

Overview and Scrutiny in Southend-on-Sea



Community Services Scrutiny Committee

“LEARNING DISABILITY SERVICES”

Final Report and Recommendations



July 2004

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FOREWORD

Early in the municipal year 2003/4, the Council's Community Services Scrutiny Committee decided to undertake a scrutiny on the subject of "Learning Disability Services." The over-arching aim of the study was to facilitate the consideration by Members of strategies for the development of learning disability services in Southend as they impact on:-

- The best use of resources currently invested in large learning disability day centres, to promote opportunities for choice and inclusion.
- The best use of resources currently tied into residential care homes which fail to meet national care standards or enhance opportunities for people to have the individual support they need.

We started the in-depth scrutiny project in November 2003, and the Committee held evidence-gathering sessions with key stakeholders in March and April 2004. We explored with them the nature of current provision and the changes needed to implement the requirements of the 2001 Valuing People White Paper for more appropriate housing and day care services. We were pleased to note that the Council is already taking a pro-active approach to these requirements and that there are a number of examples of good practice which will provide the foundation for the changes which are needed. However, much still needs to be done in a relatively short timescale. Accordingly the report makes seventeen recommendations aimed at developing learning disability services to meet the challenges of the 21st Century.

We would like to thank all those who have been involved in the in-depth scrutiny project, in particular those who took the time to attend meetings to give their evidence, and our colleagues on the Community Services Scrutiny Committee, together with the officer Project Team.



Councillor Lesley Salter
(Chairman, Community Services
Scrutiny Committee)



Councillor Julie Cushion
(Vice-Chairman, Community
Services Scrutiny Committee)



Councillor Nigel Baker
(Member, Community Services
Scrutiny Committee)



Councillor Judith McMahan
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Scrutiny Committee)

Community Services Scrutiny Committee

2003/4 Project - "Learning Disability Services"

1. SCOPE, OBJECTIVES AND METHODOLOGY

The Scope of the Scrutiny: Objectives and Outcomes

1.1 In the municipal year 2003/4, the Council's Community Services Scrutiny Committee decided to undertake a scrutiny on the subject of "Learning Disability Services". The over-arching aim of the study was to facilitate the consideration by Members of strategies for the development of learning disability services in Southend as they impact on:-

- The best use of resources currently invested in large learning disability day centres, to promote opportunities for choice and inclusion.
- The best use of resources currently tied into residential care homes which fail to meet national care standards or enhance opportunities for people to have the individual support they need.

1.2 The objectives agreed by the Committee were:-

- To compare levels of provision of learning disability services in Southend with the wider national situation.
- To examine the reasons for any differences between the local and national situations.
- To identify and examine measures which might be taken to improve service provision.
- To indicate how learning disability strategies have set the scene for change.
- To indicate where there are opportunities for Members to consider whether current investments are relevant to a modern learning disability service for Southend.

1.3 The outcomes sought from the study were identified as being:-

- To make appropriate recommendations to improve service provision.
- To identify good practice in relation to learning disability services.
- To make appropriate recommendations for the future use of resources for day opportunities.
- To make appropriate recommendations for the future use of resources for accommodation.

Methodology/Process

1.4 The scrutiny was carried out by the Community Services Scrutiny Committee supported by an Officer Project Team comprising:-

- Geoff Smalley, Principal Committee Officer and Project Co-ordinator
- John Nawrockyi, Director of Social Care
- Penny Furness-Smith, Director of Integrated Services
- Trevor Saxon, Joint Commissioner, Learning Disabilities
- Jane Whalley, Administrative Support Officer

A small Member group comprising the Chairman (Councillor Lesley Salter), Vice-Chairman (Councillor Julie Cushion) and a representative from each of the other political groups on the Committee (Councillors Nigel Baker and Judith McMahon) was

attached to the project team in order to give guidance and act as a consultative body during the course of the scrutiny. The project plan for the study was drawn up and approved by the Committee. The scrutiny commenced in November 2003 and ended with the formal approval of the final report in July 2004.

- 1.5 In order to prepare Members to undertake the scrutiny, an initial presentation was given to the Committee by members of the Officer Project Team supported by partner agencies. This provided an explanation of key concepts under-pinning the scrutiny as well as an outline of the national agenda for change and a summary of constraints in implementing that agenda locally. A pack of background information papers was also provided for Members. Following the preliminary meeting which set the national and regional scene and the context for the scrutiny, subsequent evidence sessions focused on aspects of Southend Learning Disability Services.
- 1.6 Briefing material provided the necessary background information for three formal public evidence-giving sessions at which the Committee received oral, written and presentational evidence from a large number of key stakeholders. It was hoped that the information obtained from such stakeholders would enable a valid comparison to be made between the national picture provided in the briefing documents and the local situation.

Evidence Gathering

- 1.7 The Committee took oral and written evidence from representatives of service users, advocacy bodies operating in the field of Learning Disability Services and relevant local authority and related agency officers. All the evidence was taken in public under the Local Government Access to Information Rules. In addition to these formal public evidence sessions, Members of the Committee were given an opportunity to visit some of the day centres and residential premises providing services for people with learning disabilities in the Borough.
- 1.8 The stakeholders involved in the oral/written evidence process are outlined in para.1.9 below. Witnesses were advised of the areas of potential questioning prior to the meeting and, a few days before the meeting, a final list of questions was provided to the witnesses to allow them time to formalise their answers. Stakeholders were given the opportunity to make an initial presentation on their work and its relationship with the subject matter of the scrutiny and to provide preliminary written answers to the pre-notified questions which would form the basis of a discussion with Members on the issues raised. At the committee meeting, Officers took a note of the answers and any ensuing discussion. Following each meeting, a copy of the note of evidence was sent to the witnesses for comment on its factual accuracy prior to publication.

Stakeholders

- 1.9 The Committee received evidence from the following individuals representing the organisations indicated, to whom the Council is grateful:-

8 March 2004

Advocacy Groups

Eileen Carter and Carole Houghton - BATIAS
Ros Murrin and Myra Bradley - Southend MENCAP

Southend Carers Forum

Barbara Crowe, Stan Whittelsey, Peter Stroudley

Social Care Department

Karen Bradford, Manager of Community Team for people with learning disabilities
Henry Watson, Day Services Manager.

8 April 2004

Service Users/Student Representatives/Advocacy Representatives
Social Care Representatives

Ros Murdin and Myra Bradley - Southend MENCAP
Tonda Oswald - Service User/Student Representative
Donna McClean – Service User/Student Representative
Janet Kent – Service User/Student Representative
Rosalie Mossop – Service User/Student Representative
Ruth Bull - Head of Learning Disabilities
Louise Langley – Residential Homes Manager

19 April 2004

Social Care Department

Bernard Dayer, Head of Housing Resources
Ruth Bull – Head of Learning Disabilities

South Essex Partnership NHS Trust

Denise Cook – Director of Older People’s Mental Health and Learning Disabilities

Southend Primary Care Trust

Trevor Saxon - Joint Commissioner, Learning Disabilities

An invitation was issued to the National Care Standards Commission to provide evidence for the scrutiny but this invitation was declined.

2. MAIN ISSUES FOR SCRUTINY

- 2.1 The initial phase of the scrutiny exercise involved research into what might be considered to be the main issues in relation to the subject matter of the scrutiny at both national and regional levels. It was undertaken by means of a study of the briefing documents referred to at para.1.5 above. In addition to information summarising the national and the regional picture, the documents and preliminary briefing session outlined a number of key themes or issues in relation to Learning Disability Services. The national agenda for change and the opportunities for and constraints on implementing that agenda locally are outlined below.
- 2.2 The National Vision for Learning Disability Services is set out in the 2001 Valuing People White Paper. The Chief Executive of the Council has responsibility for the effective operation of Southend's Learning Disability Partnership Board which includes representation from all key stakeholders with Southend Borough Council, Southend Primary Care Trust and South Essex Partnership NHS Trust being key partners. The involvement of Service Users and Carers is fundamental to the way the Partnership Board is required to work. The main purpose of the Learning Disability Partnership Board is to implement the Valuing People White Paper and Vision. This means ensuring that necessary changes happen to complete a transition from long stay hospital provision to ordinary citizenship through the modernisation of current services, most of which were established in the early 1970s.

- 2.3 The Council and Southend Primary Care Trust have entered into a partnership agreement the effect of which is to bring the services for people re-provided from long stay hospital into Lead Commissioning arrangements. All the people who are the responsibility of Southend services are therefore considered in the same way for the provision of future services. Southend Borough Council commissions and purchases residential services for over two hundred people. All the Care Homes that the Council purchases services from have to meet the National Minimum Care Home Standards. Southend Borough Council directly provides Care Home services at Shelford, Berland House and Saxon Lodge. There are 35 Southend people living in these homes and they do not meet the National Minimum Care Home Standards. The Council has been given interim registration for the homes whilst plans are made for their future.
- 2.4 The national trend - and a thrust of the Government White Paper Valuing People - is for people to be supported in more appropriate housing models. For this reason the number of people living in registered Care Homes is expected to decrease over the next few years as better Supported Living arrangements are put in place.
- 2.5 In this context Southend Borough Council needs to make plans for each of its Care Homes. The options for each home are:
- To modify the home if this can be achieved to bring it up to the required minimum standards whilst remaining a best value option, and if the demand for residential care justifies the investment.
 - To close the home after more appropriate housing provision has been found for the people currently living there.
- 2.6 The Learning Disability Partnership Board is required by 2006 to have modernised the way it supports people to be active and valued members of their community. Traditional day service models (which were progressive in the 1970s) are no longer seen as appropriate ways of helping people to be ordinary citizens. Most day services for people with learning disabilities in Southend are directly provided by the Council at two large centres set up as Adult Training Centres. Avro/Viking has 143 places including the provision of 32 places for people with profound and multiple Learning Disabilities. Maybrook has 135 places. These models are not regarded as modern services.
- 2.7 Valuing People requires the Learning Disability Partnership Boards to develop more appropriate ways of helping people to use ordinary services and facilities in the same way as other citizens. To achieve this, available funding needs to be spent on supporting people to live in their own homes and to access education, leisure and employment services rather than attending segregated day services. Because there is no new money available to achieve this objective, this will mean diverting resources from the traditional day centre models. The future of Avro/Viking and Maybrook need to be considered in the light of this. The necessary changes need to be properly understood and well managed taking into account the effect that any changes to services will have on people with a Learning Disability, Carers currently using them, and staff or other organisations providing the services.
- 2.8 The current demand for services is greater than the resources available and the national trends reflected in Valuing People predict a 1% year on year growth for the next 15 years. Difficult decisions will therefore need to be made about access to services using Fair Access to Care Services criteria.
- 2.9 Valuing People has set targets for achieving change and since 2001 the Council has been measured on how quickly change is happening.

The way changes happen needs to take account of the following:

- What the National Strategy for Learning Disability Services - Valuing People - says should happen and when.
- The need for services to meet National Minimum Care Standards.
- The need to involve people with a Learning Disability, their Carers and key stakeholders as much as possible in the way change happens.
- The current financial constraints of the Council and the need to manage within set budgets.

2.10 In the context of the objectives and anticipated outcomes of the scrutiny and in the light of the background outlined above, the main issues which emerged during the scrutiny can be summarised as follows:-

- the need to develop more appropriate housing models for people with learning disabilities as better supported living arrangements are put in place in accordance with the national vision for learning disability services set out in the Valuing People White Paper
- the future of the Council's directly provided care home services for 35 people at Shelford, Berland House and Saxon Lodge which do not meet national minimum standards
- the need to move away from traditional day service models for people with learning disabilities in accordance with the thrust of the Valuing People White Paper.
- the future of the Council's traditional day centres (Avro/Viking and Maybrook) in the light of this.
- the need to manage the changes sensitively and effectively bearing in mind the effects of service changes on both Service Users and carers and taking into account where possible the views of both groups
- the resource and budgetary implications of any changes in the context of both the provision of services specific to people with learning disabilities and of all adult care services covered by Fair Access to Care Services criteria.

2.11 In addition to these issues, representatives of the South Essex Partnership NHS Trust and Southend Primary Care Trust outlined the ways in which relevant NHS bodies/practitioners endeavour to meet the health needs of people with learning disabilities. Essentially, this is in accordance with the Valuing People principle that they should have the same access to mainstream health services including community health services such as dental provision, as everyone else, albeit with additional specialised support where necessary and appropriate.

2.11 On the basis of the information in the briefing documents and the themes or issues outlined above, a number of preliminary questions were drafted in batches and sent to the various stakeholder groups prior to their attendance before the Committee. The subsequent responses from the various witness groups concerned indicated that there was a broad consensus on the issues which needed to be tackled, which were largely in line with those set out above, albeit that the perspective of the stakeholders on those issues and the suggested action needed might differ.

3. EVIDENCE/FINDINGS OF THE SCRUTINY

3.1 As indicated earlier in this report, whilst background knowledge and understanding of the issues was obtained from publicly available information, evidence of the situation on the ground in Southend was obtained via the formal evidence-taking sessions with key stakeholders and the opportunity for Members to visit day centres and residential premises for people with learning disabilities in the Borough.

3.2 A detailed record of general comments and specific responses to questions posed by Members of the Committee was prepared. This record of evidence was forwarded to

a representative of each stakeholder group which contributed to the study in order to ensure that the recorded evidence was factually correct. A copy of the evidence for each witness session is attached at [Appendix 1](#).

- 3.3 For the sake of brevity and to avoid unnecessary repetition, it was not considered necessary to further summarise the findings at this stage but rather to move directly to a discussion of the evidence prior to outlining conclusions and recommendations drawn from the study.

4. DISCUSSION OF THE EVIDENCE

- 4.1 The commentary below relates broadly to the main issues of the scrutiny set out in Chapter 2, which are themselves set out in the context of the objectives and anticipated outcomes of the scrutiny.

Future Housing Provision

- 4.2 The Valuing People White Paper makes it clear that people with a learning disability should be given greater choice and control over where and how they live. The last long-stay hospitals are earmarked to close by 2006 and a range of housing options should be available. The thrust of the White Paper is a move towards greater independence, improved social inclusion and further community involvement for people with learning disabilities.
- 4.3 Whilst it is accepted that care homes are needed for a small number of people with particular needs, many who are currently in care homes could live in alternative types of supported accommodation if this were available and accessible. As the range and choice of housing and support available to people with learning disabilities increases, the need for people to move from community settings into residential care will reduce. The number of people requiring residential care is therefore decreasing and will continue to do so. This places a question mark over whether any of the Council's three care homes will be needed in the long-term. If they were to be used beyond 2007, significant resources would need to be made available to ensure that they meet the appropriate registration standards in relation to which they currently fall a long way short. Care Support and its management into any new more appropriate housing alternatives or indeed into any retained but leased care home could be provided directly by the Council as at present or by transfer under contractual agreements to the independent sector.
- 4.4 It is clear that consideration will need to be given to a range of alternative proposals including developing the availability of appropriate independent sector placements, together with the development of different types of supported accommodation, extra-care housing schemes and shared purchase ownership schemes. Crucially, changes in residential care provision need to be integrated with such alternative supported housing options and planning for each of these changes needs to be adequately co-ordinated rather than developed in a piecemeal fashion.
- 4.5 Evidence from service users, advocacy representatives and Council Officers indicated that considerable numbers of people with learning disabilities favoured the greater independence which alternative housing models represent. Approximately 40 people in private and voluntary sector homes were already making plans to live more independently and 18 residents of Council-owned care homes had expressed an interest in a move to supported tenancies or adult placements. Over a period of 3 years, some 50% of Berland residents had moved on to supported tenancies.
- 4.6 Grahame House was recommended by the advocacy services in particular as an appropriate accommodation model whereby each person has their own flat and in-house support geared to their individual needs. Grahame House is a property built in

the late 1960s recently converted to offer 12 one bedroom units which are suitable for couples. The demand for this type of accommodation outstrips current availability and 18 people with learning disabilities currently in residential care have expressed an interest in moving into accommodation such as Grahame House. The Council has responded to this by considering the feasibility of providing a further similar 12 bedroomed unit.

