

**Date:** Wednesday 26 May 2004

**Venue:** Committee Room 3, National Assembly for Wales

**Title:** Review of The Interface Between Health and Social Care: A Response from SCOVO

**Evidence to the Health and Social Services Committee, National Assembly for Wales - 'The Health and Social Care Interface'**

**Presentation by SCOVO : The Standing Conference of Voluntary Organisations for People With a Learning Disability in Wales**

SCOVO's membership comprises over 120 voluntary organisations who work in the field of learning disabilities. Our members activities span the life of people with learning disabilities, from early years through to old age. In considering the Committee's review, we look at the impact of 'interface' issues upon children and adults with a learning disability.

Learning disability is not an illness, but the Health Service continues to be an important source of assistance and support, particularly in the early years.

**1. Children and Young People**

**1.1 Early Diagnosis / Early Counselling**

Making a diagnosis and breaking the news to a parent that their child has a disability, usually rests with a health professional. Many research studies, including one conducted by SCOVO in 1989, have highlighted variations in the quality of this critically important work. The key to success is good multi-disciplinary teamwork, close collaboration between health and social services, and the identification of a key worker who will be the key point of contact between the parent and all services. Practice in Ceredigion is known to be good in this key area, and in England the Department of Health has, after extensive consultation, introduced 'Together from the Start', a package of policies and practice guidance built around the key worker approach. This package is under consideration by the Welsh Assembly Government.

**SCOVO asks that the Committee seeks introduction by the WAG of a package of policies and practice guidance for early years disabled children built on a key worker model.**

## 1.2 Behavioural Support and Advice

Some disabled children and young people have more complex needs and have behaviours that challenge parents. If unsupported or unadvised, failure to provide modest health service resources at this stage can lead to stress on families, sometimes family breakdown, and much higher costs to government further down the line.

Evidence collected by Contact A Family and SCOVO from across Wales from the parents of disabled children demonstrates a dearth of behavioural support from psychologists and other health professionals, and limited access to advice.

An example of good practice is the NHS Intensive Support Service / NCH project serving the Cardiff area.

**SCOVO asks that the Committee seek improved provision of behavioural support and advice to parents, particularly to disabled children with more complex needs, by health service professionals.**

## 1.3 Speech and Language Therapy

The problems with provision of this service, and the shortage of trained staff are very well documented. Many organisations, including SCOVO, have highlighted the issue. Without the delivery of timely therapy assistance disabled children and young people are unable to achieve their true potential, and remain more dependent on the support provided by their informal carer and by Social Services than would be the case.

A substantial consultation exercise has taken place, resulting in the publication of a report and recommendations in July 2003. While the report provided an excellent analysis of the depth and scale of the problem, SCOVO responded that the recommendations were disappointing. While they made sensible proposals about further working groups, and gradual expansion of training provision for therapists, it is unlikely that they will make any material difference to the prospects of better support for the next two generations of disabled children.

**SCOVO asks the Committee to seek:**

- **a resolution of the funding confusion that exists between the NHS and Local Education Authorities by seeking implementation of the proposal set out in the 1998 Special Educational Needs green paper.**

- **the development of practically-based training packages that professionally qualified staff can use to provide advice on simple techniques and methods to parent / carers.**
- **the creation of a new category of therapy assistant who, while not professionally qualified to degree standard, can help to fill the huge gap in provision of service that currently exists.**

#### 1.4 Generic vs Specialist Support

SCOVO wants to see better access to generic health services for disabled children, but recognises that some specific multi-agency resources are necessary to give support to parents.

Childrens Centres, where a number of agencies work alongside each other have demonstrated their value, and we would like to see their further development. An example is the NCH-led Childrens Centre in the Rhymney Valley.

**SCOVO asks the Committee to seek the expansion of the Childrens Centre model, so that integrated and holistic health and social care support can be offered to disabled children and their families.**

#### 1.5 Administration of Medication

Issues around who can dispense medication, or assist with peg-feeding and the maintenance of shunts represent a tremendous barrier to disabled children and young people developing an independent life in the community. Appalling anecdotes continue to surface.

In Carmarthenshire, a young woman who needs peg feeding has recently left school. The woman can only access a part-time day service as two years of discussion have failed to ensure that she can receive assistance with peg-feeding in the day centre. We believe that despite their best endeavours, social services have been unable to secure any nurse-led training from the local NHS Trust to ensure that the day centre staff will feel confident to assist the young woman. The woman returns home so that either her parent or 13 year old sister can provide assistance. Assistance may now finally be in prospect.

