTEL)
- Ann Alner (Parent/Carer/Friends of Sax Resource Centre)
- Julie Pasque (Parent/Carer)
- Craig Forman (Adult Community Learning Co-ordinator)
- Pat Mitchell (Parent/Carer)
- Joyce Mitchell (Parent/Carer)
- Karen Mitchell (LDD Service User)
- Tony Carr (Suffolk County Council, Adult & Community Services)
- Anita Cameron (Suffolk County Council, Adult & Community Services)
- Jane Cantwell (Suffolk County Council, Adult & Community Services)
- Linda Layton (Parent/Carer)
- Sara Layton (LDD Service User)

Appendix B: Facilitator

Don Tricker was the forum facilitator and is a:

- Parent/Carer
- Director of the social enterprise, PASTEL (Personal Development) Ltd
- Trustee of the registered charity The Friends of Saxmundham Centres for People with Learning Disabilities.
- Saxmundham Town Councillor
- Member of The Saxmundham & District Community Development Partnership management committee
- Member of the Leiston, Aldeburgh & Saxmundham Volunteer Centre management committee
- Member of the Suffolk Parent Carer Network management committee

In addition, before moving to Suffolk 3 years ago, Don had been commissioned as a business consultant by Surrey Business Link and Surrey LSC to carry out research projects and training seminars and workshops.

Appendix C: Forum Evaluation & Feedback

Participants were handed a self-completion questionnaire to record their additional responses to the following 7 questions – shown here with the corresponding response totals:

Q.1) How interesting did you find this forum?

Very Interesting 9
Interesting 6
Not Interesting 0

Q.2 How useful did you find this forum?

Very Useful 7
Useful 7
Not Useful 0

Q.3 Do you feel you had adequate opportunity to ask questions, give feedback and offer advice/suggestions?

Yes 12
No 0
Not Sure 2

Q.4 Would you like to be invited to another forum in December/January?

Yes 12
No 0
Not Sure 3

Q.5 Would you be prepared to work with others to improve local services?

Yes 11
No 0
Not Sure 3

Q.6 Do you feel there is a need for a dedicated general Parent/Carer support group focussed on this area and for all ages and additional needs?

Yes 11
No 0
Not Sure 1

NB Not all forms were completed / recovered on the day. Not all questions were answered. Those who identified more with another area grouping eg Woodbridge did not answer some questions. However, all Parent/Carers responded and were very affirmative on all questions 1-6.

Q.7 Assuming that there is a demand for another Parent/Carer driven forum, do you have any comments, queries or suggestions to improve the next event?

This open-ended question yielded a wealth of responses – highlighting the frustration and confusion as well as putting forward positive ideas. The responses are presented here, unedited and in no particular order:

- Form 12 Carer Forums to map onto the 12 new local SCC panels.
- Organise a Parent/Carer forum during on a week day – daytime
- More information required for parents.
- Direct payments are not easy to access.
- Need information on independent supported living
- Valuable contacts made at this forum. Thank you.
- A directory of local organised groups would be very useful
- More information about available resources.
- Prefer a week day for future meetings.
- Poor local service – no support workers to take service users to daytime events.
- No suitable residential care locally
- Good supplier (Papworth in Ipswich) but no transport/support to access it.
- Very happy to take part in any new local group to move forward local services.
- Ask the service users.
- Need to support local services.
- I think there is a real need for parent/carer forums
- I think 12 locality forums are a good way of taking these issues forward.
- I am happy to meet in this forum.

- Suffolk County Council is needing to consult with parent/carers and service users.
- Could there be a targetted follow up event in late November/early December linked to the local panel discussion?
- I think there is real value in a regular parent/carer forum – especially a joined up group representing younger and older people and linking this on a regular basis to statutory organisations.
- Need separate parent/carer and service users groups?
- How about a skilled “mini-day” service to enable parent/carers to attend a meeting while the son/daughter is professionally supported in a meaningful activity at the same venue?
- Support for parents with learning difficulties is only currently available in Ipswich. There needs to be centres in other areas.
- More information for those who move into the area or parents of children in transition ie services that are available 9 booklet? Website?)
- More choice of living accommodation – some need more support to remain independent, some need community homes near to their families.
- More day care services, such as Papworth Trust, with supported education.
- Work need in other areas as well as Ipswich.
- Respite should be available in all areas.
- Poor service – Other than PASTEL there is no organised leisure facility for SLD children in this area. Leisure schemes should be spread across the county not just in larger towns.
- Guest speakers on Housing, Direct Payments, Rights of Disabled Adults.
- I would prefer the idea to share ideas and concerns with other Carers for say 1 hour.
- What about a teenage/transition club for 14-25 year olds?
- Is there still a Link Carer scheme to, say, take a child/adult swimming, shopping, cinema etc.?
- PC plans very slow service.
- New transition social worker not very effective.