

THE ROYAL  
BOROUGH OF



KENSINGTON  
AND CHELSEA

Report of the Overview & Scrutiny Committee  
on  
Social Services, Health & Housing  
on the  
Public Hearing into the Primary Care Trust's  
Consultation on the Future of the Cheyne Day  
Centre

## **Chairman's Foreword**

"As an excellent-rated Authority we recognise the imperative of providing services that meet local needs. The Cheyne Day Centre provides an invaluable service to a small group of severely disabled children and their parents. My Committee considers it important that this type of quality service continues to be provided locally for those in this particular category of need."



*Cllr. Ernest P. Tomlin  
Committee Chairman*

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## **1. Introductory 'Scene Setting'**

- 1.1 The Committee faced, on 30<sup>th</sup> June, one of its most difficult meetings since its establishment in mid-2001. It had been asked to comment on proposals for the future of the Cheyne Day Centre and arranged a public hearing for that date in order that the case for change could be fully examined to enable an informed Council response.
- 1.2 In the public gallery were close relatives of the children currently at the Centre, a couple who hope to send their child there, staff who work at the Centre and a range of other interested parties.
- 1.3 The consultation exercise was being carried out by the Kensington & Chelsea Primary Care Trust (PCT) which was represented at the meeting by its Chief Executive, Paul Haigh and by Director of Nursing & Clinical Quality, Ms. Clegg. Ms. Lawrence, Chief Executive of the Chelsea & Westminster Hospital Trust, where the Centre is currently based, was also in attendance.
- 1.4 It was quite clear, early in the hearing, that the Committee was faced with a highly-charged atmosphere. The close relatives of a number of these severely disabled children were present and quite clearly on an emotional 'knife edge', with at least two breaking down during the hearing. It is difficult fully to appreciate the sheer emotional pressure these parents are under twenty four hours a day, every day of their lives: they have an immense love of their child and want the best they can for them. They also need support in their endeavours to prevent physical and emotional breakdown in themselves and their relationships.
- 1.5 Members of the Committee had taken the time, over recent weeks, to visit both the Cheyne Day Centre and the new Jack Tizard School in White City, one of the alternative options being considered for this provision being promoted by the local PCT. Members had found that although the Cheyne building was not ideal for its purpose, it did present a peaceful environment for the children who might otherwise be distressed by noisy activities around them, a point reiterated at the hearing by parents.
- 1.6 Jack Tizard, on the other hand, was a new purpose-built school catering for up to seventy children of mixed ability. There were no children there yet with the severity of disability of the Cheyne children and, although Jack Tizard did have a number of profoundly disabled children, it appeared that they were being 'contained' rather than nurtured (though this is not a criticism of the staff, but more a reflection on the ethos of the School).

*Scrutiny Hearing on PCT Proposals for the Future of the Cheyne Day Centre  
Wednesday 30<sup>th</sup> June 2004*

- 1.7 Following the hearing proper, the Committee discussed possibilities for the retention of the Cheyne Day Centre. There was consensus that the service was the important factor and the building and management set-up should not be the determining factors in the Cheyne Centre's future. It was recognised also that close proximity to the Hospital was helpful. There was an overwhelming desire to find some arrangement to retain this unique service for children and for parents faced with such an immense burden.
- 1.8 This report records in more detail the evidence given at the hearing and the Committee's key findings, as conveyed in writing to the PCT, by letter, on Monday 5<sup>th</sup> July 2004.

*[Please note: The report below does not attempt to provide a verbatim record of proceedings, rather to present the main points and arguments put to the Committee during the course of the hearing.]*

## **2. The 30<sup>th</sup> June 2004 Scrutiny Hearing**

### **Committee Membership**

- 2.1 The Members of the Committee and its Panel of Advisers in attendance for this hearing were as follows:

- Cllr. Ernest P. Tomlin (Chairman)
- Cllr. Miss Barbara Campbell (Vice-Chairman)
- Cllr. J. Robert Atkinson\*
- Cllr. Jonathan Clamp
- Cllr. Dr. Iain Hanham
- Cllr. Bridget Hoier
- Cllr. David Lindsay
- Cllr. Steven Redman
- Councillor J. M. Blakeman (Panel of Advisers)
- Caroline Ellis (Panel of Advisers)

*\*Note: Cllr. Atkinson made a declaration of interest, indicating that he is a member of the Board of the Primary Care Trust. The Chairman indicated that he had sought legal advice and been told that there was no bar to Cllr. Atkinson's full participation on the basis that the matter under consideration was a consultation document, the responses to which had yet to be considered by the PCT Board, and something in which Cllr. Atkinson had no financial interest.*

### **Others in Attendance**

- 2.2 Councillor Shireen Ritchie (Cabinet Member for Social Services & Health) was also at the Committee table throughout the hearing.