- 4.7 People with learning disabilities are also able to access other types of accommodation. A typical house share arrangement might be two or more people with learning disabilities living with a support worker. Another option being developed is an adult placement scheme, which involves a local resident opening their home to someone with a learning disability. Adult Placement schemes are registered with the Commission for Social Care Inspection.
- 4.8 Although there have already been successful moves from traditional residential care to alternative types of accommodation in Southend, it must always be remembered that the placement of people with learning disabilities can be a sensitive matter due to their vulnerability and varying needs and abilities. There was a clear consensus amongst all witnesses, including carers representatives and advocacy groups, that good planning and preparation together with adequate support arrangements are essential for people with learning disabilities contemplating a move to independent living. The in-depth assessments for each resident of the Council's care homes which are to be undertaken in the coming months will help in this process by indicating the type and range of housing needed. A recent event bringing together essential accommodation providers and people with a learning disability to consider housing options available was another useful step in this process.
- 4.9 Consultation with the community prior to either the provision of dedicated learning disabled housing such as Grahame House is essential in order to allay any fears that local residents might have. Prior to the opening of Grahame House, an open day was arranged for this purpose and consultation has already been undertaken with residents in the vicinity of the proposed additional 12 bedroomed unit.
- 4.10 It is clear that there is a willingness amongst many people with learning disabilities to move from residential care to more independent living arrangements. This fits with the proposals set out in Valuing People and the Council needs to find ways of utilising those existing capital assets which are no longer fit for purpose in order to finance alternative supported accommodation options. This needs to be raised sensitively in an integrated and co-ordinated manner in order to ensure that the outcomes from the process meet the needs of learning disabled people and their carers.

The Future of Day Care Services

- 4.11 The Valuing People White Paper requires Learning Disability Partnership Boards to move away from traditional day service models such as those provided by the Council at Avro/Viking and Maybrook Adult Training Centres. Resources therefore need to be transferred from segregated day services to enabling learning disabled people to use ordinary services and facilities, such as education, leisure, health and employment in the same way as other citizens. As with changes to the provision of housing/accommodation referred to above, moving people away from traditional day service arrangements needs to be carefully managed and changes to such services will affect both people with learning disabilities and their carers.
- 4.12 Approximately 300 service users currently access the Council's adult training centres. About 16% of places are purchased by other local authorities (Mainly Essex County Council). Clearly, a move to greater involvement in the community side by side with a reduction in the use of the centres will not be an easy task. For an individual service user an assessment of their needs on the basis of person-centred approaches will be the key to evaluating the support they need to access mainstream services rather than depending on the adult training centre. By definition, person-centred planning, which

is designed to help people with learning disabilities to be included in the community, is resource and, particularly, time intensive. The appointment of a Co-ordinator for Person-Centred Planning has helped unify the work which was already being undertaken in developing person-centred planning, in particular in standardising systems and procedures. Carers' representatives stressed that they would like assessment of carers needs to be undertaken prior to assessment of the service users in order to ensure that the whole situation is evaluated in the round. Towards this end, carers had suggested that a pro forma for use by parents/carers be prepared.

- 4.13 Carers' representatives expressed the view that caution needs to be exercised in undertaking change. From their perspective and experience, the concept of people with learning disabilities living "ordinary lives" in the community is often over-optimistic in practice particularly if other members of the public do not understand or accept that they should be "integrated" in this way. Service users themselves were particularly concerned about the effects of bullying and verbal abuse. This is particularly prevalent when people try to access public transport and other facilities. Education of the public needs to go hand-in-hand with access to public services by people with learning disabilities. Given that the main source of such bullying and abuse was from school children using public transport, it was suggested that an education programme in schools might be considered together with staggering the finishing times of day centres so that they do not coincide with school finishing times. The Learning Disability Partnership Board is currently undertaking discussions on such issues with Community Police Officers.
- 4.14 The Council's two large and one smaller specialised adult training centres provide a range of opportunities for people with learning disabilities who meet the Council's Fair Access to Care eligibility criteria. They also provide respite for many parents/carers. Although some activities are undertaken in the environment of the centre, community-based programmes such as the following are increasingly available:-
- Adult education/college - use of leisure facilities for music/sensory activities, cooking, art and craft, sports and games
 - Work orientation/work experience in the community
 - Basic education and computer skills training
- 4.15 Evidence from the advocacy groups suggested that choices available for people attending the adult training centres are limited and that many service users experience boredom and frustration. In addition, it is considered that services provided in the day centres are not of a comparable standard one with another. Shortages of staff at the day centres have not helped matters. Within any planned modernisation of day services and associated planned changes to the existing day centres, there will be a need to develop specific age-related services which will allow people to undertake activities of their choice which are age appropriate, alongside a plan that will see the development of new types of services for the younger and more active service users which will enable them to become involved in activities which are more challenging and inclusive.
- 4.16 Employment/work opportunities are provided where appropriate. An Employment Co-ordinator has been appointed to bring relevant agencies together under one umbrella to harness a system of fair access to good advice for all service users. Links have also been set up with key advisers in the Department of Social Security/Job Centre Plus. A number of employment opportunities have been provided via paid and unpaid work experience posts and volunteer placements. However, at the present time, these opportunities are limited, one example being the Snack Time café owned and operated by South Essex Partnership NHS Trust; this is essentially a training programme for female learning disabled adults to enable them to achieve basic hygiene certification etc. However, there are no measures in place to enable participants to access work in the community once accreditation has been achieved; one service user has worked there for some 14 years and this clearly prevents the

service from providing the short term training and work preparation function as part of training and supporting a broader range of learning disabled users to secure appropriate and related employment.

- 4.17 Advocacy groups highlighted the fact that smaller day services, which have been commissioned by the Social Care Department, appear to be more successful at meeting individual needs. There is a perception that such day service units have a higher staff ratio which allows service users to be given more choice in their everyday activities.

The Management of Change

- 4.18 Reference has already been made to the need to undertake the changes outlined in the Valuing People White Paper in a sensitive manner taking account of the views and needs of both parents/carers and people with learning disabilities themselves. This applies equally to bringing about greater independence in terms of housing/accommodation as to changes in day service provision. With regard to the latter, advocacy groups pointed out that day service providers are already trying to encourage change and are moving towards allowing people to have some control over their lives by making choices and taking risks within the day service setting. However, both staff and parents/carers, who are naturally concerned for the person with the learning disability can also be overly protective and this can put up barriers to such change. The fact that staff can themselves become "institutionalised" highlights the need for training in order to provide them with flexible skills which will enable them to join and participate in teams promoting independence for service users.
- 4.19 Whilst they were not completely resistant to change with positive outcomes, carers' responses did exhibit an understandable wariness of "change for change's sake". Proper consultation and an assessment of the needs of both service users and their carers were seen as essential and improved services need to be put in place before changes or developments happen to current services or they are reduced or withdrawn as part of the change and modernisation process. Preparation of person-centred plans will be the key to enabling the Council to commission services on the basis of the needs and aspirations of people with learning disabilities in terms of both where and with whom they live (housing/accommodation) and what they do to live fulfilling lives. A sensitively managed move from large scale group services to individualised support that is person-centred provides the key challenge in the short to medium term.

Resource and Budgetary Implications

- 4.20 Evidence received during the scrutiny indicates that demand for services currently outstrips the resource base available to the Council based upon the national profile. Furthermore, the Valuing People White Paper states that the demand for learning disability services is expected to increase year on year for the next 15 years. However, the Council already spends above the indicative national average for this user group. Expenditure on learning disabilities, excluding capital for finance charges, has shown a steady increase over the last few years in real terms, and increased by approximately 11% from 2002/3 to 2003/4. However, expenditure on the area of "other adult social services" (59% of which relates to learning disability services), is £3.425m above FSS. Consequently, the 2004/5 budget indicates that planned reductions need to be achieved year on year with a decrease of approximately £70,000 in the learning disability services budget in the current year. It is anticipated that this reduction will be achieved by firmly applying Fair Access to Care Services criteria and by critical examination and planned re-provision locally wherever possible of some of the most expensive out of area placements. The Valuing People agenda which will move people with learning disabilities towards more independent supported living should also reduce pressure on the budget as other streams of funding such as supporting people and housing benefit become available.

4.21 In the light of the above, the future of learning disability services requires the Council to balance what people with learning disabilities and their carers might like or want, what the Council must do in terms of the Valuing People agenda, and the available resources. In the words of the Director of Integrated Services, the challenge for the Council is to answer the following questions:-

- "Are we doing the right things?"
- "Are we doing things right?"

5. CONCLUSIONS AND RECOMMENDATIONS

5.1 The principal outcomes sought from this study were:-

- To make appropriate recommendations to improve service provision.
- To identify good practice in relation to learning disability services.
- To make appropriate recommendations for the future use of resources for day opportunities.
- To make appropriate recommendations for the future use of resources for accommodation.

5.2 Evidence from stakeholders during the scrutiny indicated that efforts are already being undertaken to improve and modernise service provision in terms of both the provision of suitable accommodation for the learning disabled and the opportunity to access more appropriate day activities. In the light of this and of the requirements of the Valuing People White Paper, we make the following recommendations for consideration and adoption by those individuals and bodies indicated:-

Recommendation 1	Action by
That a Learning Disability Commissioning Strategy be developed by Autumn 2004 setting out how services will be reshaped over the next 5 years in order to better achieve the Valuing People principles, including targets for ensuring that appropriate housing and support is made available to people who do not meet the criteria for the provision of care home services.	Cabinet/ Executive Councillor for Health & Social Care/Learning Disability Partnership Board/Director of Social Care.

Recommendation 2	Action by
That plans are put in place to ensure that within the shortest possible time-scale no one eligible for care home services is living in accommodation that does not meet the national minimum standards.	Director of Social Care.

Recommendation 3	Action by
That the future use of the Council's three care homes be considered in the light of Recommendation 1 and 2 above.	Cabinet/ Executive Councillor for Health & Social Care/Director of Social Care.

Recommendation 4	Action by
That Grahame House be adopted as a model of good practice in the provision of accommodation for the learning disabled and that the proposal to provide a similar 12-bedroomed unit be pursued.	Already adopted by Cabinet.
Recommendation 5	Action by
That a clear timeframe be established for the modernisation of day services which moves away from dependence on large, congregate and segregated services to services that are focussed on helping people to live their lives as ordinary citizens of the town.	Director of Social Care
Recommendation 6	Action by
That the timeframe for modernising day services should include a strategy to release, within the shortest possible time-scale, funding tied into the two largest day centres(Avro and Maybrook) in order to provide more individualised services that achieve the Valuing People principles as set out in the day services modernisation plan <i>Fulfilling Lives</i> .	Cabinet/ Executive Councillor for Health & Social Care/Director of Social Care.
Recommendation 7	Action by
That, in the context of the Learning Disability Commissioning Strategy, the Learning Disability Partnership Board consider agreeing an optimum number for the size of day services provided in groups.	Cabinet/ Executive Councillor for Health & Social Care/Learning Disability Partnership Board/Director of Social Care.
Recommendation 8	Action by
That consideration be given to how the transport needs of people using learning disability services might best be co-ordinated into the Council's overall transport policy.	Cabinet/ Executive Councillor for Health & Social Care/Executive Councillor for Transportation & Engineering/ Director of Social Care/Director of Leisure, Culture & Amenity Services.
Recommendation 9	Action by
That plans made for service changes specifically include an acknowledgement of the tensions between involving people as fully as possible in the way changes happen, the speed with which change is required, and any financial constraints.	Director of Social Care.

Recommendation 10	Action by
That plans for change include details of how they will be communicated both to people involved in making change happen and those affected by change.	Director of Social Care.
Recommendation 11	Action by
That a Carers Strategy be developed setting out how the needs of carers will be identified, planned for and met.	Director of Social Care.
Recommendation 12	Action by
That consideration be given to identifying within the Community Learning Disability Team a link worker for supporting carers.	Director of Social Care.
Recommendation 13	Action by
That the Learning Disability Commissioning Strategy indicate services which will be commissioned to support carers in their caring role.	Cabinet/ Executive Councillor for Health & Social Care/Learning Disability Partnership Board/Director of Social Care.
Recommendation 14	Action by
That consideration be given to developing a carers service which can operate as a focus for information, advice and the co-ordination of carer services, including the need for 24 hour crisis response.	Cabinet/ Executive Councillor for Health & Social Care/Director of Social Care.
Recommendation 15	Action by
That the important role of advocacy services be supported and, where there are opportunities to enhance the role of independent advocacy services, these be encouraged.	Cabinet/ Executive Councillor for Health & Social Care/Director of Social Care.
Recommendation 16	Action by
That the Learning Disability Partnership Board consider measures to ensure that people will be kept safe as services change and how the difficulties experienced by people being bullied will be addressed.	Learning Disability Partnership Board.

Recommendation 17	Action by
That relevant NHS health bodies continue to develop improved access to mainstream health services (including community health services such as dentistry) for learning disabled people whilst ensuring that additional specialised support is available where necessary and appropriate.	Southend Primary Care Trust/ Southend Hospital NHS Trust/South Essex Partnership NHS Trust.

**SOUTHEND ON SEA BOROUGH COUNCIL
COMMUNITY SERVICES COMMITTEE –
IN-DEPTH SCRUTINY**

“Learning Disability Services”

**EVIDENCE SESSION NO.1
8th March 2004**

ATTENDEES

Carole Houghton (BATIAS)
Eileen Carter (BATIAS)
Ros Murdin (Southend MENCAP)
Myra Bradley (Southend MENCAP)
Barbara Crowe (Carers Forum)
Stan Whittelsey (Carers Forum)
Peter Stroudley (Carers Forum)
Henry Watson (Day Services)
Karen Bradford (Community Team for People with Learning Disabilities)

1. INTRODUCTION

1.1 Members of the Committee had previously been circulated with background papers giving the following information:

- the structure and background of BATIAS Advocacy Service
- flyer for Southend MENCAP Advocacy Service
- the role of the Carer
- draft public leaflet outlining Day Services provision;
- a report ‘A New Approach to the Provision of Day Services’ by Henry Watson;

1.2 Mrs Houghton introduced the witness session with a short presentation outlining the role of the Advocacy Service.

- She explained that BATIAS could offer formal advocacy, where a paid member of staff gives support through a problem or crisis. Citizen advocacy allows a volunteer to support the person to access their community or just be a friend who will listen. Self advocacy allows people to take a more active role in the community; by joining a group they can gain confidence so their views are more widely heard.
- The aim of the Advocacy Service is to empower people to speak out, support people to make informed choices, provide a means to get their wishes heard on important issues and promote meaningful social inclusion.