**SCOVO asks the Committee to seek:**

- **the introduction of WAG guidance that clarifies responsibilities around administration of medication and provides advice on Professional Indemnity Insurance, consent and other related issues.**
- **the development by NHS Wales of training packages that will build the confidence of staff in Social Services, staff in other agencies and carers to undertake maintenance activity with peg-feeding and other essential procedures.**

## **2. Adults**

### **2.1 Access to Primary Care**

Research undertaken by Dr. Mike Kerr at the Welsh Centre for Learning Disabilities, earlier work by Welsh GP Gwyn Howells, and English research indicate that people with a learning disability:

- silently suffer simple conditions that other adults will bring to the attention of their GP, a high rate of ear wax being a typical example
- lack of up-take of health promotion
- fail to receive appropriate treatment for a range of special health needs.

The Welsh Health Survey 1995 found that people with learning disability:

- have a higher rate of psychiatric illness (32.2%) than the general population (11.2%)
- more illness than the general population (only 6% reporting no illness) compared to (37%)
- poorer eyesight (19.1%) compared to (8%)
- rarely had a healthy diet (1 in 10)

People with learning disability need special help from primary care. Sometimes this may be about giving a smooth introduction into appropriate specialist health services, but more often it is about a proactive, preventative approach being accepted by primary care.

**SCOVO asks that the Committee considers how primary health care may be encouraged to be more proactive in promoting the better health of people with learning disability.**

### **2.2 Administration of Medication**

Many of the issues identified in 1.5 above equally apply to adults.

**SCOVO asks the Committee to seek the provision of improved guidance by WAG.**

### **2.3 Resettlement and Continuing Health Care**

Members will be aware that good progress is being made on the resettlement of the remaining residents of the learning disability hospitals. Some of these individuals have been assessed as requiring continuing health care, rather than social care. While we do not wish to see anyone's resettlement being delayed by arguments over labels, it is another aspect of difficulties in the 'interface' between health and social care.

Our contention is that:

- individuals should only be given such labels after a multi-agency assessment that is person-centred and fully involves the individual, their next of kin or advocate.
- in current arrangements there are perverse incentives for Social Services to leave people unnecessarily within health service provision.

**SCOVO asks the Committee to ensure effective multi-agency assessments are developed for all people with learning disabilities.**

## 2.4 Secondary Health Care / Specialist Support

As indicated at 2.1. people with a learning disabilities are generally less healthy than the general population, and have a special need to access specialist health provision for specific conditions including coronary care and psychiatry.

There is a huge emphasis in the NHS on patient rights, patient choice, listening to patients and patient advocacy projects. The ‘Bron Davies Report’, which we attach, highlights the large gap that can exist between policy intention, and practice, and the serious consequences that can flow for people with learning disabilities.

Research has already identified the need for better training of medical and allied professions on understanding learning disability, and recognising the role of other agencies, carers and advocates. The Mental Capacity Bill will increase this need.

Working across the ‘interface’ requires sensitivity and understanding.

**SCOVO asks the Committee to consider the implications of the Bron Davies case and to identify learning points, for the NHS and Social Services that can form part of its final review recommendations.**

## Summary and Committee Questions

Giving a considered response to the key questions posed by the Committee is difficult, when so many strategic and policy issues are in the melting pot, or at early stages of implementation.

For children, the National Service Framework is in preparation, and substantial steps are being taken to ensure that the needs of disabled children are identified and addressed. For adults, policy initiatives to follow on from the ‘Fulfilling the Promises’ report are gradually taking shape, and being issued.

At policy level, the attention given to learning disabilities in Health and Social Care plans is unanalysed. Input by Local Health Boards to service planning for children and adults with learning disability is

untested, and there is a lack of clarity about what relevant special services may be commissioned by Health Commission Wales.

What can be said with certainty is that lack of communication between health and social care, and poor professional attitudes towards carers and advocates or paid support staff can lead to considerable and serious problems for individuals and families.

These potential difficulties can be overcome locally, where there is professional and organisational commitment.

SCOVO

20.05.04.