2.3 The full list of those present in the public gallery is as follows:

- Julia Brickman (Full of Life)
- Fatima Bukhari (Cheyne Day Centre parent)
- David Cameron (prospective Cheyne Day Centre parent)
- Samantha Cameron (prospective Cheyne Day Centre parent)
- Jane Clegg (Kensington & Chelsea PCT)
- John Corry (Cheyne Day Centre parent)
- Sharon Corry (Cheyne Day Centre parent)
- Hugo Gerrard (former Cheyne Day Centre parent)
- Paul Haigh (Chief Executive, Kensington & Chelsea PCT)
- Jenny Hill (Deputy Chair, Chelsea & Westminster Healthcare Trust)
- Heather Lawrence (Chief Executive, Chelsea & Westminster Healthcare Trust)
- Tracy Ledden (member of staff, Cheyne Day Centre)
- Gordana Mandic (parent of child currently at Ashburnham School)
- David Pearce (member of staff, Cheyne Day Centre)
- Kim Ready (Cheyne Day Centre grandparent)
- Melanie Smith (Kensington & Chelsea PCT)
- Hannah Terrey (Action Disability Kensington & Chelsea)

2.4 The following Council officers were also in attendance:

- Henry Bewley (Health Policy Officer)
- Jean Daintith (Executive Director of Housing & Social Services)
- Tim Keay (Head of Residential Division, Environmental Health)
- Alistair Pettigrew (Head of Children & Families)
- Tony Redpath (Head of Strategy & Service Improvement)
- Richard Sachse (Schools Division, Education Department)
- Robert Sheppard (Head of Governance Services)
- Elaine Towers (Housing Team Leader, Environmental Health)
- John Wilkinson (Head of Policy & Performance, Housing & Social Services)

### **Hardcopy Information before the Committee**

2.5 The Committee had before it report A1 (as circulated with the agenda on 22<sup>nd</sup> June) and the following documents circulated subsequently by e-mail and laid around the table at the hearing;

- David and Samantha Cameron's response to the consultation;
- Cheyne Day Centre staff response;
- Fatima Bukhari's response; and
- Minutes of the PCT's 23<sup>rd</sup> June 2004 consultation meeting

### **Witnesses Called and Evidence Heard**

- 2.6 The Committee heard from a number of individuals and organisations as detailed below:

*Jane Clegg and Paul Haigh (Kensington & Chelsea PCT) and Heather Lawrence (Chelsea & Westminster Healthcare Trust)*

- 2.7 Ms. Clegg circulated a sheet showing financial projections in respect of each of the options presented in the consultation document: the Committee accepted her offer of a few minutes break to digest its contents. Ms. Clegg commented that rental and on-site medical provision costs would 'fall out' with options 4 and 5: medical cover would be on an outpatient basis.
- 2.8 Cllr. Hanham queried the level of medical input currently available at Cheyne. Ms. Lawrence indicated that this was low, supporting the Hospital's case that the Centre was not meeting the specifications of the Hospital's governance arrangements. The Centre, she argued, was an educational facility which happened to be sited, through historical circumstance, in a Hospital: it might be reassuring to parents to have a Hospital nearby, but that of itself did not change the fact that the Centre is in fact a school, even if not formally designated as such.
- 2.9 Mr. Sachse intervened to say that the Centre had always been a health facility and had never been part of the Hospital School. It had been Ofsted inspected because it had at various times used a Hospital School teacher. Jane Clegg confirmed that the Centre was not registered as a school with the Department for Education & Skills.
- 2.10 Cllr. Tomlin sought clarification as to how things might work if the Centre was registered by DfES as a school: as he understood it, the Local Education Authority (LEA) would assume primary financial responsibility, seeking medical support from the PCT and financial contributions from those LEAs who sent children to the Centre. Hitherto, however, Education input had been minimal, even though there was some educational aspect to the Cheyne provision (in terms of helping children gain some understanding of their environment). Whilst Cheyne had always been a health service facility, it was now the case that similar such establishments elsewhere now tended to be run by LEAs. In many ways the Jack Tizard School was well-placed to offer an equivalent service, subject to the availability of the necessary resources: it was nevertheless doubtful if there was sufficient space there to offer a service like that at Cheyne.