2. RESPONSES TO QUESTIONS

2.1 QUESTIONS TO ADVOCACY SERVICES (BATIAS and Southend MENCAP)

- 2.1.1 Carole Houghton (BATIAS), Eileen Carter (BATIAS), Ros Mordin (Southend MENCAP) and Myra Bradley (Southend MENCAP) jointly responded to the following questions as previously submitted on behalf of the Committee, it should be noted that in the following responses the term 'learning difficulty' has been used as a substitute term for 'learning disability' (additional comments are in *italics*) :-

Question 1

Why do people with a learning disability need social services?

Answer

People with learning difficulties can require extra care and support to help them develop their capabilities and potential. Many people may have in addition to a learning difficulty, disabilities that can affect the way they are able to live their lives. Some people are able to lead quite independent lives while others require a great deal of support and help, this can be up to 24 hours a day.

Social Services has trained staff who can assess what a person with learning difficulties can do and what they have difficulty doing. They will do an assessment of a person's needs to ascertain what support they require. They know what services and resources are available and can put in place care packages that will support the person to live as independently as possible. The staff is able to identify housing needs, have access to benefits information, and refer the person to an advocacy service or community group. Social Services will also identify risks to a person's independence, health and safety by doing a Risk Assessment.

Question 2

Why do people with a learning disability not use the same services as everyone else?

Answer

This question only applies to specialised services, e.g. day care services. Other services like Social Services, hospitals, doctors they (should) get the same service as anyone else and sometimes it can go wrong as it does for anyone else. However it must be stated that health care services can be very difficult for people with learning difficulties to access and it is a recognised fact that the level of health care provision for this client group must be improved. There would be enormous benefits if people with learning difficulties were supported to participate in health screening, good health initiatives and preventative health treatments.

It is not always possible to explain waiting times and difficult procedures to a person with a learning difficulty and it would be a good idea to have specialised services in respect of dentistry. On visiting a dentist most of the clients will need an anaesthetic if treatment is required – and it may also be needed for a check up – and there are very few dentists in the area who will administer a general anaesthetic. The waiting time therefore, for treatment for a person with a learning difficulty can extend into many months – Southend Mencap has a client who has been waiting 18 months for treatment.

With regards both A&E and Hospitals, problems can also arise if people with learning difficulties are being admitted to hospital as many people have problems interacting

with people they do not know and become extremely worried and concerned. An advocate can support a person during this process.

There were grave concerns regarding the attendance at hospital by their clients. Support Workers do attend hospital with patients and have relevant information to hand which is usually ignored. This has been raised with the Good Health Group. Action plans detailing the individual's medical history have been done, but require the hospital service to take time to study these before diagnosis takes place. Health folders are being trialled with a full medical history and contact details.

The hospitals need to look at their own procedures and training as well as developing appropriate attitudes to aid patients with learning disability needs.

These concerns have been raised with hospital management, but nothing appears to have been progressed.

Question 3

What sorts of things do people with a learning disability need help with that social care services should provide?

Answer

Obviously areas such as health, housing, day care, financial issues, work, parenting, abuse, care packages, and direct payments are some of the areas that would come under Social Care. The number of supported employment opportunities could be increased, this is an area that Social Care is developing but it still requires further support. Currently Social Care have appeared reluctant to arrange benefits for people, suggesting that the advocates can undertake this, however this is not the role or responsibility of an advocate particularly as we do not have either the resources or the expertise in this area.

Social Care is also able to offer respite when carers need a break. However in Southend the number of beds available for respite has been reduced, currently there is one at Shelford and two at Berland. This has meant that there has been a reduction in capacity of 47 weeks.

Question 4

How are people helped to live their lives in the way they choose?

Answer

Each person should have a person centred plan which would indicate the kind of life that they would wish to have. Based upon this plan a care package or support will be accessed to enable this to happen. Direct Payments, where the person with a learning difficulty arranges their own support needs is a positive choice, but it is not the right move for every person and should definitely not be offered when service provision has become complicated.

However, many people with a learning difficulty experience problems with making choices because of their lack of life experiences and the majority of time they have to make uninformed choices. For example, given the choice of living in a flat or maisonette, the person with a learning difficulty would find it impossible to make a choice unless they have actually been to visit both.

Unfortunately choice is governed by funding and although the Fair Access to Care criteria assists those most in need or normally in crisis, for many others with a learning difficulty, there is no choice until there is a crisis.

People do choose what quality of life they want and what services will enable them to achieve it, but finance again dictates the outcome and their choices are sometimes being ignored due to the financial situation of the council.

Self advocacy groups enable people with learning difficulties to gain more confidence to speak up for what they want and aids service users in learning to deal with the challenges of daily life. Advocates also ensure that service users are given adequate explanations of all of the options that are available.

The Committee were informed that it is possible for people with learning difficulties to participate in the Duke of Edinburgh Award Scheme, various sports and attend music school.

Question 5

Tell us of your experience of Person Centred Planning.

Answer

BATIAS and Southend Mencap consider that the advocacy role cannot take place without the fundamental aspects of life planning being employed. This covers listening to the person, checking back that the issues have been understood, working out preferences and options. All staff, friends and family have skills and can contribute to life planning. However, an advocate as an independent person, with no conflict of interest can open up new ideas and possible pathways.

Person centred planning takes a long time to complete. From an advocacy point of view, as an advocate develops a relationship with a service user and shares their wishes/desires, the service user becomes more comfortable with them and is more likely to express their aspirations and feel empowered to make their own informed choices.

More emphasis is needed on Person Centre Planning but the system should be better managed and organised and should be available to all service users. It has been found that sometimes when person centred planning is treated as something done only by a special facilitator it can be used as a reason for nothing happening. BATIAS have not explicitly supported anyone in Southend in developing their person centred plans.

The Committee was informed that there is a difficulty with recruiting Advocates and it was not always possible to have 1 to 1 sessions. The more difficult cases are dealt with by a paid Advocate.

The view was expressed that proper training was essential, so that the Advocate does not instil their values/needs and the agenda discussed is client-based.

Question 6

Do the current day services help people to live ordinary lives?

Answer

The current day services are trying to encourage change and are moving towards allowing people to have some control over their lives, choices, and the taking of risks within the day service setting. However, one of the problems is that both staff and parents who are naturally concerned for the person with a learning difficulty, can also be very protective and put up barriers to change.

Smaller day services, which have been commissioned by Social Services, appear to be more successful at meeting individual needs and they have a higher staff ratio which allows service users to be given more choice in their every day activities.

However, in Southland's larger day services there is an ongoing problem with a shortage of staff and this causes problems in enabling people accessing the community and doing 'ordinary' things that people without a learning difficulty take for granted. This shortage significantly affects the quality and type of services such as planned activities and these are often being cancelled.

General feedback from Southend Mencap's self-advocacy groups, who meet in one of Southend's large day centres, is that many of the people are bored and frustrated. Although changes in the service are being implemented, it has also been noticeable for some time that the services provided in the two-day centres are not equal or of a comparable standard.

It is hoped that with the modernisation of day services, the more senior citizens will have a service geared to their needs. This will enable them to do activities of their choice which are age appropriate; likewise, people who are younger and more active may wish to be involved in activities which are more challenging and inclusive. At present, there are limited choices for people attending the centres and people's needs although listened to be not always met because of the number of people in-groups in the day services.

The service that is provided needs to be flexible now and in the future and clients need to be offered places in training programmes.

Question 7

What is the thrust of Valuing People with regard to where people with learning disabilities should live?

Answer

The White Paper is very clear that people with learning difficulties should be enabled to have greater choice and control over where and how they live. There should be a range of housing options available with closure of all long stay hospitals by 2006 (was 2004, this has now been extended). Tenancy agreements and direct payments all provide opportunities for greater independence. The whole ethos of the paper is the move towards greater social inclusion with meaningful community involvement.

One area of concern in the Valuing People Document is the growing numbers of people living with older carers. The Government wishes to see better forward planning by local councils so that carers do not face continuing uncertainty in old age and their sons and daughters gain greater independence in a planned way.

There needs to be an expansion in the range and choice of housing offered, and rather than replicating the current provision, the opportunity should be taken to broaden the range of housing available and be creative.

Care and support services are key to giving individuals more choice and control over their lives, but there are obstacles, especially so for people with a learning difficulty, when professionals decide what is good for individuals without proper consultation and the traditional 'take what you are given' attitude is implemented.

It was brought to the Committee's attention that there is a Housing Register for rented accommodation, but the specific needs for housing are not being met by the Council and the decisions are challenged but revoked.

Question 8

How good are the Social Care Department and the Housing Division at helping people to live in their own homes?

Answer

The Housing Strategy for Southend is trying to address the accommodation situation but unless more property is made available, people living in the three large residential homes in Southend will continue to live there for some time and their choices will be limited. There is generally a lack of suitable council accommodation for people with a learning difficulty and invariably they are offered accommodation that no one else wishes to rent. Feedback from our client group is that the more able adults feel that there are expectations for them to achieve more than they are realistically capable of doing.

In supported living houses and in residential homes, the rules and regulations dictate how a person lives; activities outside of the home have to fit in with staff shift changes and residents cannot establish normal relationships because they are not allowed to have people to stay overnight. Meals are at certain times and 'bedtime' is normally dictated by staff changeover. It is important that these issues are addressed by Social Care.

Graham House in Southend is a good accommodation model, each person has their own flat and in-house support is geared to their individual needs. As Advocates we would like to see Social Care and the Housing Department working towards creating more housing based on this model.

The Supporting People policy and funding framework was implemented in April 2003, this was aimed at providing greater flexibility to support services for vulnerable people and included housing, care and health planning. However there are indications in the press that there is likely to be a cut in the level of money that will be available for 2004/5.

Question 9

Is there confidence in the standard and quality of the accommodation and services provided by the Council?

Answer

It is acknowledged that the accommodation offered by Berland House, Shelford Hostel and Saxon Lodge does not meet NCSC standards. Social Care is aware of this and the matter is being addressed. Therefore, there is not much confidence in the standard and quality – there is faith and confidence in the management of the homes, which is overseen by the Borough.

With the launch of the Opening Doors Strategy Southend has set out their plan for the years 2003 – 2008 but this has been met with apprehension as parents/carers are quite resistant to change. However, advocacy services can and do support service users with choices and change.

There is a shortage of staff in some hostels, which has led to problems arising in the hostels.

The Committee was informed that as of 1st April 2004 each facility will have reduced beds as 9 sq. metres for a room is a NCSE standard requirement.

Question 10

Is there confidence in the standard and quality of the accommodation and services purchased by the Council?

Answer

Feedback tells us that the private provision of homes should be overseen by Social Services, as this would inspire greater confidence amongst all groups affected. There is a lack of confidence in the accommodation and services purchased by the council because it is felt that when a person's assessment has taken place and needs/support identified, funding takes priority over that person's needs. The NCSC has been instrumental in ensuring that private homes meet the standards but because of the lack of accommodation generally, sometimes people are 'placed' where there is a vacancy without due consideration to compatibility with the other tenants and whether that particular home really does meet their needs.

As our client group can be targets for exploitation and bullying, there is also concern that accommodation is only available in unsuitable areas.

Question 11

Who are our partners in developing socially inclusive opportunities?

Answer

All of the partners that are part of the Partnership Board should be able to promote and develop social inclusion. This covers social care, health, education, transition, employment, leisure services and voluntary community groups. Positive press, recognition and understanding by the wider community will also be a positive move.

Question 12

How could we invest resources differently, to develop modern day and community support services?

Answer

An effective review process should identify future demands and this along with the current service deficits should provide a blueprint for the development of modern day and community support services.

Smaller resource centres that people can access not only during the day but also in the evenings would be very beneficial. Some of the activities undertaken at the centres would help to focus on inclusion with the local community.

Investment in the education of learning difficulty awareness, this would be particularly aimed at transport providers, health care staff and leisure providers. Organised career progression for care staff and a high profile given to recruitment, training and retention of staff.

Question 13

What type of services should we be spending money on?

Answer

- Smaller day service units with higher staff ratios.

- The development of specialist self-advocacy groups or project groups which will empower participants to be more proactive in the development of the service.
- Long Term Planning - Expanding choice in housing, care and support service partnerships with regard to service users living with elderly carers.
- Person Centred Planning – Each person should have a PCP.
- Accommodation.
- Advocacy – the principle of formal advocacy and independent support is only currently required in crisis and on a short-term basis. Through experience advocacy has enabled people with a learning disability to gain the confidence and skills to speak up for themselves and be socially inclusive –this can be achieved through self-advocacy or peer advocacy.
- People’s Parliament – this will highlight significant issues of concern to service users and improvements should be implemented. This will enable people with learning difficulties to own and be part of their “change agenda”.

2.2 QUESTIONS TO SOUTHEND CARERS’ FORUM

2.2.1 Mrs Barbara Crowe gave a short presentation outlining to the Committee the role of the Carer. In this presentation she stressed that the Carers of adults with learning disabilities are usually lifelong carers. The life of the parents revolves around the needs of their child, causing the whole family to become a “handicapped family” without the freedom to do the things other families can take for granted. There is inevitably stress, but this can become greater as the child moves towards adulthood and the need for respite becomes essential to aid in recharging their batteries as well as giving time for other family members. There were also concerns as to what will happen when the Carer is no longer able to provide the care needed, so planning for the future is essential, so that consultation with Carers is paramount to ensure the right services are provided. The following questions were mailed to Carers registered with the Department of Social Care team and the responses collated.

Mrs Crowe and Mr Whittelsey responded as follows to the questions previously submitted on behalf of the Committee:-

Question 1

What help do people with learning disabilities need to live ordinary lives?

Answer

Carers specified the type of help they feel is needed:-

1. Help with money/budgeting
2. Choosing the right food/balanced diet
3. Help to integrate into community/Social life
4. Emotional support
5. Advocates/befrienders to fight their corner and who they can relate to
6. Part-time respite Carers
7. Community nursing (health, hygiene, safety)
8. Occupational therapy services (developing social skills etc)
9. Careers advisor/training/learning opportunities
10. Consistency of support workers (not changing every 2 weeks)
11. Help with housing/secure housing
12. Interesting work to do
13. Daily living skills

14. Need to ensure tenants in supported housing are compatible **before** they live together
15. Education beyond age 18/19 – most adults with learning disabilities are then at their peak of learning

A number of respondents stressed that good assessments and regular reviews are the key to identifying what help and support is needed by people with learning disabilities.

Some Carers were not confident that all people with learning disability can, in reality, live “ordinary lives”:-.

