

**PARENTS AND PROFESSIONAL - WORKING TOGETHER**  
**CONCLUSIONS OF A SEMINAR HELD IN BARCELONA 2011**  
**by ANITA LORING**

I want you to imagine that you are sitting in the Family Court in England. The Family Courts were set up in 1989 as a result of the Children's Act. They are there for one purpose and one purpose alone and that is to act in the best interests of the child. The Magistrates, and these are lay people in England not qualified lawyers, have heard the evidence and have retired to consider their finding and you are awaiting their return to Court. The format this report will take follows exactly the headings and the issues the Magistrates have to consider when they have an application for a Care Order.

**The Application.**

This is an application by the Children of the World with special needs and particularly those with cerebral palsy, for an Order to ensure that they will, at all times, be considered first and foremost as complete human beings and that they are not talked about as if they are a collection of parts.

Those present at this meeting have included parents and professionals, some of whom also have a disability.

We have heard oral evidence from speakers from around the world whom we thank for having given up their time to come and share their knowledge and experiences with us.

We have also heard representations from many other participants, and we would like to thank the translators who have enabled us to communicate despite language differences.

**Facts not in dispute.**

Daphne Economou told us that though the discovery of the knowledge that a much longed for child has a disability is a long and difficult journey full of the unknown and questioning about why has this happened to us, what has my child done that this should happen to him, we eventually have to realise that we need to concentrate on the child's quality of life, we each have to work out our own salvation, that our child is a gift of nature, a gift of inestimable value which functions perfectly as a human being and later Hans emphasised that the child and his family are the experts of their situation.

**Disputed facts.**

By and large we have heard no disputed facts though the meeting has been characterised by lively and informal debate

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In considering this application we have looked at **the Welfare Check List** as follows:

**The ascertainable wishes and feelings of the children concerned (considered in the light of their age and understanding.**

Liz Moulam described graphically the journey they took to find appropriate communication aids for their daughter Beth. Beth was pro-active in all these choices and decisions and Beth was determined to succeed. Beth continuously expressed the importance of her role throughout by saying, 'talk to me and not to my Mother!' and 'see me and not my chair and not my communication aid'.

Annalu Waller continued the theme by emphasising the importance of finding appropriate communication aids for those without speech, to enable not only communication but independence, so that so the individual has the chance to grow into the person they are meant to be. In other words, to provide the opportunity for the child with a disability to express his or her own wishes, their desires and their dreams.

**The children's physical, emotional and educational needs.**

Martin Bax suggested that we should all see as little of doctors as possible! Hans Forssberg took up this idea and said in order to move ahead we need scepticism, that we need inclusion and participation in family based services, the message being that the doctor is no longer God and the child and his family are the experts.. He emphasised the importance of evidence based clinical trials and reliable measurement and warned that the more high tec the proposed intervention, the more suspicious we should be!

We heard a lot about pain during this meeting. As Alain Chatelin said, pain can be sorrow or physical pain, and he told us that his son said that pain is an unnecessary experience, that it is difficult for the carers since they see suffering because of pain and that just because somebody has cerebral palsy, pain should not be inevitable.

Dr Gimeno said that the treatment of pain depends on its intensity, not the cause. Diagnosis of pain should be made as soon as possible and its planned treatment comprehensive.

This theme was continued by Julia Torrequebrada who talked about a Mother's fear of the difficult feeding situation and the possibility of malnutrition, of the time involved in feeding which meant that the family ignored other aspects of the child's development. She described the road to find a solution to her son's feeding

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problems but although now he has a gastric button it is difficult because he cannot eat with other children because it is socially unacceptable. She finished by saying that, 'now feeding is no longer a problem, his future will be alright and I can enjoy him as a child.'

Owen Hensey emphasised that we have to assess carefully feeding methods and that sometimes it is difficult to come to terms with the fact that it is not safe to orally feed a child.

**The likely effect on the children and parents of any change in circumstances: Children's age, sex, background and any characteristics which the court considers relevant.**

John Coughlan talked about his son David and posed the dilemma, 'How do we deal with this mountain of various options we are faced with? How do we make choices?'