- 2.11 Mr. Haigh confirmed that should Cheyne close, the PCT would want to use some of the money released to fund similar provision elsewhere.
- 2.12 Cllr. Atkinson sought confirmation from the LEA that they were willing to fund the educational element of provision for the Cheyne children. In response, Mr. Sachse indicated that the LEA accepted its responsibilities and was paying for children sent to the Jack Tizard School: however, under an existing agreement, four places at Cheyne were currently financed, by Health, for Royal Borough and Westminster children – which has meant that the LEA has not hitherto been required to fund places at Cheyne.
- 2.13 The Committee moved on to seek clarification as to why only two places at Cheyne were currently filled. Ms. Lawrence confirmed that whilst assessments had stopped for a short period in 2003, these had now resumed: even where assessments had been completed, however, there was no guarantee that LEAs would fund the places – which was where the real problem lay.
- 2.14 The Committee then addressed the issue of costs. Cllr. B. Hoier queried the projections showing the costs of a placement at Jack Tizard as cheaper than at Cheyne. She suggested that such a projection could not possibly include the full cost of equipment, intensive one-to-one care and variety of therapies, such as water and music therapy. In response, Ms. Clegg expressed confidence that the Jack Tizard projections accurately reflected the cost, including LEA input, transport and additional health service input.
- 2.15 Cllr. Clamp asked how the current £360K income shortfall was currently being funded. Ms. Lawrence indicated that at present this was an overspend against the Hospital's budgets. Cllr. Clamp, in response, suggested that consultation was in reality a cost-driven exercise rather than a move triggered by the Government's inclusion agenda. Ms. Lawrence explained that the Hospital had an obligation to balance its books and, in Cheyne, it had on-site a facility which didn't meet its healthcare provision priorities: because of Government policy, and the fact that Cheyne was not registered as a school, LEAs were not funding places, sending unit costs up. Without funding, the service was unviable. Mr. Haigh added that the PCT and Hospital had a duty to review the service, given the take-up of places and changing circumstances in healthcare priorities and the national agenda.
- 2.16 Mr. Haigh explained how the options would be assessed following the end of the consultation period today. Interested parties had been invited to comment at the PCT's forthcoming Board meeting and a decision would be taken in the public part of the meeting.

*Kim Ready (Cheyne Day Centre grandparent) and Fatima Bukhari (Cheyne Day Centre parent)*

- 2.17 Mrs Ready contributed from the public gallery. She indicated that her grandson was currently at the Centre and the family's wish was that he stay there. They wanted the best for their child and Cheyne was a centre of excellence which offered precisely the sort of support and care that their child deserved. If the will really existed, a secure future for the Centre could be assured. It was quite wrong to close the Centre simply as a cost-cutting exercise. She concluded her remarks with a plea for help for parents of profoundly disabled children who were constantly having to battle for services and support.
- 2.18 Mrs Bukhari, whose child was currently at the Centre, contributed from the public gallery. The consultation, she said, had been poorly handled. This was the first occasion at which the Hospital had stood in front of parents to explain themselves. Cheyne Day Centre was part of the history of the Borough and offered a unique quality service, a model of excellence in the treatment of these kinds of severely disabled children. These children and their families had for too long been hidden and beaten down, but it was important that their needs were not ignored.
- 2.19 Cllr. Miss Campbell asked about the extent to which parental choice, in reality, applied. Mr. Sachse replied that the special needs 'statementing' process took account of parental choice and the placement of children in mainstream or special schools could be made to work: at present, of course, DfES would not accept the designation of the Cheyne Centre within a child of statutory school age's statement of special education needs as it was not registered as a school.
- 2.20 Cllr. Blakeman queried whether there had been any discussions with the NW London Strategic Health Authority about making Cheyne a regional provision. How many children within the NW London sector had needs that might best be met at a facility such as Cheyne? Mr. Haigh indicated that this information was still being collected. Ms. Lawrence added that four children had been assessed and were awaiting funding from boroughs/PCTs: two of these were from Hammersmith & Fulham, one from Brent and one from Kensington & Chelsea.
- 2.21 Members of the public gallery commented that declining referrals could at least in part be attributed to the widespread perception that Cheyne was under threat of closure.