1. Neither they nor their Carers can live “normal” lives in a community where they are not accepted.
2. The idea of living “ordinary lives” in the community might sound appealing, but it is often over-optimistic in practice.
3. Unless you live with someone for 24 hours a day you cannot possibly understand all their needs and an assessment often does not give a true picture.

Mrs Crowe suggested that Carer Assessments should be taken prior to the learning disability assessment, as their needs for the future also need to be met and their wishes should be taken into consideration. A pro-forma document has been asked for by parents/carers and Karen Bradford (Community Team for People with Learning Disabilities) took note of this.

Question 2

Is the right help available?

Whilst many Carers felt that the right help was available in theory, staff shortages and general lack of resources were cited by many as being a stumbling block to access help when it was needed.

Answer

Other comments made by Carers in response to this question:

1. It was felt by some Carers that 80% of the time help is unreliable
2. Often after an assessment nothing is done
3. It appears to be available but one has to constantly remind the team and make a nuisance of oneself in order to get any action
4. There is help, but not enough
5. Staff shortages mean not all peoples with learning disabilities have contact with the Learning Disability Team and these people can fall outside the system and not receive any help
6. Project holidays at Avro centre now withdrawn – these were enjoyed by service users and provided respite for Carers
7. A lot of good work being done, but uncertain future of day care and other services is great cause for concern
8. Not enough College places, some service users get no help
9. People need to befriend adults with learning disabilities
10. A 24 hour emergence telephone number is needed

Question 3

How well are the needs of Carers being met?

Answer

Carers were very specific about what their needs are in answer to this question:

1. The needs of Carers are not met until the Carers' health suffers
2. Carers need encouragement and guidance
3. It would help if Social Care response to Carers' pleas for help was more rapid and more positive
4. Need more flexible respite care
5. Need staff that care about people with learning disabilities
6. Not enough help for older Carers thinking of "retiring" from the role, to be left no money or pensions after years of sacrifice – this is a very serious matter
7. We need time for ourselves
8. We need doctors who understand our stressful situations
9. We need practical support and people to talk to when times are tough
10. We need our own opinions to be taken into account when planning the future
11. We need a holiday to recharge our batteries and relax, to not be restricted for a while
12. Carers need some financial assistance
13. More immediate/emergency respite is needed for emergencies or late invitations, without 6 months' notice having to be given
14. Support given by the Carers' Forum is invaluable and a much-appreciated resource

Mrs Crowe felt that overall the professional advice received in Southend is excellent for informing Carers of other medical problems that may arise in adults with learning disabilities. The launch of the Good Health Project will enable all adults with a learning disability of a Health Plan and this will be a good step forward.

Question 4

Do day services have a role in supporting Carers?

Answer

Overwhelmingly, Carers stressed the importance of day services

1. Strong role – without day services may Carers would have to given up work and have no rest or breaks – it is a vital form of respite
2. Carers would have to give up caring and ask Social Care to take over full-time care if day care is reduced
3. Some Carers need to go out to work or just socialise – have time for themselves
4. Essential to enable Carers to have some form of normal life
5. Its good for Carer and cared-for to have a break away from each other
6. Day centres provide an excellent service, giving service users the opportunity to develop educationally and socially
7. Great importance for Carers, giving breathing space to live their own lives.

Carers also commented on day services as follows:-

"Most people with learning disabilities would prefer smaller units"

"Not all people with learning disabilities want to use day centres"

Question 5

How good are the Department of Social Care and the Housing Department at helping people to live in their own homes?

Answer

Carers' responses to this question showed a general lack of confidence in the availability of adequate back-up support to enable people to live in their own homes and concern that placements often break down due to lack of support. Specific comments included:

1. People with learning disability are often "persuaded" to live in their own homes, and when there is a problem it is often days or weeks before the problem is addressed
2. Some housing not in desirable areas for people with learning disabilities
3. Some Carers feel they have difficulty getting help from these departments
4. Concern that in some sheltered housing accommodation staff feel they are restricted in the help they can give
5. Good planning and preparation is necessary before anyone moves on to independent living
6. Sometimes there is insufficient support for some adults with learning disability as they move in to supported living places
7. Increasing use of "agency" staff is not satisfactory, service users need continuity and different staff coming in at different times can cause great difficulties
8. Lack of availability of support appears to be the insurmountable problem

Mrs Crowe spoke of joint tenancies, stating that the compatibility issues should be more closely monitored as supported living in smaller houses where the facilities are shared may sometimes be more suitable.

Question 6

Do you have confidence in the standard and quality of accommodation and services **provided** by the Council?

Answer

There was a general lack of confidence in the responses. Again, lack of resources, especially shortage of social workers, were cited as a stumbling block to the provision of local authority services.

1. Not enough thought given to accommodation and where it is sited – eg. on Kursaal estate residents with learning disability are afraid to go out a night
2. In some areas people with learning disability are subject to violence and abuse (windows broken, eggs thrown at their door)
3. Neighbours on some estates are noisy and violent and this is very distressing for people with learning disability
4. Some Carers feel they are not aware of any
5. Insufficient properly qualified staff because of shortage of money
6. Some Carers prefer Council accommodation because they are supervised by Social Services, however frequent staff changes are unsettling
7. Carers need to know there is a good standard of care
8. Not enough residential homes, there are always waiting lists

9. Some Carers felt their experience of social workers has been good but there is a sizeable shortfall in available Social Work time
10. Some Carers have been satisfied with the services they have experienced
11. Despite well-meaning staff who do their best the feeling is that sometimes people with learning disability are treated as second class citizens
12. Carers seem happy with respite care given at Berland and Shelford

The Committee asked if the withdrawal of some type of day care provision could lead to abuse by the carer. Mrs Crowe responded that this would rarely be the case but could mean the carer saying 'I give up – look after my child' to the Council.

Question 7

Do you have confidence in the standards and quality of the accommodation and services that the Council **purchases**?

Answer

Few Carers answered this question, and some were unsure whether they had used such services or accommodation. (In our view, this may reflect the fact that the general public does not as a rule recognise the difference between directly provided services or services purchased by the local authority). Those who did respond showed little confidence.

1. No confidence at all
2. No – because these are run for profit
3. You are always told there are not enough staff
4. There are only a few private care homes that I would be confident in
5. I have only experience Gowlands, am very confident in them
6. In spite of the move towards living in the community in supported housing, this is only appropriate for the minority
7. Care should be taken that the needs are properly assessed and sufficient support given to each individual.

Question 8

Do you think there is a role for Care Home provision in giving Carers a break?

Answer

Overwhelmingly, Carers stressed the need for residential respite care in which they can feel confident:

1. There are 140 Carers of adults with learning disability in Southend and only a few get respite, all Carers need to have a break
2. It is important that this type of respite care is available so that Carers can have periods of freedom from care
3. Also important for service users to be able to visit and get to know a certain home with a view to eventually living there when no longer able to live at home
4. Very important the Carers have regular breaks
5. Carers need to have confidence in using care homes with which they are familiar
6. Care homes need to be properly vetted and controlled
7. There is a great need for residential care breaks to help carers cope, 24 hours a day

Mrs Crowe informed the Committee about Project Holidays. These breaks were very important for the carer as well as the service user. It is known that only 66 people out

of the total number of 140 still living at home with carers receive respite in the local authority residential homes, therefore for many carers the project holiday provided the **only** period of respite. These breaks are paid for by the service users themselves and the Council pays for the extra staff time. It is therefore a very cheap form of respite as well as giving carers confidence in the care being provided by staff who know the service users well.

Question 9

What other ways are there for Carers to be supported in their caring role?

Emergency respite services were mentioned by many Carers as essential back-up support for the caring role. Flexibility of services, befriending/someone to talk to were also cited as being important.

Answer

The important role of the voluntary sector was evident with Carers specifying the value of support received from Southend Carers' Forum

1. Far more emergency respite care
2. Longer periods of respite than the one hour a day sometimes offered
3. Central source of information and support such as Carer's Forum must be retained
4. Having a sympathetic ear at the end of a phone is most important
5. Carers need to feel that service providers understand their situation
6. More flexible services
7. More contact/phone calls/visits with Carers on a regular basis
8. A plan for the future once the Carer reaches 50 (especially for single Carers)
9. Take Carers' views into account when planning independent living
10. Regular Carers' assessments (annually?)
11. More help in understanding how to use Direct Payments and help to acquire them
12. The Carers' Forum is an excellent example of support
13. Befriending/share care – although this seems to be in short supply
14. More "sitting" services to enable Carers to get out – marriages need help to survive the caring role

Question 10

How could we invest resources differently, to develop modern day and community services?

Answer

1. Most Carers do not want to change the services unless it is an improvement in some way
2. Change for change sake should not be an option
3. All change affects people with learning disability and Carers have to cope with the effects of this, not Social Services, Councillors or the Government
4. There must be continuity, change causes problems that parents/Carers have to deal with and that nobody else sees
5. Every change in services causes stress for service users and Carers
6. Any new service must be discussed well in advance to prepare for change
7. No services should be withdrawn until/unless there are concrete plans for improved services to take place
8. Constant changes are often unrealistic and do not provide what is required. Those who make major decisions are not always in touch with reality!

9. Carers should not have to worry about whether services will be closed or what services will be available in the future
10. Uncertainty about the future is very upsetting – the possibility of a reduction in services is very worrying for Carers because an extra burden of care will be placed on them
11. Before any changes are made Carers should be consulted

*Mrs Crowe made the point that **any change** in the life of some-one with a learning disability should be made gradually. Change often produces difficulties at home, unknown to the professionals.*

Question 11

What type of services should we be spending money on?

Answer

1. Support at home with a special team to help us cope with emergencies such as death or illness of the Carer
2. Centre for giving Carers a break, run by people with an understanding of people with learning disability, to help Carers cope with their problems
3. More frequent learning opportunities for people with learning disability, e.g. daily classes
4. More support centres such as the Salvation Army centre at Castle Point
5. Give at least 3 weeks per year break to every Carer – either by the use of respite care provision in Local Authority accommodation or through direct payments which the Government have stressed on many occasions should be granted, though only a few Carers are aware of this
6. Carers want to see project holidays reinstated as soon as possible as this provides for some Carers the only respite they have as well as training for the service user. **THIS IS NOT JUST A HOLIDAY!**
7. Transport – people with learning disability need help with transport to college until they finish their education, especially those using wheelchairs
8. Spending more money on all types of respite will enable Carers to carry on caring in the long-term
9. More staff to provide continuity to prevent activities/services being cancelled due to lack of staff

The general consensus is that Carers want more – more frequency of services, more resources to provide services, more help in an emergency, more breaks.

2.3 QUESTIONS TO DAY SERVICES MANAGER

2.3.1 Henry Watson gave an introduction to the Committee outlining his responsibilities as the Day Services Manager and the care provided.

He explained that the various day centres provide the opportunity for the adult with learning disability to exercise their rights, gain independence, choose how to live their lives and social inclusion. These centres also assist in accessing professional help such as speech, physio and occupational therapy as well as dental services, community nursing including consultant's clinics and social services teams.

Mr Watson also informed the Committee about the various community based programmes available such as:

- Adult Education/colleges

- Use of leisure facilities for music/sensory activities, cooking, art and craft, sports and games
- Work orientation/work experience in the community
- Basic education and computer skills training

Mr Watson responded to the following questions as previously submitted on behalf of the Committee:-

Question 1

What are day services for?

Answer

- Enable people with Learning Disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships
- Day services provide a range of day opportunities for service users with a learning disability who are 18 years old or older who meet the “ Fair Access to Care “ criteria
- Day Services provide opportunities which meet assessed needs that have been identified through a community care plan
- Day Services provide opportunities for service users to mix with their peers and other people in environments in such away as to enable them to lead full and purposeful lives

Mr Watson informed the Committee that the Viking unit has 32 service users with complex/profound needs, the staff are fully aware when they are happy/sad etc by watching for visual signs, by eye, hand or facial movements.

The service users at Avro/Viking and Maybrook have a part in developing their own care programme, but some of these will not meet ‘Fair Access to Care’ criteria.

Approximately 300 service users access the 3 units. With 95 staff, there is access to the community in small groups.

Question 2

What do they do for people?

Answer

- Valuing People says that whatever plans we make must help people to:
 - Exercise their rights
 - Achieve as much independence as possible
 - Have more choice about how they live their lives
 - Be included in their community the same as everyone else
- Our Day services provide support which facilitates access and inclusion in a variety of community resources and activities which generally would be available to non disabled members of the Southend community.
- Provide a range of services which allow eligible service users to lead “fulfilling lives”

Mr Watson informed the Committee that there is an average of 1 member of staff for 2.5 persons, for services provided to users of Viking House with profound and multiple learning disabilities (the ratio for most day services is more like 10:1). When service users are taken on community based outings the ratio should be 1:1, but if specific needs are to be met the ratio is 1:2

Question 3

Do day services have a role in supporting Carers

Answer

Following a carers assessment many family carers are eligible for “Day respite”. The department’s day services fulfil these assessed and eligible needs allowing carers the opportunity to have more fulfilling lives. The provision of such support allows carers to contribute in their caring role for longer.

The Committee were informed that Viking House is the only purpose-built facility for people with profound and multiple learning disabilities, but is full. At any time 2 service users must be out of the building accessing the community to comply with regulations. A Day Centre prolongs the service user’s ability to stay at home with parents/carers.

Question 4

Does helping people to work achieve the Social Care Department aims?

Answer

- Integral part of modernisation strategy
- Focus on ‘ability’ NOT ‘disability’
- Provides true route to community inclusion
- Promotes independence/choice/sense of being valued and equal
- Invests time in individuals

Question 5

How is the employment strategy “Making it Work” changing people’s lives?

Answer

- People have the OPTION of moving out of day centres
- More control over spending power
- New social circles of friends
- Learn new skills
- The choice of working like the rest of family/friends
- Achieve greater independence
- Gain confidence – feel valued

Question 6

Do the current day services help people to live ordinary lives?

Answer

- All Our service users have individual views about what they believe to be an ordinary life
- Our services must reflect this in the way they are provided
- We have developed an improved review system and a more comprehensive approach to “Person Centred Planning”.
- The employment of the “person centred Planning co-ordinator” has further focused the considerable amount of work that has already taken place within the service in standardising our approach to “person centred planning”
- These opportunities allow service users to express their views in respect to the format/content of the services that we provide and the type of support that they receive.
- Regular consultation opportunities have been established for our service users through advocacy/Deciding Together groups.

- By providing these various channels of communication our service users can express their views which ultimately allowed us to assist them in achieving the ordinary life that they want.

Mr Watson gave an example that through the advocacy service a request was made to visit the London Eye, and with careful planning this was achieved.

Question 7

How is money currently being spent on day and community support services?

Answer

Mr Watson provided the details for the total expenditure for the Viking, Maybrook and Avro Day Centres as follows:-

Expenditure

Employees	£1,576,900
Premises	£ 152,900
Transport	£ 222,050
Supplies/Services	£ 143,150
Management Admin/Tech Serv	£ 247,850
Capital Financing	<u>£ 131,000</u>

Gross Expenditure **£2,473,850**

Income

Other Grants	£ 824,700
Sales	<u>£ 69,750</u>

Total Income **£ 894,450**

As the above figures show transport/staff are a very high priority with regard to the provision of services.