**ANNEX**

**PLEASE DO NOT QUOTE OR CITE WITHOUT PERMISSION**

**AS IT IS NOW? A 2003 'DELAYED DISCHARGE' CASE STUDY OF A WOMAN WITH A  
LEARNING DISABILITY**

Margaret Flynn\*  
Adrian Roper  
Aled Griffiths  
Anita Watkins  
Carolyn Griffiths  
Michelle Burns  
Jill Nicholson

December 2003

\* Contact details for corresponding author:

School of Nursing and Midwifery  
University of Sheffield  
Samuel Fox House  
Northern General Hospital  
Herries Road  
Sheffield  
S5 7AU

Email: [m.flynn@sheffield.ac.uk](mailto:m.flynn@sheffield.ac.uk)

## **An introduction to Bron Davies**

On July 27 2003 Bron Davies, a single Welsh woman of 71 years, died within two days of being admitted to a Nursing Home. This fact is tragic not solely for the distressing events immediately preceding her death, or even for the sadness that generally attends a death. Bron Davies was a loving and loved woman. She had lived in a long stay hospital for most of her life. She was offered a service by Cartrefi Cymru in the wake of the long stay hospital closure programme given impetus by the All Wales Strategy (1983). Cartrefi Cymru staff who supported Bron Davies described her:

*'Anybody who met Bron would love her...She had lots of ways of talking that came from being in a [long stay] hospital for so long, for example, she'd never ask to go in my car, she'd say, 'Take me in your taxi!''// Not everyone would understand Bron without one of us to explain some of her phrases and ways.// Bron loved flowers. She was a chapel woman and went every week. She loved her embroidery, threads and scissors, having cups of tea, going to the hairdressers every week, being warm, and going to the corner shop for a packet of chocolate raisins. That was her life. She had her little habits and we knew what she liked and what she didn't like//*

*I suppose Bron was institutionalised from the time she was in [long stay] hospital. Here she had and wanted her routines and we didn't vary them because she found it too hard and it was difficult for her to understand explanations. She was a creature of habit and we respected that.// Bron had some contact with a sister, Morwenna, who lived in Australia. She rang every few weeks and we would keep her in touch with how Bron was doing. When Bron was in hospital we kept Morwenna constantly informed by 'phone// There was a family friend too, a Mr Hedges who lived in England. He visited a couple of times a year, but in honesty, he didn't really know Bron. He didn't know what to say to her and she didn't warm to him. He wasn't an easy man to get on with. We'd give him some ideas for things to talk to her about and sometimes we'd stay to help. Nothing really worked. He was visiting out of a sense of duty really. Often she'd tell him to 'Buzz off!'*

*She had become [doubly] incontinent in the last two years of her life, but we managed this. Waking night staff were accustomed to helping Bron [a fact borne out by both Night Records and Continence Records]. As she became more frail we got a bath-seat for her and we had a wheelchair for her [a community Occupational Therapist had assessed Bron for this as she had become less mobile]. She liked the GP who was always very supportive and patient with her. She used to get urine infections and so she saw him quite a bit. We were pleased that he was on call when she became ill. He diagnosed an allergy to a new drug she had been prescribed to help her sleep. It resulted in large and very sore looking blisters in her mouth and throat and on her tongue. It made swallowing painful and difficult. She was hospitalised immediately. We were very worried.'*

Bron's tenancy was shared with another woman who had known her for many years. They had become tenants when their home was de-registered at the beginning of 2003, as advised by the local inspectorate. They had lived on the same ward in a long stay hospital for over 20 years. Both women were looking forward to moving to a new home, not least because their kitchen was too small, they needed a larger bathroom and improved laundry facilities, including a drying area. Cartrefi Cymru staff were preparing the women for this prospective move when Bron became ill.

## **The Rationale for a Case Study about Bron Davies**

This case study has been compiled by the support staff who knew Bron Davies well (i.e. for between eight and 12 years), and by the managers and two Trustees of the service supporting her, Cartrefi Cymru. It draws on:

- our detailed request to the Local Authority, which commissioned Bron Davies' service from us, to investigate events leading up to Bron Davies' death;
- the outcome of the Local Authority's investigation;
- Cartrefi Cymru's case notes and records;
- our reflections on Cartrefi Cymru's experience of caring for Bron Davies during her 12 weeks in three acute hospitals; and
- a meeting with a senior member of the Local Authority and a Social Services Inspector.

Our decision to write about Bron Davies has three strands:

1. Bron Davies is not the first patient with a learning disability to be admitted to secondary care from her own tenancy and she will not be the last;
2. if health and social care are to change the way in which they provide care for vulnerable adults, then this case study illustrates the importance of improving professional judgement;



3. Care Managers, clinicians and ‘nurse assessors’ need to take a broader, long range and more inclusive approach to assessment, or at least be prepared to build for a future we all want.

