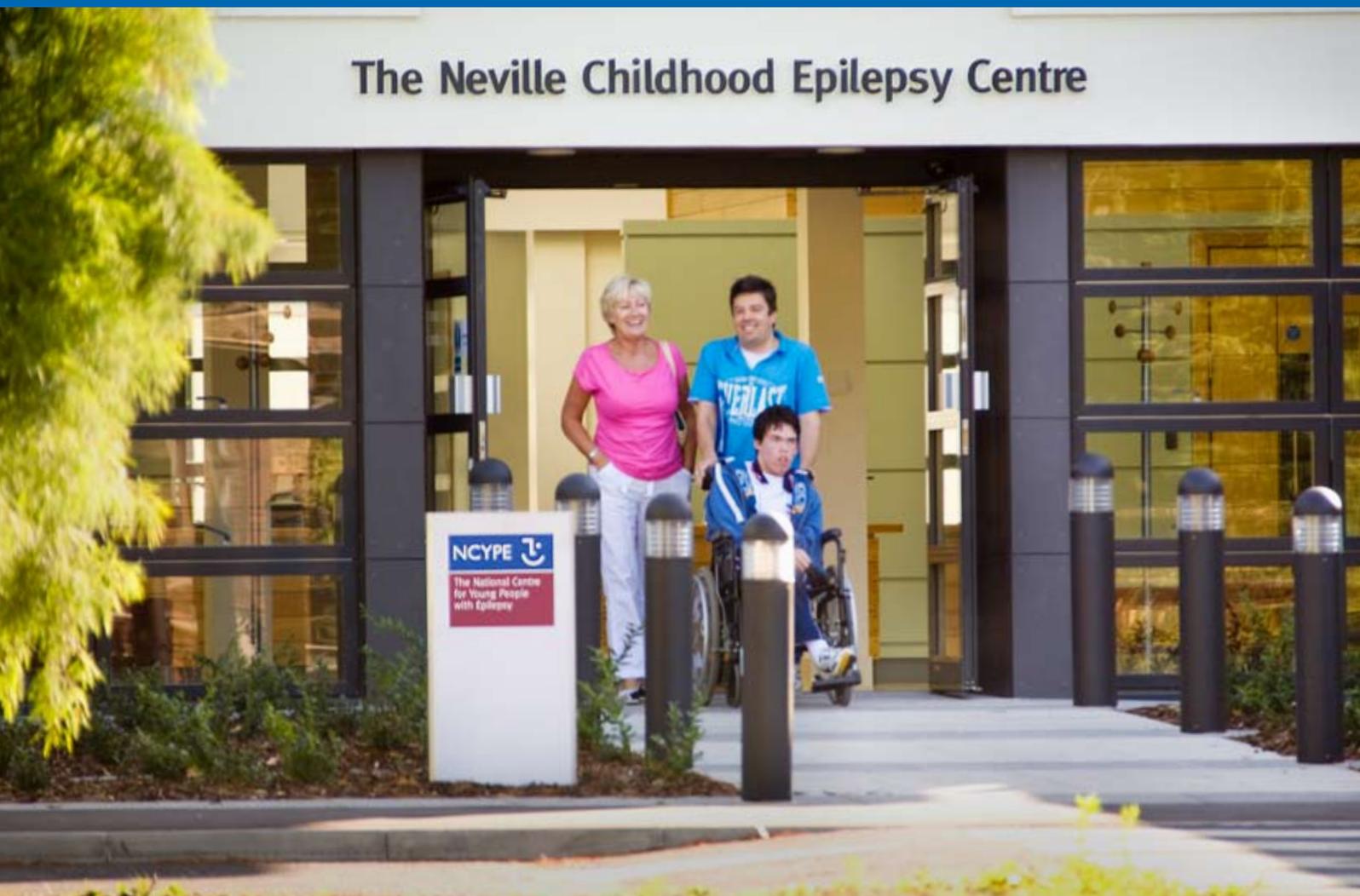


# The Better Futures Summit

## 25 March 2010



An event organised as part of the National Centre for Young People with Epilepsy's Champions for Childhood Epilepsy Campaign

## Summit Report and Action Plan

June 2010

[www.ncype.org.uk](http://www.ncype.org.uk)

## **1. About The National Centre for Young People with Epilepsy**

The National Centre for Young People with Epilepsy (NCYPE) is a national charity providing specialist services and support for children and young people with epilepsy and other neurological conditions. The NCYPE offers residential and day services at St Piers School and at its Further Education College. Our residential houses offer 24 hour home-from-home residential care and we also run a Sure Start Children's Centre for all local families.