Diana Damiano suggested a way forward, that any option should be practical, accessible and feasible and the goal is that it should be used to enhance activity and mobility. What is done outside of therapy is even more important and that many things can wait but the child cannot and that positive actions enhance the child and the parent's circumstances.

Charles Clua used words like, crisis and expectations during his paper and he voiced a question which most parents have but which they often find difficult to ask, what is going to happen to him in adult life and when I die? This question was not pursued during the meeting.

**Any harm which the children or their parents have suffered or are at risk of suffering:**

This is summed up by Stefan Holmberg's story of the pirate game in which he and his brother Thomas tied up their brother Per, who has CP, and interrogated him about where was the hidden treasure! Quite clearly Per faced both harm and risk in the same way as his able-bodied brothers.

Quite simply Stefan's message was, take part together and with friends in all activities, the types of activities that all adventurous children get up to!

Eulalia Calado's contribution suggested that for the child with CP, having a sibling is a great advantage since they can act as change agents to minimise disability and encourage emotional, social and cognitive development.

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The final session of the meeting dealt with a kind of risk and possible harm since, as Charlotte Holmberg said, 'you still have to cope with real existing challenges even if it seems that appropriate support services are in place. There is a big challenge in finding a balance between overprotection and independence and it is important to plan for this, to plan for self-reliance, even if it includes risk.

Helen Healy, however, talked about real risk in that many young people are not properly prepared for the transition from childhood to adult life. She talked about shared management and planning so that goals are realised, and risk and harm minimised so that the transition can take place and responsibilities accepted as part of growing up.

**How capable are the parents, and any other persons in relation to whom the court considers the question to be relevant of meeting the children's needs:**

We have heard that parents are the experts of their own child. Lluís Farres described how to try to achieve a good quality of life and above all that the child should be loved and cared for. He emphasised that parents need the support of professionals, not only to be able to ensure that the family functions as a family unit, including siblings, and that the quality of life means different things to different families, but that families MUST, above all, be masters of their own destinies.

Allan Colver told us that the child itself does not have the disability, it is the inability of the child's environment to adapt to enable the child to have a good quality of life. He described briefly the SPARKLE projects in which children across Europe self-reported on their perceptions of their own well-being. Perhaps the most significant finding was that there was no difference in children's perceptions of their quality of life regardless of whether they had CP or whether they were children from the general population.

It is perhaps reassuring for parents of children with CP that they will experience the same quality of life as children in the general population and that environment plays a crucial role in this social model and therefore affects the child's participation in activities which in turn affects their quality of life,

Karen Horridge reminded us that the child, his brothers and sisters and his family need to remain in charge and they need to be in charge right from the start. We need to concentrate on responsibilities and goal setting through communication to empower people to achieve their goals and we have come full circle because this philosophy will result in people with disabilities being seen and accepted as perfect human beings.

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First and foremost parents are the best experts on their child. However they need to learn to take risks to allow their children to grow, to experience life to the full as far as their disability will allow. Parents are first and foremost Mother and Father and siblings Brothers and Sisters, that is their most important role. Although they need to accept that the child with a disability has special needs they must NOT lose sight of the importance of normal everyday life.

We have considered the No Order Principle but find that it is in the best interests of the children to make the Order to safeguard their dignity and rights in accordance with the Human Rights Act. What is important is PEOPLE and not their disability, and we therefore grant the application

In making the Order we also make the following Directions:

1. That the Internet should not take over human contact.
  2. That the child should not become a medical case and simply given a label.
  3. That Marc Torrequebrada be allowed to continue to eat sweets through his gastric button.
  4. That Marc Clua continues to be the lead singer with the band.
  5. That Matthieu must be allowed his goal, 'he wants to walk, he wants to speak and he wants to be free of pain.'
  6. That Regina has her music and her bird song to enjoy her life.
  7. Finally, that we always look on the bright side of life,
- and that ASPACE continues to enjoy and celebrate its 50th Birthday!

THANK YOU.