As a case study it provides a means for Cartrefi Cymru to learn from our experience of attempting to challenge the treatment that Bron Davies received and to set out some principles and priorities for a more hopeful future. Of necessity we have changed some potentially identifying details of Bron Davies’ life and treatment in secondary care. This is because we want to engage with the professionals responsible for what happened to her and encourage them to set about changing the worlds in which they work. We would encourage all readers with an interest in ensuring that the weakest do not get the worst, to share this case study with colleagues in their own services and across service sectors, to check their practice against the priorities we have identified, and to engage with the task of offering responsive and humane health and social care services.

This case study outlines our concerns about custom and practice at the interface of health and social care in Wales. It poses questions about clinical hegemony, the power of professionals undertaking multi-disciplinary/ integrated working, unified assessments, the significance of issues around confidentiality when assessing vulnerable adults, the experiences of vulnerable people in secondary care, and the disproportionate influence of people who did not know Bron Davies well.

**Cartrefi Cymru’s August 2003 outline of events requesting an investigation by the Local Authority and their response**

The following figure abstracts information from (i) Cartrefi Cymru’s Chief Executive’s letter to the Director of Social Services employing Bron Davies’ Social Worker/ Care Manager and from (ii) the reply by the Local Authority’s Investigating Officer. To the written quotations we add italicised, verbal quotations arising from discussions with Cartrefi Cymru support staff.

<p><b>(i)</b></p> <p>May 7 2003 Bron admitted to Hospital X due to reaction to medication</p>	<p><b>(ii)</b></p>
---	--------------------

May 10 Hospital staff asked for Bron to be taken home, even though she still had a drip attached...discharge was delayed a few days until her drip was removed...had not taken any fluids by mouth...was looking dehydrated.

The Social Worker was informed that Bron was in hospital and that one to one support was required from Cartrefi staff. The Social Worker 'phoned ward staff and was informed that Bron appears better with [Cartrefi Cymru] staff [present and assisting with] eating and drinking. However, one to one support was being provided by a bank nurse when hospital staff felt it was necessary.

May 21 Bron was discharged...support staff became concerned at her dehydration and she was readmitted on 23 May.

Social Worker was informed that Bron was being discharged...[and] the situation was to be monitored by the District Nurse over the next week...Social Worker telephoned staff at [Cartrefi Cymru] to confirm this.. The Social Woker agreed to do a post discharge visit...received a 'phone call from [Cartrefi Cymru] staff informing her that Bron had been [readmitted].

In hospital Bron was supported by Cartrefi Cymru staff for four hours a day (nearly double the allowance of time available within the staffing budget)...Hospital X requested support from 8am to 11.00pm...could not be agreed without significant extra funding.

[Social Worker] telephoned ward to enquire Bron's level of need...informed that no increase in support was necessary...Hospital staff did not request that [Cartrefi Cymru] staff provide assistance...Social Worker received contradictory information regarding supporting Bron in hospital. It is hospital policy that should a patient need one to one support the Health Authority provides this and on this occasion this policy was adhered to.

Approx. June 3 hospital staff advised that Bron was doubly incontinent, not mobile, had bed sores, had a water infection and needed turning hourly at night, and constant care. Cartrefi Cymru staff, some of whom had supported Bron for years, were surprised by this as the only symptom they recognised...was Bron's proneness to urine infections.

*They said she needed 24 hour nursing care! She didn't. We had managed her incontinence for*

The Social Worker received a telephone call from the ward to discuss Bron's discharge from hospital. The Social Worker discussed [this] with the hospital consultant's staff and requested a nursing assessment to identify Bron's needs and establish whether they could be met in a residential or nursing setting. Discharge would not go ahead until this level of care was established. This is usual practice. The Health Authority have dedicated nurse assessors who undertake this work. Therefore the nursing assessor who undertook this assessment are

*two years and it wasn't a problem.*

qualified to do so.

June 12 Bron transferred to Hospital Y [the rehabilitation ward].

*They said she was eating her food but she wasn't. She didn't have teeth and we used to ask, 'Please can she have her food mashed?' as this was how we encouraged her to eat when she was unwell. She was treated like a dog. Her clothes were stinking, soaking wet and she'd plead, 'Take it off.' She was stuck in a hospital chair, saturated and medicated to keep her quiet. The pads were falling off with the weight of the urine.*

At some stage during her hospitalisation Bron was assessed (by hospital staff?) and a decision made (by Social Services) that she should not return home but instead receive nursing care in a Nursing Home.

[From Bron's case record of June 4: 'Bron's Social Worker rang to say...Bron will not be coming home unless the hospital will sign a form stating Bron does not require nursing care.']