In addition, the NCYPE offers consultant-led diagnosis, assessment and rehabilitation services in collaboration with Great Ormond Street Hospital, as well as the Childhood Epilepsy Information Service which provides training and information for professionals, parents and young people themselves. The Neville Childhood Epilepsy Centre on the campus is the base for a programme of international paediatric epilepsy research in partnership with University College London's Institute of Child Health.

The NCYPE wants to see better health and education services for all children and young people with epilepsy in the UK in order to address the current serious inadequacies and inequalities. Put simply, '*Better futures for young lives with epilepsy*'.

## 2. The Champions for Childhood Epilepsy Campaign

This is the campaign run by The National Centre for Young People with Epilepsy to improve the lives of children and young people in the UK with epilepsy<sup>1</sup>. The NCYPE's Childhood Epilepsy Information Service already provides professional, high quality information to parents, families, carers and professionals.

The Champions for Childhood Epilepsy Campaign (formerly the 'Better Futures Campaign') builds on the NCYPE's wealth of knowledge and expertise and promotes better services and support for young people with epilepsy. The Campaign is pressing for improvements to education, health and other services for the 60,000 children and young people living with epilepsy across the UK.

We know we can really make a difference by working with a wide range of partners, providing training, guidance and support, and by lobbying those in charge to ensure the right policies are in place.

The Campaign's health action plan is set out in Appendix 1 and offers a practical way forward for health organisations. It poses the question: Can you go an extra MILE for children and young people with epilepsy by:

- **M** easuring the need and the current level of service?
- **I** ncluding and informing children, parents and careers?
- **L** ooking after the whole child?
- **E** nsuring services meet nationally recognised guidelines?

*<sup>1</sup>The NCYPE is grateful to The Peter Harrison Foundation, The Hugh Fraser Foundation, The Linbury Trust, The Rank Foundation and The Gosling Foundation for their generous support of the Champions for Childhood Epilepsy Campaign. For a full and up to date list of our supporters, please visit [www.ncype.org.uk/campaign](http://www.ncype.org.uk/campaign)*

### 3. Why a 'Better Futures Summit'?

On 25 March 2010, the NCYPE held a Summit to discuss how to improve health services for children and young people with epilepsy across the South East of England.

The invitation letter, which was sent to a wide range of interested parties, explained the challenge:

*"The personal, social and economic impacts of epilepsy can be enormous for children and young people unless their condition is accurately diagnosed and managed. The research evidence confirms the statement last year by the Health Minister, Ann Keen MP, that 'services are still not good enough'. As a national charity with over 100 years experience of dealing with epilepsy, we want to work with health colleagues to develop practical and cost effective changes which make a real difference to primary care and acute services.*

*"What do you think are the gaps in paediatric epilepsy services? Can you help us identify solutions? Have you tried new approaches – and if so, what works?"*

The Summit programme is set out in Appendix 2.

### 4. Who attended?

The Summit was attended by around 30 participants from a range of backgrounds including parents, consultant doctors, specialist nurses, strategic and local health managers and commissioners, representatives from charitable trusts, and a cross section of NCYPE staff. A list of the participants is shown in Appendix 3.

## 5. Presentations and learning points

**Anna Walker CB**, the Chair of the NCYPE's Trust Board and former Chief Executive of the Healthcare Commission, introduced the Summit and explained the importance of improving health services for children and young people with epilepsy.

The participants then heard from a range of key people about their experiences of living with epilepsy and the support they had or had not received from childhood epilepsy health services:

- Kim Deville – a parent whose son has epilepsy,
- Sandra Cook - a school welfare officer,
- Jennifer Mackay – a parent whose daughter has epilepsy,
- Students with epilepsy from the NCYPE's Further Education College, and
- Caroline Muir – a parent whose daughter has epilepsy.