Question 8

What do we know about the needs and preferences of people of different ages, abilities, interests and ethnic background?

Answer

- Various actions have been undertaken to ascertain the needs of the above-mentioned groups in order to plan and establish more appropriate services. These have included
- A project identifying the different ethnic minority groups in the Southend area. This work needs to be further developed the contacts that have been made.
- A research project has taken place to look at age appropriate opportunities as people go through different stages of their lives
- Some specific joint working has taken place between Adult Education, Education and Social Care to start developing a post school provision in the form of a specialist 19-25 Project
- Additional work needs to be completed in the following areas
- Develop services to suit people of all ages, including (Transition) planning for people leaving school, and as they go through different stages of their lives.

- Various collaborations need to take place between schools colleges and social care etc to look at service users who have a mild disability and may not meet the “Fair access to care” criteria as well as the increasing population of service users with “complex” needs due to improved health provision

Mr Watson informed the Committee that the services provided must be flexible. Across the 3 units there is a high proportion of older users.

Question 9

What steps are being taken by the Borough, PCT and other large employers to offer work opportunities to learning disabled people?

Answer

- All Department Heads were contacted and invited to be creative with vacancies. Unfortunately there has been a very limited response so far.
- SBC participates in the Workstep Programme
- Proposals awaiting approval to create three paid work experience posts as a stepping stone to mainstream employment
- Two people with Learning Disabilities recently contracted to employment
- Provides Volunteer opportunities in Viking House
- Provides unpaid work experience placement opportunities

Mr Watson stated that the day centres had a good relationship with SAVS, and overall relationships in the public sector were growing. There was a therapeutic project in Maybrook which has changed as initially it only benefited 4 users. Disabled Access provision is being dealt with by the Corporate Disabled Access Working Party.

Question 10

What is being done to tackle the difficulties surrounding employment and the effects on benefits?

Answer

- Appointment of Employment Co-ordinator has brought agencies involved with employment together under one umbrella to harness a system of fair access to good advice to all Service Users
- All existing work placements brought into line with Permitted Work Rules and Employment Laws
- Information Sheets produced
- Links set up with key advisers in the Social Security and Jobcentre Plus
- Participation with Benefits Network
- Liaison with Carers/Employers on the implications of employment on benefits
- Partnerships formed with NDDP Job Brokers
- Participation with Advocacy Groups to a National level to address benefit issues

Mr Watson stated that the Government wanted employment opportunities to be provided for all who want it, but they did not provide any funding. Day Centres train users for employment and hopefully for inclusion into a project. The Committee were informed that it is not every service user's wish to work, that they do not all use the facility 5 days a week, usage varying greatly. The service users are profiled and an appropriate opportunity found by a co-ordinator.

Question 11

What is being proposed regarding Southend's Day Centres?

Answer

The current "Scrutiny Process" will decide the direction that the council wishes its services to develop. There have been some significant changes following "Valuing People".

These include

- The establishment of an overall operational manager for day care as opposed to three separate managers
- An incremental approach to the modernisation strategy "Fulfilling Lives" and implementation of its action plan
- The establishment of a joined up approach to service provision and the necessary acknowledgement that this needs to be a council initiative across all departments.
- More radical changes would be needed to achieve all the "Valuing People" objectives" following the scrutiny process.

Mr Watson stated that any changes must meet the aspirations of the Service Users.

Question 12

Will they be used as the base for work, education and leisure activities both within the centres and in the community?

Answer

- It is envisaged that we will for the present need a centre based service from where service users will meet and from where they will receive support from staff and their peers
- Many of the activities that need to be supported can be directly accessed in the community such as work, adult education and various leisure activities.
- Transport is an important part of our services and currently we are reviewing the way in which transport is provided following the recent "Best Value review".
- The following three main types of service delivery will be established within day services as a whole to meet these assessed needs.
- "Community Access Teams" providing the appropriate support to access all community activities
- "Specialist programs provided by the day care services based on assessed need including specialist health provision.
- The development of Social clubs to promote social independence and provide respite care

The Committee was informed that when the Community Access Teams need facilities for specific personal care needs of the service users, they have to return to the Centre.

Question 13

Are the needs and aspirations of forthcoming school leavers being property planned?

Answer

- There are structures in place for the transition process to take place.

- There are joint working initiatives over the 19-25 Project.
- An integral part of the Employment Strategy is that Employment should be a necessary choice/option by right
- In transition planning school leavers should not be confined necessarily to one route into employment opportunities

Mr Watson informed the Committee that Remploy does not have any links with the Day Care Centre employment provision.

2.4 QUESTIONS TO COMMUNITY TEAM MANAGER

2.4.1. Karen Bradford responded to the questions previously submitted on behalf of the Committee as follows:-

Question 1

Why do people with a learning disability need social services?

Answer

- To carry out assessments.
- To co-ordinate care packages and multi-disciplinary inputs. To arrange long term accommodation and care
- To arrange short breaks and support family (unpaid) carers.
- To arrange day opportunities and community support
- To protect people who have learning disabilities from abuse.

Question 2

Why do people with a learning disability not use the same services as everyone else?

Answer

Until the 1950's it was generally accepted that people who had learning disabilities were best placed in segregated long stay institutions. The terms mental deficiency and mental sub-normality reflect the underlying attitudes of the day.

This legacy has meant the people who have learning disabilities are often excluded from services used by the rest of the community.

Today, Valuing People is very clear that people who have learning disabilities should be able to use the same services as everyone else.

Question 3

What sorts of things do people with a learning disability need help with that social care services should provide?

Answer

- Southend has set its eligibility criteria for the receipt of services at the level of critical and substantial risk for all adult services (Ref FACS policy)
- The following types of support may be provided following assessment:
 - Help with personal care
 - Help with daily living activities
 - Support in accessing ordinary community opportunities such as leisure, education, employment and housing.
 - Maintaining a supportive social network

- Support in being safe.

Question 4

How are people helped to live their lives in the way they choose?

Answer

- **Person Centred Planning.**

This means doing things in a way that the person wants and which helps them to be a part of their community.

This involves listening to and learning about what people want from their lives, both now and in the future.

- **Advocacy**

Formal advocacy and supporting self advocacy

Question 5

How does Person Centred Planning tie in with the Social Care Department's responsibilities for assessment, care planning and provision of services where there is critical or substantial risk to people's health or independence (FACS)?

Answer

- The NHS and Community Care Act 1990 places a duty upon Local Authorities to carry out an assessment where a person appears to be in need of services.
- Following assessment, services will be provided in line with eligible needs as set out in each local authorities' Fair Access to Care Policy. In Southend this is where there are critical or substantial risks to a person's health or independence.
- Person Centred Planning is about helping people plan their lives. Some areas of a person's life will involve services arranged by their local authority. Other areas of a person's life will involve activities supported by people who love and care about the person. Person Centred Planning helps everyone involved with a person to work together to achieve what a person wants.

Question 6

What is the shift in national thinking, driven forward by Valuing People?

Answer

- Ensuring that people who have learning disabilities are supported in exercising their civil and legal rights; that they have the same choices as everyone else; that independence is promoted and that people who have learning disabilities are included in every aspect of their local community.
- This means moving away from large scale congregate services and any service that segregates people.

Question 7

What is the direction of good practice nationally and regionally for people with a learning disability?

Answer

- Shift from congregate to individualised support.

- Separating out accommodation and support so that people who have learning disabilities no longer have to move when their support provider is unable to meet their needs.
- Direct Payments for care and support.
- Support for self-advocacy
- Better access to ordinary health services, social and leisure activities, education and housing.

Question 8

Is it leading us towards a re-focus of the way we commission, procure and provide services for the people of Southend?

Answer

- Yes - Southend currently has mainly large scale day services and registered care where people live with people they have not chosen to.
- In the future we need to commission services on the basis of what we learn from people's person centred plans.
- Fair Access to Care is challenging us to redistribute resources to those in the greatest need.

Question 9

What are our present levels of investment, through directly provided and externally purchased services? How do we know if this is Best Value?

Answer

Registered Care	4.5 million
Day Care	£367,600
Home Care & Community Support	- £337,100
	- £84,200 (one-to-one support)
Respite Care - In-House Services	- £108 a night
- Gowlands	- £209 - £313 a night

Total - 5.4 million

Best Value is about spending money on the right things. At present we spend a huge amount on residential care when Valuing People is challenging us to separate care and accommodation arrangements.

Question 10

What are the key responsibilities of the Local Authority?

Answer

- To carry out assessments under the NHS and Community Care Act 1990 and the Carers (Recognition and Services) Act 1996.
- To arrange services for those who are eligible under Fair Access to Care following assessment.
- To lead commission services for people who have learning disabilities
- To promote rights, independence, choice and inclusion.
- To support people who have learning disabilities in being safe and healthy.

Question 11

What value is added through Partnerships, both in the formal Partnership Agreement and working through a Partnership approach with local organisations, including the voluntary sector?

Answer

- Access to the same statutory and community services as everyone else.
- Breaking down barriers to accessing ordinary services.
- Pooled funding through Health Act flexibilities.
- Multi-disciplinary Community Team enables prompt specialist assessment of individual need.
- Over time, more formal partnerships will enable greater accountability for the work of staff against local partnership arrangements.

Question 12

How do we achieve a balance in considering the specialist health needs of learning disabled people, and their place alongside all other Southend residents who need access to Health Services?

Answer

- Most people who have learning disabilities have greater health needs than the rest of the population. They are more likely to experience mental illness, chronic health problems, epilepsy or have physical or sensory impairments.
- As life expectancy increases age related diseases such as chronic respiratory disease, cancer and dementia are of particular concern.
- Please refer to the Southend Learning Disability Good Health plan.

Valuing People says that specialist Learning Disability health services need to get better at helping people to access mainstream health services, and mainstream services need to reduce inequalities.

Question 13

How well are the needs of Carers being met?

Answer

- 159 sets of family carers
- 66 families use residential based respite in 2003/4:
- 875 nights at Berland
- 546 nights at Shelford
- 937 nights at Gowlands
- Carers Support@home provides a home based "sitting" service to 5 people.
- Carers Grant funded one-off services to 19 families.
- Greater flexibility is needed in the future.

2.5 **ADDITIONAL POINTS**

2.5.1 **Advocacy Service**

The BATIAS service is commissioned by a range of organisations such as Essex County Council, Thurrock Social Care, Thurrock PCT, Brentwood, Basildon, Billericay and Wickford PCT, Southend PCT, Castle Point and Rochford PCT. The anticipated income for 2004-5 is expected to be in the region of £290,000.

Southend MENCAP funding was from the National Lottery - £116,000 for 3 years.

There is no budget within Southend Social Care for Advocacy, the money for the service being allocated from the Health Budget and the LDDF, total £27,000. Over the last three years BATIAS has paid for an average of 3 hours of formal advocacy per week in Southend at a cost of £4,500 per annum.

Over the next financial year it will not be possible to provide the three hours of advocacy.

2.5.2 **Day Services**

The possible use of buildings in the evening is being looked into for social clubs etc. This would provide a link between the local community and the service users.

Private providers are coming on stream for Day Care Centres, but costs are high. Mr Watson was not aware of private provision for Special Needs, as the costs would probably be astronomical.

2.5.3 **Southend Community Team**

The team is a partnership between Southend Borough Council Department of Social Care and South Essex Partnership NHS Trust.

The core team currently consists of 5.5 qualified social work staff, 5 social work assistant staff and 3.5 nurses.

The extended team includes psychiatry, psychology, behaviour therapy, occupational therapy, and speech and language therapy staff together with an inclusive communication worker, a person-centred planning worker, an adult placement worker, a shared leisure co-ordinator, an employment co-ordinator, and two home care assistants.

The team currently serves 575 people who have a learning disability and their families. Of these:-

252 people live in registered care homes
164 people live in their own homes with support provided via this Council
159 people live with family
10 people are currently detained under the Mental Health Act
155 sets of family carers are known to the team
2326 nights of planned short breaks (respite) provided in 2003 (service provided for 66 people, 23 of whom have special care needs).

Other points made were:-

- More children with very profound disabilities are living well into adulthood while many adults are living well into older age.
- There are a number of adults who have a learning disability and are parents or who wish to become parents. There has been a sharp

increase in the numbers of people diagnosed with Autistic Spectrum Disorder

- There are more older family carers
- Improving access to mental health services should be a priority
- Adjustments need to be made to the level of service to people who do not have critical or substantial risks to their health or independence under Fair Access to Care, but who have received services for a number of years. Demand for services currently outstrips resources and Valuing People predicts that demand for LD services will increase year on year for the next 15 years.
- Moving from large scale group services to individualised support in line with person-centred planning.

2.6 **OVERVIEW**

2.6.1 Mrs Penny Furness-Smith the Director of Integrated Services ended this session by stating that, whilst she heard the presenters' pleas for more resources, the Council already spent above the indicative national average for this user group.

Requests for additional resources would need to be considered in the light of:-

- The Council's overall budgetary position
- The need to comply with the 'Fair Access to Care' eligibility criteria for all adult care services.

If the Council wished to provide additional resources for this group, the possible impact on other user groups would also need to be considered and such a course of action could lead to a possible legal challenge.

There was also a need for a corporate approach to transport for the service users and the Committee was informed that marked transport was not now used.

The impact of nationwide registration is a further constraint since it also applies to other services and therefore requires flexibility in the use of resources.

The ultimate questions were:-

- "are we doing the right things?" and
- "are we doing things right?"

**SOUTHEND ON SEA BOROUGH COUNCIL
COMMUNITY SERVICES SCRUTINY COMMITTEE –
IN-DEPTH SCRUTINY**

“Learning Disability Services”

EVIDENCE SESSION NO.2

8th April 2004

ATTENDEES

Carole Houghton (BATIAS)
Myra Bradley (Southend MENCAP)
Tonda Oswald (Student Representative)
Donna McClean (Student Representative)
Janet Kent (Student Representative)
Rosalie Mossop (Student Representative)
Ruth Bull (Head of Learning Disabilities)
Louise Langley (Residential Homes Manager)

1. INTRODUCTION

1.1 Members of the Committee had previously been circulated with background papers giving the following information:

- Responses to questions from the student representatives
- A report from the Learning Disability Task Force – Rights, Independence, Choice and Inclusion
- Introduction to Standards 24 to 30 relating to Care Homes

1.2 Myra Bradley gave an introduction regarding a film presentation about the Southend People’s Parliament. This was produced to aid in the application of a grant.

- The presentation featured various service users/student representatives, who voiced their views and opinions and who would like to be an MP in the People’s Parliament.
- The points that were highlighted in the presentation were the need for access to more sports facilities and buses, the need to address issues relating to bullying and concerns with environmental issues such as flying tipping and vandalism.