The Social Worker visited Hospital Y to plan a case conference to discuss Bron's future care needs. However, the Multi-Disciplinary Team gave sufficient evidence to establish that under no circumstances could Bron's care needs be met in a residential home and that her needs now required nursing care. Again, this is usual practice for agreeing how to meet care needs.

No one from Cartrefi Cymru was invited to participate in the assessment of Bron's future care and accommodation, nor was anyone from Cartrefi Cymru ever provided with detailed information about her assessment or an opportunity to comment based on their unique, in-depth knowledge of Bron.

*We struggled very hard to be involved in the assessment. Bron's GP couldn't understand why we were being excluded. He was really helpful and said it should include people who know Bron. I was there the day they assessed Bron and I wasn't allowed to go in.*

The Social Worker, through discussions with senior management, health professionals and next of kin, agreed the process for placing Bron in a Nursing Home. Cartrefi staff were not involved as it was a multi-disciplinary professional decision which agreed Bron's care needs. Cartrefi staff were not provided with detailed information about Bron's assessment as this was confidential.

It appeared to Cartrefi Cymru staff that Bron was not advised of the outcome of her assessment (that she was not allowed to go back to her home), nor was she given any choice in the matter. Her nearest relative...was in Australia and Mr Hedges in Birmingham, who did not know Bron in any depth, if at all, appears to have been the sole point of contact used by the hospital and/ or LA for ratifying the decision to discharge Bron into a Nursing Home. No one with any knowledge of Bron's rights, as a tenant or as an adult citizen in receipt of domiciliary social care, or with an independent (non-statutory) perspective of her interests, was involved in the decision-making processes leading to her being denied the opportunity to return to her own home.

*Mr Hedges wouldn't talk to us when Bron was in hospital. He was offensive on the 'phone on the single occasion we got in touch to tell him what was happening to Bron. He yelled at me 'I am not arguing with you I am listening to medical advice. I don't want to speak to you I'll speak to your manager.'*

*I was there when the Care Manager arrived to assess Bron. Bron was hugging me in floods of tears and begging me, 'take me home.' I felt useless. I felt we were letting her down and we couldn't do anything. I stayed with her all that night. Everything was taken out of our hands.*

It appears that Cartrefi staff have made assumptions regarding events during the assessment process. The Social Worker's role was to ensure that this process involves all appropriate persons who will be involved in Bron's future care needs – this process was followed thoroughly.

By July 7 Cartrefi Cymru staff observed that Bron was back to her usual self, eating and drinking and requesting to go home. She followed staff out of the hospital and asked them to take her home in a taxi.

*She used to beg us 'take me home.' It was terrible that they didn't think this was important. Even after the hospital said she couldn't walk another visitor told us that Bron had been crying, trying to leave the ward and asking her and other visitors to take her home. They medicated her to keep her quiet.*

July 9 – Cartrefi Cymru staff were advised by the LA social worker that an assessment of Bron had been based on the fact that Bron got up at night and wandered around the ward, and that she had stood on her bed and urinated. This was just a few days after [we] had been advised that Bron was unable to walk. Bron's behaviour was cited as grounds for her to be discharged to the Nursing Home. [We] felt that this behaviour was a dubious basis for assessing Bron's future care and support, as the [hospital environment] contained none of the opportunities for constructive activity which Bron was familiar with [in] her home...against her wishes she found herself living in a ward without any personal space or social facilities. She was also residing in her second hospital in eight weeks.

*Because she wasn't easily understood she was ignored. One day the hairdresser did everyone's hair on the ward but Bron's. She loved having her hair done!*

The risk element of Bron returning to a residential home was addressed via the multi-disciplinary assessment and consideration was given under the Care Standards Act. Bron's next of kin was happy with this decision. Although Cartrefi staff felt that such a decision was made on a 'dubious basis' I have to reiterate, once again, that no decision was made without professional advice being sought and the assessment of Bron's needs was central to the decision-making process. The next of kin was happy with this decision. The Social Worker involved has since received a thank-you letter from Australia.

July 14 – [We were] advised that the LA had withdrawn its...funding for Bron's support and that this decision was final. Bron's sister was [to arrive within the week from Australia] but the decision had already been made.

[From Bron's case record: The Social Worker 'phoned this evening. Said that Bron would not be coming home. The Social Worker had spoken with Mr Hedges and he agrees and says the decision cannot be challenged...will be in touch about Bron's money and personal belongings.']

July 19 Bron was transferred again, to Hospital Z, whilst awaiting a bed in a Nursing Home. [We] were still unaware whether Bron had been consulted about the assessment decisions being made, or if her family had given consent.

