MINUTES OF CARERS FORUM MEETING MONDAY, 21 MAY 2007 RIVERSIDE CENTRE

PRESENT:

Sarah Talbert – Parent/Carer Barbara Eglinton – Parent/Carer Bill and Rose McKenzie - Parent/Carer Paul Smith - OSEL Enterprises Chris James – Transport Services, Isle of Wight Council Elizabeth Sturton - Parent/Carer Ed Dench - Parent/Carer Judith Gentry – Parent/Carer Debbie Michalski – MENCAP Pathways Bob Marks – Isle of Wight Primary Care Trust Jo Wills - Mother/Carer Christine Law - Parent/Carer Jenny Mundell – Sister/Carer Marie Hodge – Mother/Carer Daron Perkins – Team Manager – Adult Learning Disability Team Tina Snow – Operational Support Assistant (Minutes)

Daron opened the meeting by welcoming both Paul Smith from OSEL and Debbie Michalski from MENCAP Pathway who will be undertaking presentations around employment issues.

Any specific queries around Permitted Work should be addressed through Jan Taylor, the No Barriers Co-ordinator, who can be contacted at Ryde Social Services Centre on 566011.

MATTERS ARISING FROM THE PREVIOUS MINUTES:

It was noted that the questionnaires were not included with the minutes. Daron apologised and said he would send these out.

Barbara Eglinton raised concerns that a private meeting had been arranged with Lena Paterson from Quay Advocacy and that a young man on work experience had been present. Daron agreed to discuss this with Lena.

All carers raised concerns re the shortage of speech and language therapists.

Barbara Eglinton raised concerns regarding the wording of the Disability Transport Pass and that the word "Disabled" was very negative and damaging for some service users.

The Carers Conference has funding for another conference next year and will be reviewing progress between February 07 and 2008. Bill McKenzie felt that

the Day Service Modernisation Agenda should be incorporated into the conference.

Bill will feedback at the next meeting about the conference.

Parents felt that the hydrotherapy service should be centralised in one area. Bob said hydrotherapy will be a starting point at tomorrow's meeting and he will address this with Laura Timms.

CHRIS JAMES – ISLE OF WIGHT COUNCIL TRANSPORT OFFICER:

Chris said that the mapping exercise is progressing very well. He has had difficulty in identifying funding for escorts, but now has a strategy to present to Social Services.

Chris has spoken to the Public Transport Department and it is not thought to be financially viable to recall cards as this would take months and in April 2008, the National Scheme for England for free travel will be implemented. The new travel pass would have a different logo and be in smart card format and will not have any negative wording. It will identify whether a person has a disability by means of a stripe on the back of it.

Daron will discuss with Andy Morris amending individual cards where this is currently causing difficulties.

ACCESS TO HEALTHCARE GROUP:

Bob summarised the Access to Healthcare Group. This has been running for three or four years looking at inequality of healthcare provision for people with a learning disability. It was acknowledged that some people are not receiving the right level of pain relief.

Many health professionals do not have sufficient understanding of communication issues relating to people with a learning disability. MENCAP are running a campaign called 'Treat Me Right' which is addressing healthcare issues and suggesting how things could be improved.

'Treat Me Right on the Isle of Wight' has been presented to GP practices on the Island. A leaflet has been sent to every department and clinic.

'Death by Indifference' states that things have not changed quickly enough. Bob left copies of this document for people to review. 'Death by Indifference' can be downloaded from the MENCAP web site. An easy read version is available.

There is a National Enquiry regarding the death of six people with a learning disability questioning whether they would have received a better service if they had not had a learning disability.

It was acknowledged that all carers are always advocating for people with a learning disability. Bob said we needed to look at this report and look at our own NHS on the Island and check that staff training is being carried out.

All present to look at report and feedback at next meeting. It was felt that the Mental Incapacity Act would probably help in some situations. All are welcome to future Access to Healthcare meetings at St Mary's Hospital, which is an open meeting.

If there are issues re individual healthcare, these to be addressed through the complaints system.

Health Action Plans were developed on the Island through trained staff and carers. It identifies an individual's health needs and has a treatment plan. Health Action Plans explore general issues such as keeping people healthy through good diet and exercise.