- 2.22 On the issue of 'parental choice', Ms. Ellis suggested that a parent could only make a choice if they were provided with realistic options to consider: the closure of Cheyne would mean a limited set of options, making a mockery of 'parental choice'. Furthermore, what was the point of carrying out assessments if it was clear that boroughs could not be persuaded to fund places? Ms. Lawrence indicated, in response, that the Hospital was duty bound to undertake the assessments, but was not the funding body. Cllr. Atkinson asked what efforts had been made to establish why other boroughs were not prepared to fund places at Cheyne. Cllr. Tomlin indicated that Westminster felt they had made their own provision.

*David Cameron, M.P., and Samantha Cameron (prospective Cheyne Day Centre parents)*

- 2.23 Mr. Cameron explained that for his son the possible closure of Cheyne was a "life or death matter". In Cheyne he and his wife felt they had found what they initially feared didn't exist and, for their son, Cheyne was more than good, it was perfect – a mixture of therapy, nursing and education.
- 2.24 Mr. Cameron contended that the consultation exercise had been somewhat "topsy-turvy". The PCT's position seemed to be that Cheyne was an inappropriate model of care, but no satisfactory case had been made to support this. Furthermore there was no evidence that the PCT was listening to parents. All the arguments so far put against Cheyne were "bogus". The Centre **did** include an element of education – learning through play and therapy. Contrary to what had been so far reported about the 'inclusion agenda', the Government did in fact accept that special schools remained appropriate for some children.
- 2.25 The consultation was flawed in many respects because it had begun without any meaningful breakdown of costs in relation to the current Centre and the various options. Even the information circulated at tonight's hearing (on the very date that consultation closed) was incomplete.
- 2.26 The Jack Tizard School, indicated Mr. Cameron, was not a satisfactory alternative to Cheyne as it mixes active and passive children and hasn't the space to separate the two and offer intensive one-to-one care, with no provision for hydrotherapy or music therapy. It was quite evidently a good school, but not an appropriate model for all children.
- 2.27 Mr. Cameron argued that with close co-operation and ongoing discussion between health, relevant LEAs and local Social Services

a way could be found that would enable Cheyne to survive as the centre of excellence it demonstrably was. He urged the Committee to reject all options that involved the closure of Cheyne. Closure, he said, would be a historic mistake.

- 2.28 Cllr. Tomlin reported that, on his visit today to the Jack Tizard School, he had witnessed four severely disabled children coming from a separate room. In addition, the Head had indicated that, given the appropriate resources, he could deliver services comparable to those at Cheyne. Mrs Cameron contested this strongly: the Head had made it clear to her that active and passive children would not be separated at all times – and indeed could not, given current space constraints. Jack Tizard was already close to full capacity.
- 2.29 Ms. Ellis indicated that she had visited Jack Tizard with the School's Deputy, who had expressed confidence that the School could ensure the safety of the more passive children: the nursery unit would be quite separate. Mrs Cameron contested this: vulnerable children would not be separate or safe and an autistic child (say) could easily harm another, more vulnerable, child. Mr. Cameron commented that even with the best will in the world, Jack Tizard was "a million miles away from Cheyne".
- 2.30 Cllr. Atkinson asked for comments from officer representatives of the LEA and Social Services and the Committee heard as follows:
- Ms. Daintith indicated that Social Services has responsibilities to ensure that children in need have their needs met. In general terms the Authority would seek to accommodate parents' choice, tempered by pragmatic considerations (including what the Council could afford). There were a range of different arrangements in use in the Royal Borough: some children were in family centres, some in day/respite care, others in special schools.
  - Mr. Sachse indicated that the LEA had an inclusive approach. The Borough used special schools in other boroughs where it was not feasible to include particular children in mainstream schooling. The Council's approach was not one of 'blanket inclusion', however, and an assessment was made of each child's needs to find what was appropriate for them. Having said that, the 1994 Code of Practice and the 2001 Education Act included a presumption of mainstream education for most children. Any referral to Cheyne Day Centre would need to be done by a consultant paediatrician or neurologist, and not by the LEA.

- 2.31 Mrs Cameron commented that the LEA had not been terribly helpful to date in removing obstacles to her son's attendance at Cheyne. Social Services, however, had been very supportive.
- 2.32 Ms. Lawrence intervened to comment that the Cheyne Day Centre's current accommodation was not in any way 'fit for purpose' with narrow corridors and as such was not suitable for more than about six children. In response, a member of the public reminded the Committee that the recent consultants report had said the Centre could accommodate 8 and, on this basis, the costs were lower, per child, than the PCT's projections.