2. RESPONSES TO QUESTIONS

2.1 QUESTIONS TO SERVICE USERS/STUDENT REPRESENTATIVES

Myra Bradley (Southend MENCAP) introduced the Service Users/Student Representatives to the Committee. The Committee was informed that the responses would be given by Tonda Oswald and that she would give a short introduction about herself. The Advocate also responded to the questions and these responses are shown in *Italics* along with any additional comments. The introduction and responses to questions were as follows:-

My name is Tonda and I am here today to answer the questions that the Scrutiny Committee has asked of people using the Learning Disability Service.

My Advocate, Eileen from BATIAS has helped me to understand the questions.

First of all, I will tell you a little bit about myself.

I am Tonda and I am 37 years of age. I live in Southend with two other ladies in a house, which is supported by Mencap. My housemates are Paula and Lorraine. We have lived together for a long time.

We have a support worker, Denise, who comes in to help us every day, Monday to Friday. She comes in to see us when we get home from work at about 4.30 p.m. and stays until 7.00 p.m. We do not have any support at the weekend now because we are all out with our boyfriends and it's nice not to always have people coming into our house. At weekends I normally have a meal at my boyfriend's house.

I am engaged to Martin who lives in Westcliff with three other gentlemen. Martin also lives in a supported living house, which is run by Mencap.

I work at Snacktime Cafe for 3 days a week and I go to Maybrook Day Centre on Friday. On Wednesday my support worker comes to the house for much longer because it is my 'training day'. On this day, we might go out shopping for clothes and she also supports me with anything I might need help with. I also do my washing and ironing. In the house we have a rota for cleaning and we have house rules.

I like to do the housework and shopping. I like going out to buy clothes. At home we have a 'girlie night' and it is good fun - we might have lots of food on the table and watch a video, or we might go bowling, or do make-up or polish our nails. I love discos and karaoke. I am in a drama group and played Maid Marion - the picture on the front is of me dressed as Maid Marion. I also like the gym.

Question 1

Is the right help available for you to live an ordinary life?

Answer

I have help in the house when I come home from work. I also have one day off in the week on Wednesday when my support worker comes to help me -

- sort out my clothes
- fill in forms which come in the post
- with cooking if I am unsure about what I am doing
- She also comes with me to do food and clothes shopping.
- She takes us to the supermarket once a week to do a big shop.
- I go to the Doctor on my own but she goes with the other ladies.

When our permanent support worker left last year, we had lots of different agency staff and they did not help at all. We were all very unhappy in the house at that time because the agency staff just came and watched television and it was lots of different people. I kept crying because I could not cope.

Now we have a permanent staff member and it is lovely because she supports us.

I do not go out at night on my own because I don't have support.

I go to club one night a week with my fiancé. If I go out I usually travel by taxi although I do go to work by bus and I can do this on my own.

The question 'ordinary life' is hard to describe as the definition of 'ordinary' is usual or normal. Nowadays, what is an ordinary life?? Tonda feels she is living an ordinary life because this is all that she has experienced and what she is doing is normal to her. She knows that lots of people go out to work but she feels going to work at Snacktime is the same and this is normal. She works very hard at the Café, as do others in catering and she has taken her Basic Hygiene Certificate.

Tonda is very able and has an independent nature. This, coupled with living in a supported house, has enabled Tonda's skills to develop and she tries to do most things herself. However, if she were living in a residential home, she would not be leading an 'ordinary life'. This could be for many reasons but the main one would be that the majority of things are done for the residents, even though there are people who would like to and can do more. There are also not enough staff members to accompany the residents to access the community on a frequent basis.

Question 2

Do the current day services help you to live an ordinary life?

Answer

I work at Snacktime and have been there for many years. Sometimes I like it but I would now like a change. I do the same things at Snacktime and get a bit fed up.

I like Maybrook on Friday because I do drama and karaoke. I think Maybrook is a lot of fun and I can meet up with all my friends.

I would like to do a hairdressing course but Maybrook do not do this. Linda Walsh at Maybrook said she would help me with this.

I also want to do a computer course and I would like to do this at Maybrook with my friends but I only go there one day. If I can't do this at Maybrook I would like to go to college.

Going to a day service is not in reality living an ordinary life because people without a learning difficulty do not go to day centres, although there are exceptions like mental health and elderly clubs.

In the past day services did not usually access the community but this is now happening although there is still a long way to go. However, taking out service users in large groups immediately puts a 'label' on them and it would be preferable to have more staff to take out smaller groups of, say, 2-3 people.

Again, Tonda has only experienced the day service of Snacktime and Maybrook and this to her is ordinary (usual and normal) because of her lack of life experiences in any other field. Tonda is aware that lots of people do lots of different things but her experience of the day services is living an ordinary life.

Advocacy has helped people to become more assertive and confident to speak up for themselves and enabled them to express their choices and feelings to someone independent of Council services.

The Committee was informed that Snacktime is owned by South Essex Partnership, as a training programme for learning disabled adults, female only, to achieve basic

hygiene certification etc. There does not appear to be anything in place at this time to access work in the community once accreditation has been achieved; this was highlighted when Tonda informed the Committee that she had worked there for 14 years.

Hadleigh Training Centre also provides some training for both male and female learning disabled adults.

Proposals for improvements to the service, such as gaining skills in consultation with local employers and finding future employment are currently being considered.

The other service users/student representatives informed the Committee about their lives;

Donna lives in a Group Home and works at MENCAP filing/photocopying and helping in the shop.

Rose attends College twice a week, taking courses in Self Advocacy, Dealing with People and Drama, she enjoys visiting friends and family, and at the moment her mother is unwell, which she finds distressing.

Question 3

Tell us of your experience of Person Centred Planning.

Answer

I do not know what Person Centred Planning is. When my Advocate asked me this question I told her I had not heard of it. She explained it is about me, a sort of map about my life, what I want to do in my life, who I want to do it with, how I can do it. I would like to do a person centre plan.

I believe that because Tonda attends Snacktime, this type of work environment does not include talks/discussion about what is actually going on in Southend for people with a learning disability. Although she attends Maybrook one day per week, she has a timetable that does not include any discussions, which may take place about Person Centred Planning (PCP), or the various strategies in place.

The Committee was informed that there is a difficulty in getting new strategies to people who do not attend day centres on a regular basis. Letters are sent out but for some these can be intimidating, so are binned unopened. It showed a need for this process to be streamlined with the aid of employers, advocates and day centres. There was a suggestion that perhaps this information could be left at a central point and then distributed by the support workers, for placement on notice boards or discussion on a one to one basis. If client then requests further information this can be accessed.

Question 4

How is the employment strategy "Making It Work" helping people?

Answer

I know that Linda Walsh helps people to find jobs but I don't know about `Making It Work` - I have never heard of it.

Again, I feel that because Tonda is at Snacktime, she misses out on what's going on. As her formal advocate, I only work on 'issues' and am not responsible for going through the various strategies with her.

Generally the feeling is that the learning disabled adult would like to take paid employment. Unfortunately, this can lead to the loss of some or all of the benefits, and it is very difficult for them to get them back.

One of the witnesses was employed, but due to the diagnosis of epilepsy was then sacked.

Question 5

How good are the Social Care Department and the Housing Department at helping people to live in their own homes?

Answer

I want to live with my fiancé. We would like our own flat in Southend. When we decided this is what we wanted, I asked my Social Worker if we could have a meeting with my parents, support work, advocate, homes manager and my manager at Snacktime. I wanted to tell everyone what I wanted for my future. My mum and dad were worried that me and Martin would not be able to manage but we all talked about it and what type of help we would get.

We talked about the future and made a few plans. The meeting was to plan the way forward, to make sure everyone is happy for me and to talk about housing options because I did not know where we could live.

My social worker visited me to fill in the Council Housing Forms and this will also go to other housing associations.

Martin and me will still need support when we get a new home.

The options for Tonda and Martin are quite limited as the majority of vacant flats would not particularly suit them or their needs. This is because they are either in high rise blocks or on disadvantaged estates where we know that people with learning difficulties are discriminated against.

Rose Mossop informed the Committee that she suffered problems at home, but after a visit to Grahame House decided that she wanted to move there, but was scared of telling her mum. Rose was initially refused a place, but as there were concerns for her future, her mother not being fit, and Rose having medical problems such as self mutilation and temper problems, a place was allocated.

Since moving into Grahame House, Rose has been able to suppress her temper and lead a very independent life, such as going out in the evening and travelling abroad with her friends, something that could not have been contemplated when living at home.

Donna McClean lives at Elm Lodge, a group home, and informed the Committee that she is fully supported by the workers.

Question 6

Are day services a way of supporting Carers?

Answer

Yes because when the person goes to a day centre, it gives the carer time to themselves.

Tonda found this question a little difficult to answer because she has not been in that position herself. Tonda did have respite at Berland, but she was not aware that it was really for the benefit of her carers.

Question 7

What is the quality of the Care Home services directly provided by the Council?

Answer

This is a difficult question. I have only stayed at Berland House but that was a very long time ago and I really can't remember. I think everyone was nice to me and the food was ok.

Tonda felt she could not really answer this question. We talked about Berland but like many people, because it was such a long time ago she had difficulty in remembering the experience.

Donna, Janet and Rose had mixed feelings about the quality of the staff and services provided, but meals seemed to be an issue with not enough choice being offered.

Advocate's Response.

Obviously, Tonda is quite an independent young lady. Her dreams for the future are no different to many other young women - she wants to have her own home with her husband. Hopefully, Tonda and Martin will achieve this with the help of Social Care and the Housing Department but they will be vulnerable. It is important that the Council recognises that there are not enough housing opportunities for people with learning difficulties to live 'ordinary lives' in a safe environment.

Because Tonda works at Snacktime Cafe - which is a work-training environment - it is apparent that the service users at this establishment are not given the opportunity to discuss the strategies and any other opportunities which have been launched in Southend.

I believe Snacktime was set up to train people to move on, yet there appears to be extremely slow movement in this area. A lot of the trainees have been there for many years, thereby excluding others from having the experience of working in a Cafe.

Tonda thoroughly enjoys Maybrook - this is an opportunity for her to mix with her peers and not to be judged. For Tonda and many other people, it would be devastating if there was not some kind of Resource Centre where they could meet, because life for a person with a learning difficulty can be a very lonely one.

2.2 QUESTIONS TO HEAD OF LEARNING DISABILITIES

Ruth Bull responded as follows to the questions previously submitted on behalf of the Committee:-

Question 1

What sorts of things do people with a learning disability and their carers need help with that social care services should provide?

Answer

- People with a learning disability need help with personal care and accessing services that enable them to exercise control over their own lives.

- Social Care Services provide advice and information, and a Community Care Assessment, and Carers Assessment in accordance with Fair Access to Care Services.
- Social Care identifies help that is required to make sure there is not a critical risk to people's health and independence.
- The sorts of things Social Care Services provide for people with a learning disability are:
 - Care and Support at home, for daily living activities;
 - Support to access day opportunities;
 - Support to develop skills in independence at home and in the community;
 - Support to move to different accommodation;
 - Support for life-time changes, like transition from school, having a baby or becoming old and frail.
- The sorts of things Social Care Services provide for Carers are:
 - Planned breaks;
 - Help at times of crisis.

Question 2

What does Valuing People say about where and how people should live?

Answer

- Increase the range and choice of housing open to people with a learning disability in order to enable them to live as independently as possible;
- Ensure people with learning disabilities and their families obtain advice and information from appropriate authorities;
- Enable all people currently in NHS long-stay hospitals to move into more appropriate accommodation and reviewing the quality of outcomes for people living in NHS residential campuses.

The Committee was informed that this Council has no long stay residents in hospital.

Question 3

What is the direction of good practice nationally and regionally? Is it leading us towards a re-focus of the way we commission, procure and provide services for the people of Southend?

Answer

- That people with Learning Disabilities should be able to access the same opportunities and facilities as every other member of the public. This means more housing that is adapted; paid employment; going to clubs and dances etc.
- Social Care should not act as a substitute for these things but should provide support to enable learning disabled people to participate.

Mrs Bull informed the Committee that once opportunities in the Community open up, there are infrastructure and strategies in place to ensure the safety for the adult with learning disabilities in the community.

When a learning disabled adult is identified by staff as being at risk (personal safety), it would be followed up with a team meeting to gauge the level of support needed and address the situation.

A recently appointed Community Employment Co-ordinator is working to implement the Council's learning disability employment strategy "Making it Work" involving local employment agencies, to aid in finding work for people with the right skills. Funding for this is not given to Social Care, but to other outside agencies.

Question 4

Much emphasis is put on choice and there is a lot of emphasis on independent living. Can we be sure this is what is best for people and this is what they want?

Answer

- 40 years ago, NHS inpatient care was seen as the only way to make users with a learning disability safe, and sometimes this meant locking them up on special wards. 15 years ago residential care was seen as a better and thus reasonable alternative but working to the same principle – that we needed to make people safe; but in doing so we took away the users' choice and control over what they did and where they did it.
- How many ordinary people make a positive choice to live in someone else's home, never able to close their own front door?
- How many people are not to be able to prepare food or the types of meals of their own choosing or to determine the type of furniture they are surrounded by; and to have people supervising them most of the day?
- We know older people who find it difficult to manage their everyday lives who would still rather be in their own surroundings with people coming to help and support them rather than moving into a care home, no matter how wonderful or caring that home is. Why is it different for a person with a learning disability?
- Assessments, reviews and surveys tell us about the sort of accommodation people choose.

Mrs Bull informed the Committee that some learning disabled adults can also have mental health problems which may require admission to a secure unit under the Mental Health Act 1983. The issue of dual diagnosis is being addressed at regional levels.

The Committee was informed that learning disabled adults who have been in the system for a long time may find it very difficult to make choices, whereas the adults that are in transition from children to adult services are clearer about what they need or want to do.

Question 5

How are people helped to make realistic choices?

Answer

- More information is becoming available in accessible formats.
- Person Centred Planning is helping people say who, and what is important in their lives now and in the future.
- Multi-agency assessments through the Community Team for People with Learning Disabilities help people focus on their abilities and strengths not their disabilities; their needs, and what is currently most important, realistic and achievable.
- Advocates help people formulate and express their own views, and be realistic about what they can expect.

Person Centred Planning is a plan that includes all aspects of a persons life. Social Workers, Advocates, MENCAP, family and friends are asked for their contribution so that a total picture can be achieved.

The Committee was informed that staffing was a problem. There were not always enough people of the right calibre to fill the vacancies. However, the quality of the staff currently employed is high and on-going training is always available.

Question 6

How good are we at helping people who want to live in their own homes and communities?

Answer

- In the Southend 18 Southend people expressed an interest in a move from Council-owned residential Homes to supported tenancies or Adult Placements. About 40 people in Private and Voluntary Sector Homes were already making plans to live more independently.
- Over 3 years about 50% of Berland residents have moved on to supported tenancies. Many keep a link back to Berland with visits back to staff from time to time.
- The Community Team offers support as people move on.
- People are encouraged to be part of the community, joining in the local life of Southend.
- There are lots of different approaches. Lots of people stay with their extended families in the community for a long time. Then something happens that means they can no longer stay – maybe their relative dies or becomes seriously ill. At this point there is not the range of options to choose from, so they move into a residential care placement because that is all there is, not because it is the right solution. More often than not it is the only solution.
- The three residential homes were built to give people places to live in Southend, instead of living in the old hospitals. Some staff have worked in these homes for many years and have no experience of helping people live differently. Many people who live there now would not, if coming into the service today, ever be expected to live in a care home throughout their adult life.