**Dr Sheila Shribman**, Clinical Director for Paediatric and Maternity Services at the Department for Health, had agreed to give the keynote presentation. Unfortunately Dr Shribman was unable to attend but asked Dr Dougal Hargreaves, her clinical adviser, to present in her place. Dougal Hargreaves' presentation is available on the NCYPE's website ([www.ncype.org.uk/campaign/health-action-plan](http://www.ncype.org.uk/campaign/health-action-plan)) and the key points were:

- 1. The objective should be to achieve the Every Child Matters outcomes for children and young people with epilepsy and a number of Government initiatives are in place to assist with this;*
- 2. One analysis shows that there were over 9,000 annual emergency admissions costing over £9 million a year;*
- 3. Current initiatives include revising guidance on managing medicines in schools, improving transition arrangements, and the introduction of personalised care plans;*
- 4. The 'Quality, Innovation, Productivity and Prevention' programme is aimed at making everywhere as good as the best;*
- 5. Future opportunities for improving care included: better support for commissioners, a stronger evidence base, self-management and outcome measures, and new technologies.*

**Professor Helen Cross**, the Prince of Wales's Chair of Childhood Epilepsy, reviewed the research on children and young people with epilepsy and concluded that the appropriate health services were not available. Helen Cross' presentation can be accessed from the NCYPE's website (<http://www.ncype.org.uk/dmdocuments/HC25Mar10.html>), and the key points were:

- 1. The services that children and young people with epilepsy need are not available to them;*
- 2. Half of children and young people with epilepsy have associated behaviour disorders, and one third of them have continued seizures;*
- 3. Families need accurate diagnosis and access to information, expertise, changes in treatment and multi-agency working;*
- 4. Those services should include a paediatrician with expertise and training in the epilepsies, nurse specialists, mental health services, and easy referral to tertiary care;*
- 5. It is important to plan and manage the transition from children's to adult services*
- 6. The ways forward include: knowing the individuals affected, providing clear care pathways, and developing managed clinical networks and regional specialist services.*

The participants discussed the issues raised in these presentations and each identified specific improvements that were needed in childhood epilepsy health services. These were grouped into four vitally important areas:

- Joined-up working between health organisations, schools, and other services
- Support and information for children, young people and their families
- Public awareness, lobbying and communications
- Improved clinical services

Each of these critical topics was explored by the participants in groups and the conclusions presented back in the afternoon's plenary session.

## 6. What ideas were identified?

A wide range of ideas were identified and considered, and the following 'top ten' ideas were distilled from that discussion:

1. Put epilepsy on the agenda of Children's and Young People's Trust Boards (e.g. through letters to Chairs, attending public meetings, PCT representatives, School representatives, clinicians inputs via PCT professionals groups, councillors);
2. Seek advice from the Government Office of the South East about promoting childhood epilepsy, e.g. through Trust Board 'sub-structures';
3. Approach the Directors of Children's services in local authorities;
4. Follow-up with Dr Dougal Hargreaves to ensure a full knowledge of the evidence base on childhood epilepsy (e.g. 'ChiMat', source of admissions map, evidence on economic impact);
5. Harness 'patient reported outcome measures' as a topical initiative;
6. Consider coordinating the collection of information from parents about the health services their children and young people experience;
7. Explore the opportunity for a pilot improvement scheme with the Brighton and Hove City Primary Care Trust;
8. Play a role in developing the Sussex and other childhood epilepsy clinical networks;
9. Repeat the Summit in other regions;
10. Use the Department for Health's 'Quality Innovation Productivity and Prevention' (QIPP) initiative to fund a project.

In addition, individual participants at the Summit went away with a better understanding of the issues, highly relevant information, and their own ideas and conclusions.

## 7. What has been done since the Summit?

Since the Summit, the NCYPE has been pursuing both the education and health aspects of the Champions for Childhood Epilepsy Campaign. The action plans for health and education have been re-shaped, based on the concept of asking people to *go the extra mile* for children with epilepsy.

The NCYPE has also taken the following actions which arose from the Summit itself:

- The NCYPE has explored how to maximise the use of the Quality Improvement, Productivity and Prevention (QIPP) project, led jointly by the Joint Epilepsy Council and the Department of Health's Long Term Conditions team. This will produce a tool that will support local commissioners to redesign effective services;
- The NCYPE has met with representatives from NHS Brighton and Hove to explore the opportunity for improvements to paediatric specialist epilepsy nursing services, including access to the NCYPE's recently launched specialist nurse development programme;
- The NCYPE has also held a very productive meeting with representatives from the Government Office of the South East to consider how best to work with local strategic partnerships, Strategic Health Authorities, and schools to achieve the Campaign's objectives;
- The NCYPE has reviewed the leading ideas with an group of expert internal advisers to identify the actions that should be prioritised as part of the Campaign.