*Morwenna said to us on at least five occasions on the 'phone 'I'll fight tooth and nail to get her back to Cartrefi.' We got a thank you card from her after the funeral and an invitation to meet her and choose something from Bron's things so we could all remember Bron. We hadn't the heart to meet her. We'd even had to fight for Bron's funeral to be held in the chapel she'd attended for 12 years.*

Again, staff had made assumptions that the Social Worker did not liaise with the next of kin – again this being confidential information that she did not need to share with Cartrefi staff. In fact the Social Worker received a complaint from the family friend, Mr Hedges, that Cartrefi staff were overstepping the mark by becoming too involved in the assessment of Bron's future care needs – family were only interested in professional opinions. This complaint was not taken further as a decision was already made between appropriate persons that Bron was to move to a Nursing Home.

Social Worker visited Hospital Z following a 'phone call from the ward sister expressing her concerns regarding the appropriateness of Cartrefi staff interfering with Bron's care whilst in hospital. The Social Worker requested that this be put in writing. Complaints were also received from other members of the Multi-Disciplinary Team as Cartrefi carers appeared to be having difficulty accepting decisions made and questioning professional opinions i.e. Consultant, Physiotherapist, Occupational Therapist, Nurses. July 11 Meeting held with [Cartrefi's] Regional Director where issues raised by professionals was discussed. I acknowledged the letter of complaint from Hospital Z. Bron was admitted to Hospital Z approximately 14 July. Again, the care management process is to inform Bron and next of kin, and is confidential information. Social Worker did not identify the need to share such information with Cartrefi staff.

Between July 19 and 21, the hospital staff stopped Bron having her embroidery, which she had been used to having with her for many years without incident, and which helped her to relax. She requested her embroidery on July 21 but this was refused. Bron was also asking for her stockings because her legs were cold but the hospital staff were leaving her legs bare.

*She was supposed to have the same rights as other patients but she hadn't because they wouldn't ask us things and if we offered information they ignored it. She fell over in hospital and was hurt. Her being in hospital had lots of risks but they could only identify ones about her embroidery.*

There was no provision in the hospital for Bron's laundry or personal shopping to be done. This was undertaken voluntarily by Cartrefi Cymru staff in their own time.

*We used to go in on our days off to take her washing home.*

July 25 Bron moved into the Nursing Home. No request or extra provision was made for the transfer of her personal belongings or for making her new bedroom as nice as possible. Cartrefi Cymru staff undertook this work of their own volition.

*We took her curtains and tried to make it look like home to her. She couldn't understand how she wasn't at home with us.*

The Social Worker attempted to explain to Cartrefi staff that this was for Health and Safety reasons. The Social Worker received a complaint from Ward Sister that Cartrefi staff were unable to accept the reason for Bron not being given her embroidery. They did not appear to be able to identify the risks involved to Bron and to other patients. Bron did not appear agitated in any way during visits from the Social Worker, neither was there any reports of Bron being unsettled whilst in hospital without her needles and scissors. The issue of Bron's legs being cold is being looked into by health personnel at Hospital Z.

This is usual practice within hospital settings. My understanding is that you were paid for provision of Bron's care up until the agreed termination date, hence I do not feel this was an unreasonable duty for your staff to carry out.

Bron moved into the Nursing Home with full agreement from the Multi-Disciplinary Team and the next of kin. The Social Worker liaised with Cartrefi staff regarding moving of belongings, at no point was the Social Worker asked to take over this role, in fact Cartrefi staff volunteered to undertake this task.

July 26 Two Cartrefi Cymru staff visited Bron separately and noticed a problem with mouth blisters. Messages were left with the Nursing Home as this was the...symptom [of] Bron's reaction to the medication [to which she was allergic]. The Nursing Home rang to ask Cartrefi Cymru staff to describe the [allergic reaction] symptoms...Bron's medication was changed prior to her discharge and a drug prescribed that is similar to the one that caused the original reaction.

The Social Worker visited Bron at the Nursing Home on the day of discharge – Bron appeared relaxed and settled. I am unable to comment on any health issues leading up to the events that followed as it is out of my jurisdiction. It is likely however, that such information has been shared with Bron's next of kin and should remain a confidential matter within the family. I trust this clarifies the situation.

July 27 Bron passed away. Her body was taken from the Nursing Home to Hospital A for a post mortem...no post mortem was carried out...Bron's body was taken to [a] Chapel of Rest.