Mrs Bull informed the Committee that some staff require training as they themselves can be classed as being institutionalised, as they have worked in the system for so long.

There were concerns raised that these staff could create mini-institutionalised homes, but it was re-iterated that the level of on-going training was very high, but this was not compulsory. As time goes on, it will become essential as a result of legislation which comes totally in force by 2007.

Question 7

What other Council departments are you working with to make this happen?

Answer

- Social Care being one department inclusive of Housing, we work together.
- We work closely with the Leisure, Culture and Amenities Department, to help people make use of the town's range of community leisure facilities. In this way people with a learning disability feel included and valued.

- The need for care and support is vital, to ensure those who are most vulnerable receive help in the way they choose and can manage risks in a safe way.
- Service users, students and carers still value the current types of services and service model. Until there is an effective network of places where people feel confident to meet there remains a need for established support and infrastructure in Southend.
- The best way of helping the people of Southend to become familiar and comfortable with those who have a learning disability is for them to become neighbours in the same streets, living in a mix of supported tenancies, using the same shops and services.

The Committee was informed that Community Inclusion Workers, who is in a sub-group of the Community Team, is part of a project to find places in Southend which welcome adults with learning disabilities, some of whom have profound behaviour difficulties, so that they can meet in confidence and hopefully create a safe network.

Question 8

We have heard from Advocates and Carers concerned that individual needs and wishes should drive change rather than financial constraints. How will these concerns be addressed?

Answer

- The Council often has to achieve a balance between what people might like or want, what the Council must do, and the resources available to do this.
- Fair Access to Care Services, as has been referred to at previous witness sessions, is the Council's criteria for determining when we will respond, and that in doing so it will be only to eligible needs.

Question 9

Why is it appropriate for some people with learning disabilities to live in care homes?

Answer

- Very few people *need* to live in care homes; they do so because different types of accommodation and care support is not available or accessible presently. The numbers of people requiring residential care is decreasing.
- Some family carers need their loved-ones to have residential respite stays, to give carers a break.
- People should not have to live in a residential home, which is a very different style of living from the average citizen of Southend.
- Some people may need residential care because they are getting old, like the other residents of Southend.
- It may be necessary for some people at difficult times of their life, while they get the help they need. This includes people who:
 - have severe and complex needs, (Usually with mental health or behaviour;)
 - have very specialist needs such as severe autism;
 - have profound and multiple learning disabilities;
 - have specific problems or health needs.

Mrs Bull informed the Committee that the life expectancy of adults with learning disabilities has lengthened due to the improvements in health care. At this time there is an increasing need for residential accommodation for adults with Down's Syndrome who have early dementia.

Question 10

How is the Council currently investing its resources to provide quality accommodation?

Answer

- We recognise that the services that we currently provide at Berland Shelford and Saxon do not meet the National Care Standards, and were never designed to meet these standards. The council has invested some capital resources into the 3 sites to meet Health and Safety requirements and to provide basic comforts.
- None of the Council's 3 Learning Disability Residential Homes will meet registration standards by 2007. All three of the existing sites have a significant proportion of their current bedrooms that are less than the national minimum of 9 square metres. In securing registration for them, the NCSC have so far imposed very strict conditions and criteria that some bedrooms have got to come out of use to create "compensatory living space."
- Currently less than 10 of the 50+ bedrooms are big enough to get the minimum furniture and equipment in.
- **Shelford** offers care unacceptable to NCSC because of:
 - the small size of almost all the bedrooms,
 - The lack of access for disabled people and the poor structure and amenities of the building.
 - Peoples' needs could all be better met elsewhere, leaving the Shelford building surplus to requirements.
 - The land has potential for development.
- **Berland** similarly offers an unacceptable model of care because of:
 - The small size of most of the bedrooms,
 - Lack of access or amenities for disabled people.
 - Most of the Southend residents have been assessed as having the potential to move to supported accommodation
 - Peoples' needs could be better met elsewhere leaving the Berland building surplus to requirements.
 - The land has potential for development.
- **Saxon Lodge** is the most modern and smallest of the 3 homes, with homely living space on each floor but no lift.
- All rooms are undersized so it fails to comply with NCSC Standards.
- All residents are long-stay, some Southend people are frail or approaching older age, and most will need residential care in future;
- Saxon offers a good standard of care in a pleasant setting but in unsuitable accommodation. There is limited access for people needing help with a hoist as room sizes hinder this.
- It may be adequate for the next 2/3 years prior to the requirement to cease the use of any home with undersized rooms;
 - Residents will by then need a new place to live unless Saxon undergoes major refurbishment involving significant capital outlay to increase the size of all the bedrooms through provision of extensions to each room. Alternatively knocking 2 rooms into one, whilst it would create registerable room sizes – the capacity would reduce to nearly half and would thus affect the unit cost of each placement.
- There has been some investment in alternative solutions such as that at Grahame House but this has been small scale given the number of people benefiting from the schemes.

The Committee was informed that the Supporting People Budget is fully supportive of people with learning disabilities and that the Support Housing Schemes mean that housing costs are met by Housing Benefit.

Part of the appraisal process will be to look at all of the options that would be available.

Question 11

How could we invest resources differently to develop modern services?

Answer

- We could make a significant shift from building-based to community-based activity and from residential care to supported accommodation options.
- It is likely that some of the existing capital assets can no longer be used- but in order to re-provide and secure alternatives there is need for some new or pump-priming investment. This could come from the private sector, from registered social landlords or potentially from capital tied up in these existing assets.
- Staff from the three residential homes have the potential to develop flexible skills to join teams delivering care and promoting independence for new tenants.

Question 12

In the context of the above what is the thinking about the future of the Council's three learning disability homes?

Answer

- Given the response to questions 9, 10 and 11, it is clear that the council's 3 learning disability homes are not fit for their future purpose. Consideration will need to be given to a range of alternative proposals including securing some private/independent sector care placements, developing supported accommodation, developing extra-care housing schemes, creation of shared purchase ownership schemes amongst other ideas.
- In being aware that the current homes in the current condition do not have a long term future as registered care facilities, any development and planning needs to dovetail with a programme for development, through partnerships, of a range of supported housing options. Through TACT Consultants and RSL and private partners, opportunities are becoming available or are in progress. The shift from traditional residential care to a modern service is becoming a reality in Southend.

Mrs Bull informed the Committee that the Council does use independent registered residential homes, individual rates being negotiated dependant on type of need.

2.3 QUESTIONS TO RESIDENTIAL HOMES MANAGER

Louise Langley responded as follows to the questions previously submitted on behalf of the Committee:-

Question 1

What is the situation in relation to the Learning Disability Homes run by the Council (Shelford, Berland House and Saxon Lodge)?

Answer

The environmental standards in accordance with the NCSC I have brought with me as a pack for your information.

In recent months the homes have been working very hard in order for the homes to be registered. One of the major problems in this area is that most of our bedrooms are under the size that is required by the NCSC. For existing homes, which ours are a requirement of 10 square meters is needed, and if a client is a wheelchair user a room size of 12 square meters is needed. In order to give you a pen picture of current room sizes I enclose the following information.

Berland House

Have 11 beds between 7 & 8 square meters

1 beds between 8 & 9 square meters

4 beds over 10 square meters

Saxon

9 beds between 8 & 9 square meters

2 beds between 9 & 10 square meters

2 beds just at 10 square meters

Shelford

7 beds under 7 square meters

11 beds between 7 & 8 square meters

2 beds between 8 & 9 square meters

3 beds over 10 square meters.

For each of the homes we have had a redecoration program and looked at the space within each unit, and reduced beds in Shelford and Saxon to make compensatory living space. The homes have had to complete a great deal of work in order for them to become registered, but at the moment there are some restriction on the registration that John Nawrockyi has written to the care standards about. At this present time from April 1st the care standards are saying that we cannot admit to any rooms under the accepted room requirement amount. At the moment there is only one client who requires the use of moving and handling equipment, and she is in a room that is not really big enough to accommodate her needs. A review has been held on this client and she will be moving to a service that could better meet her needs.

Question 2

What action is currently being taken to ensure the homes meet the National Care Standards minimum requirements?

Answer

The homes have had to be creative with the space they have. Shelford and Saxon have reduced bedroom numbers in order to supply additional lounge areas.

In addition to this our property services department have been completing additional health and safety requirements needed. The items include:

Radiator guards on all radiators, which the clients can individually control.

All pipework boxed in that could cause the clients harm.

Window restrictors on all windows.

At least 2 double sockets in each bedroom.

Thermostatically controlled water to ensure clients cannot burn themselves

Lockable space for each client in their room.

Work in respect of fire safety

In addition to this many bathrooms, bedrooms, toilets and communal area have been decorated by the homes. There is a requirement for all clients to be offered certain

equipment in their rooms like a table, 2 comfortable armchairs. Obviously this is difficult due to the size of the rooms so the homes have looked creatively at how they could do this by purchasing fold up tables and chair which we have available if clients so wish. We will also consult with the client and if they say they do not require this we will record this in their care plan.

In recent months all clients in the homes have been reviewed to see where their care needs can be best met. Some clients do not require as much support as they have in a residential unit. Where other clients needs could be better met in other specialist unit this work is currently being completed.

Question 3

Do the homes provide a realistic long term housing option for people

Answer

With all three homes there are many restrictions in their room space, which we would have to comply with by the year 2007. Long term the homes are likely to need to provide care for client that are more dependent and this would be very difficult in the space that is currently available. The council would need to invest a great deal of money to bring these homes up to the required standard, and it would probably mean knocking 2 bedrooms in to one, which would reduce the income. In some areas this could even present problems. In addition to this Saxon only has one main fire escape from the first floor, and Shelford has a fire exit across a flat roof.

3 ADDITIONAL POINTS

3.1 Service Users/Student Representatives

The group informed the Committee that the People's Parliament was a very important issue to them. The Parliament allows them to discuss everyday issues in the same way as everyone else.

The group expressed a view that they would like to participate in the Council's Scrutiny Process.

The service users/student representatives informed the Committee that bullying by children when using public transport is a problem and people with learning disabilities are entitled to respect in the same way as everyone else.

It was suggested that there should be a programme in schools educating children. Solution such as staggering the finishing time of the day centres, so they do not coincide with the schools could be considered.

This problem is known to the Partnership Board and discussions are being undertaken with Community Police Officers.

**SOUTHEND ON SEA BOROUGH COUNCIL
COMMUNITY SERVICES SCRUTINY COMMITTEE –
IN-DEPTH SCRUTINY**

“Learning Disability Services”

**EVIDENCE SESSION NO.3
19th April 2004**

ATTENDEES

Trevor Saxon (Joint Commissioner, Learning Disability)
Denise Cook (Director of Older People's Mental Health & Learning Disabilities)
Bernard Dayer (Head of Housing (Resources))
Ruth Bull (Head of Learning Disabilities)
Phil Stepney (Acting Director of Social Care)

1. INTRODUCTION

1.1 Members of the Committee had previously been circulated with background papers giving the following information:

- Responses to questions from Southend PCT and South Essex Partnership Trust
- The Good Health Plan
- Responses to questions from Head of Housing (Resources)
- A paper from the Director of Integrated Services relating to available resources for Learning Disability Services

1.2 Trevor Saxon started the proceedings by outlining the role of Learning Disability Services.

- He explained that people with learning disabilities should be able to exercise their rights, have the chance to live independent lives wherever possible, make life choices and experience inclusion by living in their lives as ordinary members of their community.
- To achieve these goals the Learning Disability Partnership Board has agreed some principles, such as more service user involvement and carer participation as well as providing accessible mainstream services rather than specialist services.

2. RESPONSES TO QUESTIONS

2.2 QUESTIONS TO SOUTH ESSEX PARTNERSHIP TRUST/SOUTHEND PCT

Trevor Saxon (Joint Commissioner, Learning Disability) and Denise Cook (Director of Older People's Mental Health & Learning Disabilities) jointly responded to the following questions as previously submitted on behalf of the Committee (additional comments are in *italics*) :-

Question 1

What is the role of Southend PCT in ensuring that people with a learning disability get the best health care possible?

Answer

Southend PCT is responsible for the planning, provision and development of local health services.

“All means All” is a document produced by the Valuing People Support Team explaining how the Planning and Performance Framework should be used by Primary Care Trusts and Strategic Health Authorities to ensure that their plans for NHS Improvement, Expansion and Reform benefit people with learning disabilities.

Southend PCT therefore has to ensure that its Local Delivery Plan takes account of the needs of people with a learning disability and where there are inequalities (people underrepresented in screening programmes for example), action is taken to reduce these.

People with learning disabilities should have the same access to health services as everyone else, with additional support where necessary.

Southend PCT is responsible for commissioning appropriate specialist and specialised learning disability services where these are required.

Question 2

What does the national guidance say about how health services should be provided to people with learning disabilities?

Answer

The first principle is that people should access mainstream health services (see above).

The history of learning disability services shows that for most of the last century much of the investment in learning disability services was in long term hospital care for people. With the change in thinking as the century progressed, a long-stay hospital closure programme was initiated. Funding for people re-provided with services remained with Health Authorities and later PCTs as statutory successors.

Signposts for Success (1998) was commissioning guidance produced by the Department of Health that required all health service commissioners to consider whether the re-provided services were sufficiently focussed on helping people to access ordinary community health services.

In Southend the Learning Disability Partnership Agreement between Southend PCT and the Council brings the commissioning of services for this group of people in line with the rest of the learning disabled population.

Valuing People (2001) is quite clear that health services must focus on:

- Reducing health inequalities experienced by people with learning disabilities
- Enabling mainstream health services, with support from specialist learning disability staff, to meet the general and specialist health needs of people with learning disabilities
- Promote the development of NHS specialised learning disability services

Valuing People has set three key measures of progress:

- Every Learning Disability Partnership Board area should be clear how Health Facilitation will happen (That is how people will be helped to have a Health Action Plan and to use ordinary community health services)

- Every person with a learning disability should have a Health Action Plan if they want one.
- Every GP should know the people with a learning disability registered with them.

Southend Learning Disability Partnership Board's Good Health Plan sets out in its Action Plan how and when these things should happen.

Mr Saxon explained to the Committee that the specialised Assessment, Treatment and Outreach services for the majority of people in South Essex with learning disabilities who also have a mental health problem or other complex needs are provided by South Essex Partnership NHS Trust at Willowbrook and HeathClose.

Ms Cook confirmed that all providers of learning disability services from 2003 must ensure that staff are inducted and trained within the new Learning Disability Awards Framework.

Question 3

What is the role of specialist learning disability health services?

Answer

Southend Primary Care Trust commissions specialist and specialised learning disability services from South Essex Partnership Trust. The services are currently provided as part of a South Essex wide Service Level Agreement through Southend, Essex and Thurrock lead commissioning arrangements.

