

Health and Social Services Committee HSS-04-02(p.2a)

Date 6 February 2002, 9.00am to 12.40pm
Venue Committee Room 3, National Assembly for Wales
Title Response from Cardiff and the Vale Parents Federation

Children and Disability

Report on the consultation with parents of children with physical and learning disabilities in Cardiff

November 1999

Parents Federation

Contents

Page 1 Report

Page 10 Appendix

Background:

This report is based on discussions with parents which have taken place during 1999. In January a meeting for parents was organised jointly by the Children's Health and Disability Team and the Parents Federation. This was widely publicised and was attended by over 40 parents of disabled children. This was the first time such a number of parents of children with learning and physical disabilities had met together to discuss common issues in Cardiff County. For many parents what was most striking was the similarity in the issues which disabled children and their families face. Contributions were also made by telephone and letter. The initial purpose of the meeting was to discuss issues arising from the proposed move of disabled children's social services from the adult divisions to the children's services. A further meeting was arranged in June to discuss developments. It was agreed at this meeting that parents would

prepare a presentation on the main issues to be made to key individuals and groups. This presentation is based on issues identified by parents during this wide ranging consultation, which included a questionnaire sent to over 150 parents. The series of meetings has been independently facilitated and the presentation will be made by parents drawn from the wider group.

Context:

The current context includes increasing emphasis on the importance of inclusion and of consumer participation.

Recent Legislation and Policy includes:

- The Disability Discrimination Act
- Messages for Managers: Learning the Lessons from Joint Reviews of Social services, 1998, Social Services Inspectorate Department of Health, Audit Commission

This says: *'Achieving consistent services that can continue to improve requires that councils 'listen to users, carers and their representatives about what matters to them'*

And

'Empowering citizens by working with them contributes to 'inclusive' communities'

'Findings from the reviews show that councils are better placed to shape better services when:

- *information from current services can be analysed to establish what is working well*
- *users and carers are supported in a structured and independent way to say what they think about the councils services'*

From 'Caring About Carers', a National Strategy for Carers. 1999, HMSO Available from the Welsh Office Pg. 53: *'Giving strong support to carers over service planning and provision will help to ensure that they become partners with the statutory services in the provision of care. Better supported carers will be better able to make better lives for those for whom they are caring'*

Pg 15: *'The Government wants all organisations involved in caring to recognise that they can no longer have a focus on just the client, patient or service user. They must see the person needing care or support within the whole environment of their family, neighbourhood and their community.'*

Involving the Public: NHS Wales 1998, putting patients first

'Public participation in decision making about health and health services is important not only in the

context of delivering more effective services, but as part of a broader programme to improve the quality of democracy and accountability.' and 'The process of giving account can be of value in its own right as a means of increasing the dialogue between public officials and users/citizens' pg 2

Section 3 of the Draft Inter-agency Framework for Disabled Children in Cardiff contains a useful compilation of further information on the current legislative and policy context, particularly concerning the emphasis on inclusion. (see appendix)

Vision:

To achieve the best possible support in Cardiff for disabled children and their families

Access:

The point is:

There should be no discrimination: the child is a child first.

Access is the major theme of this presentation

'there should be an agreed definition of accessibility: an access plan':

Information:

'as my son is nearing school leaving age, I think I would like to be more aware of what is available and how to go about getting what is best for my son':

Issue

- So many agencies: confusion

Action

- A comprehensive pack
- One-stop shop that pulls together all the strands for you.

- Accessibility/language and locality.
- Simple, brief information:

Who to go to
What is available

- Support for parents
- Support groups.

Short-Term Breaks/Leisure:

'we are a loving and happy family, supportive of each other and immensely proud of our little girl. We keep afloat very well during term-time but frustrated tears are not uncommon at weekends and during school holidays'

Issue:

- a constructive and normal time out of the home and specialised resources if it is residential.
- Accessibility across Cardiff
- The opportunity to use local resources and inclusive opportunities: this varies across Cardiff.
- Physical access.
- Transport

Actions:

- Confirm commitment to inclusive opportunities.
- Each local authority leisure resource should take responsibility for inclusion.
- Audit accessible resources and provide information.
- Access to after school clubs, special schools, mainstream schools,
- Transport available for children to get to places.

- Needs-led access to residential support, foster support, home.

Further issues

- Need access to specialist equipment
- Criteria for grading facilities as accessible
- The investment in making schools accessible, including special schools, needs to be increased and accelerated
- Seek out examples of good practice
- Transitional planning at the correct time for further education, career planning etc.
- There are also concerns about special schools and their future.
- Most information goes from parent to parent.
- The responsiveness of the system to comments is important.
- Information could be included in bounty packs.
- Parents may be prepared to pay something towards help.
- Information on benefits etc is needed.
- The different points at which disability is identified has implications for how information is made available.
- Disability does not necessarily mean being in a wheelchair
- There is not much action happening to back the commitment in words to inclusion.
- There are services currently only available for people with learning disabilities which should be available for children with physical disabilities as well.
- Co-ordination within and between Cardiff and the Vale and other counties, particularly in relation to health and education
- Disability training should be a normal part of the training of teachers, playscheme staff etc.

- There should be an agreed definition of accessibility: an access plan.

One Stop Shop:

Parents have discussed the potential advantages of a one-stop shop. It would provide a place to focus information and provide feedback both positive and negative. A building with access for everyone could include a room for information. A place for equipment.

Key points for consideration are:

- What it is
- Why it is important
- What it needs to deliver
- Who should run it

It should be a multi-agency venture which includes a significant role for parents.

Knowledge is not just about creating more demand for services. It is about a more effective use of resources. Transparency and involvement will help everyone.

Summary:

Key points:

1. Access to schools and community resources: a culture of inclusiveness
2. Short-Term Breaks
3. Co-ordination within and between Cardiff and the Vale and other counties, particularly in relation to health and education.
4. Information: a pro-active approach is needed: Where You Stand should cover all disability and sources of funding: include a charities section..
5. A one-stop shop: consult on this. Involve parents at every stage
6. Work in partnership: networks and support groups.
7. Training and awareness for staff in mainstream facilities.

The Parents Federation on behalf of all the parents involved wishes to thank John Gilkes (independent facilitator), June Hoy (Child, Health and Disability Team) and Maxine Smiley (ABCD) for their much-appreciated assistance with the process of this consultation.

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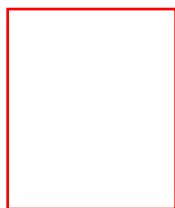
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APPENDIX

- **Definition of Disability**
- **Summary of responses to the September Childrens' Services Questionnaire**