## 8. What are we planning to do next?

The NCYPE is now working on a range of actions to improve health services for children and young people with epilepsy. These include approaching NHS organisations to discuss current services, and to offer help in developing improved services. The NCYPE also plans to set up or be involved in a series of events to highlight the needs of children and young people with epilepsy.

In addition, the NCYPE is planning to take the following steps related to ideas that arose from the Summit:

- Discuss the issues facing children and young people with epilepsy with Dr Sheila Shribman, Clinical Director for Paediatric and Maternity Services at the Department for Health, and Dr Dougal Hargreaves who spoke at the Summit;
- Continue to identify and disseminate all the relevant data relating to childhood epilepsy health services and research about childhood epilepsy;
- Use the output from the 'Quality, Innovation, Production and Prevention' (QIPP) project mentioned in section 7 to help health commissioners consider how to improve their childhood epilepsy services;
- Approach Directors of Children's Services in local authorities to highlight the successful pilot scheme in schools and highlight the positive impact on education that arises from improved health care;
- Look for opportunities to hold a similar Summit in another region, perhaps in conjunction with the Strategic Health Authority;
- Develop links with paediatric epilepsy clinical networks to see how the NCYPE might be able to support their work;
- Hold further discussions with contacts established at the Summit.

## 9. Conclusions

The NCYPE's Champions for Childhood Epilepsy Campaign is pressing for improvements to education, health and other services for the estimated 60,000 children and young people living with epilepsy right across the UK. These young people face a 'triple whammy' from:

- *Seizures* – the impact of continuing seizures and/or the side-effects of medication;
- *Services* – the impact of education and health services that do not enable them to fulfil their potential;
- *Stigma* – the impact of misunderstanding in the society that surrounds them.

More must be done and this Summit provided a vital opportunity to consider how best a range of organisations and individuals could achieve the right outcomes. The presenters offered excellent insights into childhood epilepsy health services from a wide range of perspectives, and the participants identified and explored an equally excellent set of ideas. The NCYPE would like to thank the presenters and all the participants at the Summit for their time, energy and ideas.

The NCYPE is already working on the most promising ideas and will continue that work in the weeks and months to come. The question for participants at the Summit and other readers of this report is:

***Will you go the extra mile to develop and deliver the right health services for children and young people with epilepsy?***

The NCYPE is keen to work with organisations that provide or influence services for children and young people with epilepsy.

We would also like to hear from children, teenagers, and their parents or carers who want to be involved in the campaign or want to share their experiences of education and health services.

If you would like to know more about the Champions for Childhood Epilepsy Campaign, please contact Alison Cornell ([acornell@ncype.org.uk](mailto:acornell@ncype.org.uk), 01342 832243) or visit [www.ncype.org.uk/campaign](http://www.ncype.org.uk/campaign)

### ‘Champions for Childhood Epilepsy Campaign’ health action plan

#### Health services can go the extra MILE for young people with epilepsy by:

##### Measuring

- Commissioners must know the number of young people with epilepsy in their area
- Commissioners must know what level of resources they have in place
- Commissioners must know how long young people with epilepsy are waiting for initial appointments, diagnosis, treatment and tertiary assessment

##### Including and informing

- Commissioners must know what young people with epilepsy and their parents think about services
- Children, young people and their parents/carers need easy access to high quality information and advice material about epilepsy

##### Looking after the ‘whole’ child

- Children and young people with epilepsy and their parents/carers must have easy access to high quality multi-disciplinary services such as speech and language therapy and psychology

##### Ensuring services meet national recommended guidelines

- Commissioners must adopt an easy to use, efficient process for referring children and young people to specialist epilepsy services
- Commissioners must have one or more care pathway that ensure all young people with epilepsy are seen by paediatricians with training and expertise in the epilepsies
- All children and young people with epilepsy must be offered a care plan, and there should be a high adoption rate
- All children and young people with epilepsy must have their case reviewed annually by a health professional with training and expertise in the epilepsies