*Half an hour before Bron died the Nursing Home rang to ask if Bron was allergic to any medication. She'd be alive today if we had been listened to at the time when the professionals were deciding on her needs. Our knowledge was not seen as important. We have felt, ever since she died, that we should have done more. It can't be right that what Bron wanted was not seen as relevant by the professionals.*

Bron's death certificate states that she died of pneumonia.

## Some preliminary conclusions

The Local Authority investigation and conclusions led to us set out our assumptions about the influences shaping the work of their Care Manager and their beliefs regarding the Care Manager's work:

- There is an issue of professional sovereignty in this Local Authority and the unquestioned deference to perceived clinical expertise;
- Being an older woman with a learning disability meant an inevitable progression from hospital to placement in a Nursing Home. Although Bron's support needs had not altered during her



hospitalisation, aside from her evident distress at being removed from all and everything familiar in her life, she was assessed by clinicians and a Care Manager as requiring nursing care. So Occupational Therapy visits to the homes of older patients with learning disabilities, pre-hospitalisation or post-hospitalisation, are unnecessary;

- Discharge from hospital is regarded as an isolated event. Further, it is a confidential event and as such it is unnecessary for patients with learning disabilities to contribute to, or understand, the planning for this;
- Assessments in hospital need take no account of patients' pre-hospital lives or their expressed preferences;
- The limited experience of staff and nurse assessors in Hospitals XY and Z of patients with learning disabilities, the likely 'overshadowing' of her health status with unhelpful and negative beliefs about the implications of her learning disability, led to Bron's placement in a Nursing Home;
- The knowledge monopoly of clinicians and Care Managers is absolute;
- The grounded and experiential knowledge of staff supporting vulnerable adults for many years is irrelevant, most particularly when vulnerable adults are being assessed;
- There is no need for a 'handover' mechanism to transfer, inter alia, information regarding an allergy arising from medication to Nursing Homes or to any post-secondary care placement;
- Experienced support personnel are not eligible to be members of, or to contribute to the work and deliberations of, Multi-Disciplinary Teams and nurse assessors. Neither can they have the status afforded to 'all appropriate persons' responsible for assessing future care needs;
- The authority of an intermittent visitor can and should eclipse the knowledge of support staff.

As we were troubled by such assumptions, we sought a meeting with the Director of the Social Services. In the event, the Chief Executive and a Trustee met with the Head of Adult Services and a Social Services Inspector with a view to challenging some of the procedures to which Bron had been subject. We were concerned that no one involved in Bron's care, once she had been admitted to Hospital X, would be challenged to operate differently unless we undertook to start a reflective process involving them. Further, five streams of complaints, to the Local Authority, Hospitals XY and Z and the Nursing Home, and perhaps subsequently to the Health Services Ombudsman and the Local Authority Ombudsman would consolidate an adversarial position and delay, perhaps by years, the beginning of a process to negotiate and design different service responses.

## **Some emerging conclusions**

The meeting with the Local Authority and the Social Services Inspector opened with an acknowledgement from the Director of Social Services that support personnel do have information that is pertinent to the assessment of vulnerable adults. We moved on to address a concern that Cartrefi Cymru personnel were perceived as overreaching themselves in aspiring not merely to influence the assessment but also the care planning. We challenged the view that the Care Manager knew Bron sufficiently well to either represent her adequately or to ‘translate’ her utterances and behaviour without reference to her support personnel. There was acknowledgement that much had been lost in representing Bron without reference to the staff who had known her for many years. The initial value placed on Cartrefi Cymru staff in Hospital X gave way to mutual frustration as successive ward staff sought to exclude them from assisting with Bron’s feeding and drinking, irrespective of her weight loss and dehydration. They resented being challenged about, inter alia, leaving Bron on saturated pads. There was consensus that it is very hard to challenge clinicians, most particularly when your role is afforded no status by the Care Manager or hospital staff. We learned that the Care Manager did not know that Bron no longer resided in a residential home and had become a tenant irrespective of the fact that the local authority personnel were informed on two occasions. The local inspectorate had observed of Bron’s home ‘The accommodation is too small.’

There was some recognition that the status afforded to Mr Hedges might have caused anguish to Bron’s support staff as they do not believe he knew her well enough to represent her. However, in the absence of any discussion about Caldicott Guardians, his perspective held sway.

It was astonishing for us to learn that Bron was designated as a hospital ‘delayed discharge’ patient awaiting a nursing home. It was especially surprising as this placement would have required a more costly ‘package’ in total than Bron returning to her existing tenancy with support. Such a course of action, even in retrospect, is puzzling given the considerable pressures on health and social care to reduce ‘bed blocking’ (Department of Health 2003, Eley 2003, Glasby 2003).