*Tracy Ledden and David Pearce (members of staff, Cheyne Day Centre)*

- 2.33 Ms. Ledden explained that she had worked at Cheyne for over ten years. The Centre had evolved over the years and, whilst many disabled children could now be included in mainstream schools, there were still those for whom health issues were paramount (even whilst, at the same time, some degree of education was required). Cheyne was a small, nurturing, calm, quiet environment where intensive and early intervention work could be undertaken, offering these severely disadvantaged children a chance to make sense of their world.
- 2.34 Mr. Pearce, who had also worked at the Centre for some 10 years, endorsed what his colleague had said. He expressed his personal commitment to the Centre and some frustration that children who would benefit from Cheyne were clearly not being referred there by their home boroughs.
- 2.35 In response to a question from Ms. Ellis, Ms. Ledden and Mr. Pearce together supported the consultants estimate of 8 children as the appropriate number for the Centre.

*Hugo Gerrard (former Cheyne Day Centre parent)*

- 2.36 Mr. Gerrard referred to his child's experience at Cheyne to explain why the Centre was the right environment for particular children. Educational progress was often slow, but when it was evident it was significant and moving to see. A family centre or mainstream school would not enable this sort of intensive input and slow progress and the needs of the most severely disabled children would be squeezed out.
- 2.37 In terms of funding, Mr. Gerrard expressed frustration at the emphasis on whether or not Cheyne was essentially a health or,

educational facility. Policy should be more 'joined-up' and, if Cheyne was the right place to send certain children, the appropriate funding package should be made available to assure the Centre's viability. He then told the Committee that Hammersmith & Fulham Council had provided funding for one of their children through their Education Department. He did not regard the non-designation of Cheyne as a school necessarily to be a stumbling block for other local authorities.

- 2.38 Clearly, Mr. Gerrard accepted, there were difficulties for the Hospital but, that aside, parents saw a lack of joint effort in seeking to resolve matters in a way that might secure the future of the Centre. In Mr. Gerrard's view, Cheyne was primarily a health provision with an educational input. He recommended that the PCT take the lead in getting Cheyne a separate status and management board. He had no doubt whatsoever that, on a new footing, Cheyne **would** quickly get up to full capacity. These facilities, he stressed **are** very much needed, as evidenced by the strong end emotional support of parents tonight.

### **Conclusion of the Hearing**

- 2.39 The Chairman warmly thanked all those who had attended, in particular those who had come to give evidence to, and submit to questioning from, the Committee. He indicated that copies of the Committee's findings and formal report would be sent to anyone who wished to leave their contact details in the attendance book.

## **3. The Committee's Findings**

- 3.1 Having considered all the evidence, the Committee has found as follows:
- That the Cheyne Day Centre (CDC) offers a rare service which is invaluable to children with certain types of severe physical disability and their parents. It can be described as a 'centre of excellence'. Such a service is difficult to replicate or create 'from scratch'. The skills and deep commitment of the Centre's staff are quite evident.
  - That the only option that will satisfactorily maintain the high quality service currently provided for severely disabled children like those at CDC is retention of the Centre at its current location. The Committee has serious doubts that the Jack Tizard School, albeit an excellent facility, can satisfactorily meet all the needs of children with the level of profound physical disability looked after at Cheyne and offer

them the range and level of support and therapy that they need and currently receive at CDC.

- That the PCT be urged to bring together all interested parties jointly to develop the management arrangement and diverse financial package that will best assure the future of the CDC from 2005/06 onwards. Such an arrangement might well involve the establishment of a voluntary organisation with a management board to run CDC and a formal application to DFES for registration as a school. In order to develop a viable funding solution, full financial information on the real cost of CDC must be made available and there must be transparency from statutory partners about what level of contribution each might reasonably make.
  - That, following the early commitment from all interested parties to the above, publicity must be given to the fact that the future of CDC is assured (at least in the medium term) and neighbouring boroughs should be made fully aware of the very special services on offer at the Centre. Assessments must continue with a view to the early filling of a total of up to 8 places at CDC and, subject to the DFES's registration of CDC as a school and its approval in each individual 'statemented' case, LEAs should be encouraged to seek to place at CDC children whose special needs suggest they might benefit from this sort of environment.
- 3.2 Subsequent to the hearing the Committee secured the formal agreement of the Council's Cabinet to the above response, which was conveyed on 5<sup>th</sup> July 2004 to the Kensington & Chelsea PCT as the response of the Council in its various capacities.

Councillor Ernest P. Tomlin  
**Chairman of the Overview & Scrutiny Committee  
on Social Services, Health & Housing**