## Appendix 2

### Better Futures Summit Programme 25 March 2010

|       |   |
|-------|---|
| 10.00 | Registration<br>Coffee/tea available  |
| 10.30 | Welcome to the Better Futures Summit <ul style="list-style-type: none"> <li>• Anna Walker, CB, Chair of NCYPE</li> </ul>  |
| 10.45 | Living with epilepsy <ul style="list-style-type: none"> <li>• Views from young people, parents, and professionals</li> </ul>  |
| 11.15 | Are children with epilepsy getting the health service they deserve? <ul style="list-style-type: none"> <li>• Professor Helen Cross, Prince of Wales's Chair of Childhood Epilepsy</li> </ul>  |
| 11.40 | <i>Keynote speech:</i> The challenge of improving health services for children with long term conditions <ul style="list-style-type: none"> <li>• Dr Sheila Shribman, National Clinical Director for Children, Young People and Maternity Services</li> </ul> |
| 12.00 | 'Reactions' <ul style="list-style-type: none"> <li>• Comments from delegates on the presentations</li> <li>• Challenge: what specific improvements are required to childhood epilepsy health services?</li> </ul>   |
| 12.40 | Buffet lunch  |
| 1.20  | Group work <ul style="list-style-type: none"> <li>• What levers can be pulled to make a real difference to childhood epilepsy health services?</li> <li>• Questions for the panel</li> </ul>  |
| 1.50  | Conclusions <ul style="list-style-type: none"> <li>• Feedback from the group work</li> <li>• Panel discussion on the groups' questions</li> <li>• Concluding remarks from David Ford, Chief Executive, NCYPE</li> </ul>                                       |
| 2.30  | Close   |

## Appendix 3

### List of delegates

| Forename | Surname    | Role & Organisation  |
|----------|------------|--|
| Patricia | Atkinson   | Consultant Paediatrician – Surrey and Sussex   |
| Richard  | Balfe      | Government Office for the South East   |
| Geoff    | Burgess    | NHS Brighton and Hove City – Strategic Commissioner  |
| Sandy    | Clarke     | Department of Health Long Term Conditions Support Team                                     |
| Jill     | Conium     | East and North Hertfordshire   |
| Wendy    | Cooke      | The Children’s Trust   |
| Helen    | Cross      | The Prince of Wales’s Chair of Childhood Epilepsy  |
| Trish    | Dabrowski  | South East Coast Strategic Health Authority – Strategic Lead for Children and Young People |
| Kim      | Deville    | Parent   |
| Dougal   | Hargreaves | Clinical Advisor with Dr Shribman at the Department of Health                              |
| Elaine   | Hughes     | Paediatric Neurologist – Kings/Evelina   |
| Vijay    | Kandala    | Consultant Paediatrician - East and North Herts  |
| Roger    | Kendall    | Epilepsy HERE  |
| Monica   | Kendall    | Epilepsy HERE  |
| Fiona    | Mackison   | South East Coast Specialist Commissioning Group  |
| Caroline | Muir       | Parent   |
| Madeline | Peasgood   | Epilepsy Action Brighton and Hove Coordinator  |
| Ruth     | Williams   | Paediatric Neurologist – Kings/Evelina   |
| Emma     | Williams   | Matthew’s Friends  |

| Forename | Surname     | NCYPE role                               |
|----------|-------------|--|
| June     | Atkins      | Deputy Head, St Piers School             |
| Sarah    | Aylett      | Consultant                               |
| Hayley   | Bath        | Head of Health Services                  |
| Alison   | Cornell     | Campaigns Coordinator                    |
| Sheila   | Craft       | Outreach epilepsy nurse                  |
| Alan     | Cruickshank | Strategic Development Manager            |
| Krishna  | Das         | Consultant                               |
| Karen    | Deacon      | Director of Health & Social Care         |
| Linda    | Edwards     | Senior Speech & Language Therapist       |
| David    | Ford        | Chief Executive                          |
| Maria    | Fowler      | Head of School Therapy & Psychology      |
| Jackie   | McFall      | Service Development Manager              |
| Brian    | Neville     | Director of Innovation and Best Practice |

## **Better futures for young lives with epilepsy**

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