Finally and importantly, we all took the view that the ‘nursing assessment’ was too narrow in its focus. Necessarily Bron required a clinical assessment but not one so instrumental in determining her post hospital destination that it excluded all other considerations, not least of all a Person Centred Plan (Learning Disability Advisory Group 2001). ‘Fulfilling the Promises’ states:

‘The Learning Disability Advisory Group recommends that people with learning disabilities...

have an equal right to expect a high quality of life – in practice this means having exactly the same expectations of decent health, education, housing, safety and financial security, protection from harm, positive social relations and roles within the family and community, employment opportunities, personal development, emotional well being and civic rights.’

The Courts are known for their thorough, but not speedy, consideration of problems. Even if they were speedier, the time required to involve them is too unwieldy to be of use in managing day to day patient

care. Yet Bron Davies has reminded us that the health and social care interface is replete with conditions that can exclude challenge. In retrospect, we might have challenged Bron's circumstances under the Human Rights Act. A Judicial Review and a High Court Judge have buttressed our concerns about Bron Davies' experience. North Yorkshire County Council *ex parte* Hargreaves 1994 held that a severely disabled woman's needs should be taken into account in assessing her needs for respite services, irrespective of the challenges for professionals of communicating with her. More recently, a High Court determined that an elderly woman should return to her home after hospital treatment and irrespective of the continuing care panel's decision that she should move to a nursing home. The woman's daughter observed, '[Local Authorities] have an outcome in mind and they make the person fit the reasons instead of looking at that individual's needs' (Brindle 2003).

We are co-planning a high level seminar with the Local Authority and Health Authority responsible for commissioning Bron's service in early 2004. This is for the senior managers, 'nurse assessor' and therapy managers, ward sisters of Hospitals X,Y and Z, and the Nursing Home where Bron was transferred. A question we want participants to consider before the event is: how had Bron's support needs changed during her 12 weeks in three hospitals such that her return home was not merely deemed impossible, it was beyond challenge?

## **Conclusion**

Bron Davies' death is tragic because:

- it was preventable;
- the relationships she had developed with people over some 12 years had been displaced;
- those who had developed a commitment to her over many years were purposefully distanced from decisions regarding her needs and wishes;
- in the closing phase of her life she was looked after by people who did not know her, and as crucially, were unfamiliar with her allergy and health needs; and
- most significantly, her repeated and explicitly stated wish to return home was ignored.

## **Some Proposed Priorities**

The seminar will provide an opportunity to build on and extend the following priorities:

1. Protecting the interests of vulnerable patients in secondary care is a profound challenge. The responsibility for this should not lie solely with professionals without utilising the experiential knowledge within vulnerable people's networks (where these are known to exist);

2. Provider services and the statutory sector supporting vulnerable adults should commence a programme of educational campaigning with health and social care organisations with a view to highlighting detrimental practices within secondary care and exploring ways of reducing the likelihood of these occurring;
3. Introducing quality assurance systems with a specific focus on vulnerable patients in secondary care should play a part in stimulating change and raising awareness of the importance of purposeful information and skill-sharing;
4. Effective hospital discharge planning acknowledges that people want 'to return to their previous lives as soon as possible and every effort should be made to help them to do so' (Department of Health 2003a). Unified Working Practices and Hospital discharge planning as they are currently experienced by people with learning disabilities will require ongoing scrutiny if they are to receive a service that compares with that of the population in general.

## **Acknowledgements**

Special thanks are due to Ruth Eley, Gwyneth Roberts and Jan Scrivens who made helpful comments on an earlier draft of this paper.

## **References**

- Brindle D (2003) Older people know what they want and it's time we listened. Society Guardian 22 October 2003
- Eley R (2003) Missing the Point: The experience of the Change Agent Team in the use and abuse of Performance Indicators (Draft Working Paper)
- Department of Health (2003) Changing Places – Report on the work of the Health and Social Care Change Agent Team 2002/03 London, Department of Health
- Department of Health (2003a) Discharge from Hospital: Pathway, process and practice London, Department of Health
- Glasby J (2003) Hospital Discharge: Integrating Health and Social Care Oxford, Radcliffe Medical Press
- Learning Disability Advisory Group (2001) Fulfilling the Promises Cardiff, Welsh Assembly
- North Yorkshire County Council ex parte Hargreaves 1994
- Welsh Office (1983) All Wales Strategy for the Development of Services for Mentally Handicapped