'Valuing People' felt that people's health was generally quite poor and everyone should be offered a Health Action Plan.

If anyone requires a HAP, please contact the Arthur Webster Clinic who will be happy to circulate.

Bob will be discussing Health Action Plans in detail at the next meeting on Monday, 16 July.

Parents stated that unless they were very assertive, it was not possible to support their son/daughter on the hospital ward.

EMPLOYMENT:

Daron welcomed Paul Smith from OSEL and Debbie Michalski from MENCAP to the meeting.

MENCAP Pathway:

MENCAP Pathway are funded through the European Social Fund and help people gain employment. The Work Preparation Program runs between six and 13 weeks offering work experience and opportunities for paid employment. Job trainers will undertake regular visits to discuss issues with employees/employers. Each person will have a learning plan to identify goals. The Work Preparation Program is open from ages 18 to 65.

Anyone working 16 hours or over would come off benefits and receive Tax Credits.

Debbie said MENCAP will liaise with Job Centre Plus and work out each person's finances. They help people to build up confidence and motivation.

MENCAP have recently put together a menu of options for a group setting or on an individual basis. Cost will vary depending on level of support required. The topics which are covered include assertiveness, communication skills, travel training, creating a CV, helping people to decide what sort of job they want, looking at people's qualities and skills. 1:1 support would be charged at £16 an hour and funding would depend on individual care plans.

All referrals for MENCAP should be signposted through the Connexions Adviser. MENCAP circulated information sheets. Their contact number is 529461.

OSEL Enterprises

OSEL began in 1985. It was set up by the Isle of Wight Council to provide employment opportunities for people with a learning disability in 1997. OSEL are on contract with the Local Authority providing work placements. They also run Wight Crystal, a charity shop, and Sunnycrest Nurseries that provide work opportunities and help fund the organisation. OSEL also run a Workstep Program to help people gain employment in the community. OSEL start where the person is currently at and help to build upon people's skills in order to hopefully access work whilst acknowledging that some service users are unlikely to gain independent work or do not wish to do so. For these people they start with photography or art sessions or some form of voluntary work.

OSEL have a Consumer Forum meeting at the nursery regularly. They have 15 people who concentrate on the provision of social activities and unpaid work, 10 workers provide support with open and supported employment, Permitted Work and access to training opportunities.

OSEL are regularly inspected by the Adult Learning Inspectorate. They can be contacted on 867324.

Lee White mainly works with people who are not in paid employment.

Julie Sandford runs the Work Preparation Schemes. She can be contacted on 523000.

Wight Crystal employ people with disabilities and are providing the water for this year's Isle of Wight Festival.

OSEL hold regular meetings at the Isle of Wight College and liaise closely with St George's and Isle of Wight Council.

OSEL support people on a life-time journey.

No Barriers:

Daron apologised that Jan could not attend the meeting.

No Barriers are funded through Social Services and they have one full-time worker and two part-time workers. People are referred by Care Managers. No Barriers looks at individual situations and hopes to find voluntary or paid employment. No Barriers hope to get them involved in some activity of value to them with the potential of earning a living wage.

Social Services are trying to avoid placing people at day centres and are promoting people's independence giving them much greater presence in the community.

No Barriers currently supports 60 people and hopes to increase these numbers.

Barbara Eglinton circulated a magazine called "Progress" which is a valuable resource for those in transition.

AUTISM CONFERENCE:

A two-day conference was run by Tony Attwood, a noted national expert on autism, which was organised by Mike Vickers. Concern was expressed that the majority of carers were not aware of this conference. Daron advised that the conference was not organised by anyone within Adult Services and was poorly advertised and apologised for this fact.

ANY OTHER BUSINESS:

Mrs Eglinton requested that some research be undertaken as to how Autism affected siblings. Daron explained that whilst these meetings were a valuable opportunity for carers to raise issues that affected them it could not deal with individual concerns.

DATE OF NEXT MEETING:

Monday, 16 July. The subject for discussion will be "Leisure". The agenda will be set for the next two or three meetings.