There are two distinct aspects to these services:

- Specialist learning disability health services
- Specialised learning disability health services.

Specialist services are those such as Community Nurses, Occupational Therapists, Speech and Language Therapists, Psychologists, that specialise in work with people with learning disabilities. These are seen as important elements in delivering comprehensive services through the Community Team for People with a Learning Disability alongside Social Care staff.

In their specialist role staff should recognise the importance of enhancing the competence of local services to enable service users to remain in their usual surroundings. The tasks that specialist staff undertake will include:

- A health promotion role, working closely with the local health promotion team.
- A health facilitation role, working with primary care teams, community health professionals and staff involved in delivering secondary health care.
- A teaching role, to enable a wide range of staff, including those who work in social services and the independent sector, to become more familiar with how to support people with learning disabilities to have their health needs met.
- A service development role, contributing their knowledge of health issues to planning processes.

Specialised services are Assessment, Treatment and Outreach services as defined within the Department of Health's specialised services definition set (No.21) and are required for the minority of adults with learning disability who also have:

- Severe challenging needs and present major risks to themselves and/or others
- Severe mental health problems which cannot be addressed by general psychiatric services
- Autistic spectrum disorder with severe challenging and/or mental health needs

Over the next few years the direction for these services will emphasise the importance of specialist services undertaking an increasing health facilitation role to ensure that wherever possible people receive mainstream NHS services to meet their health needs, with the support of specialist services where necessary.

Mr Saxon informed the Committee that a Health Profile Document was just being published; these will be held in the Community Team, and information will be provided through the Health Facilitation Co-ordinator about how to get a copy.

The document will include all the information provided by the Carer/Service User and will belong to the service user.

Question 4

What is being done locally to improve the situation where some learning disabled people who require general anaesthetic for fairly routine dental procedures are waiting for periods of more than 18 months?

Answer

This is being addressed through the Good Health Plan along with a number of other inequality issues. Southend PCT are important contributors to the Good Health Plan implementation group and representation includes Andrew Stride the Primary Care Development Manager who presented evidence to the Community Services Scrutiny exercise in relation to "Access to NHS Dental Provision". South Essex Partnership NHS Trust deliver the specialist community dentistry service and is represented on the Good Health implementation group by David Bowry who also presented evidence to the previous scrutiny exercise. So far the group has:

- Engaged with Southend PCT and South Essex Partnership Trust Patient Advisory and Liaison Services to ensure information in relation to unmet need is properly recorded and appropriately addressed for individuals affected.
- Agreed the content of a survey questionnaire to go to all people with a learning disability in Southend known to services so that the extent of the reported difficulties is properly understood.
- Contributed to Southend Hospital Disability Discrimination Act Access group
- Fed back through Southend PCT routes to ensure that there are no Service Level Agreement issues that inhibit the addressing of any problems identified

There is agreement that current waiting times are unacceptable. The major difficulty highlighted is the need for more anaesthetists and it seems that addressing this single issue will have a dramatic impact on the current problems.

David Bowry, Head of Dental Services, South Essex Partnership Trust commented as follows:

I have reduced the waiting time for comprehensive dental treatment for patients with LD under general anaesthesia at SGH from 24 months to the current wait of 12 months for non-urgent care.

I maintain a free 'slot' for urgent cases on each monthly session so the maximum wait for emergency care should be no longer than 4 weeks unless we have a sudden influx of urgent cases. If this occurs we have an arrangement with the Consultant Oral Surgeons to see urgent cases but they will only extract teeth as they do not have the facility to restore them.

I last met with Andrew Stride, (Southend PCT), on 1st March 2004 and have been liaising with him for many months with regard to access to dental care locally for LD patients. He is currently looking to fund additional sessions at SGH for us, in liaison with Castle Point and Rochford PCT, which will effectively enable me to reduce the current backlog of cases over the period of a year and thus facilitate a far more flexible and responsive service in the future for our LD patients.

Our CDS dental activity at SGH has been built into the proposals for the new DTC in Southend, which may also enable a more streamlined service in future years.

I am meeting with the Trust Service User Empowerment Group next Tuesday 20th April to give a presentation on the role of the CDS and to answer questions on this very topic.

Ms Cook informed the Committee that, following a number of fatalities during dental treatment, South Essex Health Authority had reviewed dental services. There is a strain on hospital resources, which allows for only 1 emergency for a person with a learning disability a month. There is a 12 month waiting list for non-emergency treatment. Extra money has been provided for 2004/05 to achieve these targets.

Question 5

What practical training and support is being given to clinical staff to ensure that patients with a learning disability are treated in ways which are appropriate to each individual?

Answer

(This answer refers back to question 2 and 3 and the Good Health Plan.)

Health Facilitation is key to ensuring that people with learning disabilities are helped to stay healthy and to access the health services they need. It is also important in helping people providing services to understand better the needs of people with learning disabilities.

Specialist health services – provided by South Essex Partnership Trust – have a key health facilitation role. Specialist staff receive training on person centred planning along with their colleagues from social care.

South Essex Partnership Trust has designed a course for health and social care staff called 'Learning From Me'. This course is part of a programme of education where people with learning disabilities demonstrate to specialist health and social care professionals and other service users what it is like to be cared for by paid carers. Service users themselves present most of the exercises, which are designed to make the experience real and relevant for the health professional.

Health Facilitation is the job of everyone helping people with learning disabilities and can be undertaken by friends, advocates, relatives or paid workers. The Good Health Plan establishes a new Health Facilitation Co-ordination role to make sure people are able to undertake the role of health facilitation effectively. South Essex Partnership Trust are fully committed to making this co-ordination role a success which includes liaising with all community health service providers including GPs.

Southend Hospital has a Disability Discrimination Act Access group, which is also actively looking at how the services provided by the hospital can be made more accessible to people with learning disabilities and other groups. Information and training for staff will be informed by this group's work.

Southend PCT has recently funded printing costs for a health profile document that has been developed by the Good Health Group specifically for people with learning disabilities.

Mr Saxon informed the Committee that the Learning disability Partnership Board used £10,000 of the Learning Disability Development Fund allocation to fund a worker for Southend through the Speech and Language Therapy services of South Essex Partnership Trust.

Question 6

How is information from carers used to ensure this happens?

Answer

Carers are represented on the Learning Disability Partnership Board and the Good Health Group.

The difficulties with some health services not taking sufficient account of the knowledge Carers have in providing appropriate services are reflected in the work described in previous answers above. The Health Profile document particularly is seen as key to improving communication and shared ownership of this represents good progress so far.

Part of the Health Facilitation Co-ordinators role is to make sure Carers are properly supported and have sufficient information, knowledge and confidence to advocate effectively for their family member (health facilitation).

Mr Saxon stated that the Health Action Plan supports carers so that the correct medical treatment can be provided.

Question 7

What is being done to address the difficulties of learning disabled people receiving one level of service as children, for example physiotherapy and other therapy services, but a different level of service once they come under the remit of adult services?

Answer

A Survey was undertaken on people who left school over a three-year period to identify the difference in services.

Children and Adult health services are managed differently in health as they are in Social Care. This means that sometimes people have access to some services when they are children but access to these services is more difficult when adult eligibility criteria is applied once they have turned 18 or have left school.

The Good Health Plan includes actions in relation to a number of adult services that are allocated on the basis of need but which some people are having difficulty accessing. The actions include:

- Discussions with health providers about the accessibility of services
- Looking at whether the setting and interpretation of eligibility criteria takes sufficient account of the needs of people with learning disabilities
- Considering the way some services are resourced – through the Local Delivery Plan and Service Level agreements.

Physiotherapy is a good example of the type of service that is currently being looked at in the above context.

The emphasis of the work in this area is ensuring that people with learning disabilities get fair and equitable treatment in relation to services provided to all adults on the basis of need.

2.3 QUESTIONS TO HEAD OF HOUSING NEEDS

Question 1

Valuing People states that in all aspects of life learning disabled people should have choice. Much emphasis is being placed on independent living. It is also clear that in order to meet current standards the 3 hostels currently owned and run by the Borough will need radical alterations which may not be viable. Whatever course is eventually taken the residents of these establishments will have to deal with considerable disruption to their lives, whether it is moving permanently or temporarily to new accommodation. Is each hostel resident being individually assessed, with their needs and wishes being given priority, to establish firstly how they would wish to live and how that can be achieved?

Answer

Each resident is receiving an in-depth assessment over the next 3/6 months involving a Social Worker and their key worker. This will establish the type and range of housing needed and give an opportunity to discuss how and where this can be achieved. Housing officers are ensuring that each resident who is considering taking up a tenancy is provided with a housing application form, and is then given due priority for the Housing Register.

Question 2

When residents are advised of the options available will they be given a full and realistic picture of what they offer? How will Social Services and Housing work together to help people to live as independently as possible with the right help?

Answer

Social Services and Housing are part of a single Department whose Director has responsibility for both the strategic functions of both services, he will ensure the housing needs of the whole community is included into the Councils Housing Strategy. Officers from both Services meet on a regular basis to ensure all needs are being met. Leaflets have been produced for people with learning disabilities to explain all the housing options available in the Borough. Support will be provided through the Social Services and the resident's key worker. Each resident's needs will be continually assessed to ensure the service meets their requirements. The accommodation subgroup of the LD Partnership Board, known as the Opening Doors Stepping Forward Group, is taking forward the strategic action plan. The group last year planned an all-day event at the Civic Centre, bringing together potential accommodation providers and people with a learning disability, to broaden their awareness of housing options. This is part of their ongoing work to involve people in understanding about available housing and the processes involved in making a move.

Question 3

Is the housing support which people with a learning disability are offered flexible so that, if the person is more confident at some times than others, there is always someone available to give appropriate help and advice if required?

Answer

Support for each resident will be assessed as in the beginning a high level of support will be necessary and tailored so that this can reduce as they become more independent. Supporting People revenue may be available to offer support for housing and independence in some daily living activities. Social Care support is available to meet critical and substantial care needs based on assessment and ongoing reviews.

Question 4

What are the opportunities for local provision of the supported housing which people want?

Answer

The Council has a range of housing available which people can apply for and be given floating support. However there is limited supported housing available in the Borough for people with learning disabilities, currently there is only one 12 unit property available at Grahame House.

Mr Dayer informed the Committee that Grahame House was built in the late 1960s. It has a waiting list for units and it offers 1 bedroom units that are self-contained and suitable for couples. When Grahame House was first opened an open day was arranged to allay any fears that local residents might have.

Another 12 bed unit is under consideration and arrangements have been made for visits by concerned residents. When residents are offered a unit they can choose the colour of their paint and carpets.

Demand for this type of accommodation outstrips availability and approximately 18 people want to move there.

A range of accommodation is offered, including house share. Housing Associations have been involved in house sharing over the last 10 years. An example of a house share would be 2 learning disabled adults with a residential support worker. The Housing Department is constantly looking for a wide range of supported living. This year, a local resident is opening their home to take in a learning disabled adult. Hopefully, more residents follow this initiative.

The placement of learning disabled adults is always a sensitive matter, due to their vulnerability. Local residents are always consulted and advocates are placed to aid in the moving process and are given full support by care workers.

3 ADDITIONAL POINTS

3.1 At the evidence session on the 8th April 2004 concerns were raised regarding how information was distributed to Service Users. Mr Saxon commented as follows:-

Southend's Learning Disability Partnership Board has produced summary information setting out plans in relation to:

- Accommodation - Opening Doors
- Modernising Day Services - Fulfilling Lives
- Employment - Making it Work

The Plans and Strategies were developed with active participation from Service User and Carer representatives as well as all key stakeholders.

The Learning Disability Partnership Board decided that this summary information should be sent to every person with a Learning Disability in Southend known to the Council.

On 8th April there was a question mark raised over the efficiency of distribution during the Service User presentation in answer to member's questions and whether every person had been sent the information referred to. Following the Scrutiny Session I have checked the distribution of this information and can confirm that the information was sent to all Southend Service Users including those using the Snacktime Service.

In making the decision to send this information to every Service User the difficulty of how people would be helped to understand the content and the implications of the information for them was acknowledged by the Partnership Board. A lot of thought was given to the style and presentation of the information and to how Providers of services would be briefed.

By sending the information to every Service User the Partnership Board achieved one key ambition which was to ensure that those people who are able to read the information for themselves or to have it explained to them, were given this opportunity.

The raising of the issue at the Scrutiny Session on the 8th April demonstrated that there is still considerable work to do in co-operation with Advocacy Services, Carers and Service Providers, to ensure that these Plans and Strategies are meaningful to people.

I will ensure that the concerns about this expressed by some Scrutiny Committee members is fed back to the Learning Disability Partnership Board for action.

3.2 Resources – note from Acting Director of Social Care.

The Director of Integrated Services provided comment to this Scrutiny Committee concerning the level of available resources for Learning Disability Services.

I have prepared this short paper to provide members of the Committee an overview of expenditure on learning disability services, and how this fits within the resources available to the Council.

For 2004/05 the Council plans to spend at FSS (the FSS for Social Services is £43 million). The budget allocated to the Health and Social Care Portfolio for social services excluding capital financing costs is £45.358 million, £2.358 million above FSS. Consequently other Council services need to spend below FSS to compensate for social services.

Within the Health and Social Care Portfolio budgeted expenditure compared with FSS demonstrates further differences. These can be seen in the table below:

	FSS 2004/05 (£'million)	Budget 2004/05 (£'million)	Difference (£'million)
Area of Service			(Over FSS+) (Below Fss-)
Children and Young People	13.328	14.704	+1.376
Older People	19.208	16.432	-2.776
Other: Adults			
Learning Disability		8.238	
Mental Health		2.241	
Physical & Sensory Impairment		3.410	
Total Other Adults	10.464	13.889	+3.425
Other expenditure less capital charges		0.333	+0.333
Total	43.000	45.358	+2.358

It can be seen from this table that expenditure particularly in the area of other adult social services (59% of which is on learning disability services) is £3.425 million above FSS.

This means that we must spend well below FSS on older people's services.

Expenditure on learning disabilities, excluding capital finance charges, has shown a steady increase over the last few years in real terms. The increase from 2002/03 to 2003/04 will be approximately 11%.

Budgeted expenditure on learning disability services for 2004/05 excluding capital finance charges is split as follows:

	(£'000)	(%)
Care Assessment and Management	608	8
Residential Care		
External	3,746	47
In House	1,149	14
Homecare		
External	363	5
In House	32	0
Daycare		
External	580	7
In House	1,527	19
Total	8,005	100

The financial position of the Department is such that for 2004/05 we have budgeted for a decrease in cash terms of about £70k. It is also necessary for us to maintain a

steady reduction in other adults services in an attempt to shift the pattern of overall expenditure towards the FSS profile.

For learning disability services it is expected that this will be done by firmly applying Fair Access to Care Services criteria, and by critical examination of some of our expensive out of area placements. The Valuing People agenda moving towards more independent supported living should also reduce pressure on this budget as other streams of funding come into play (e.g. supporting people and housing benefit).

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