

## **SUBMISSION FROM CATRIONA SPINK**

1. I wish to mention my experience of autism, what we need is help to support the family in the family's own local environment and on occasions accompanying them further afield, such as a family holiday away. Care should be able to achieve everyday outings as a family, not to be separated or segregated by autism.
2. Care should be provided to help tidy our homes, they are not in an unkempt state because we are dirty or not bothered — in fact it is amazingly beautiful and relaxing to have a clean and tidy space to live within — and often extremely important to the autistic person.
3. Our homes become a state because of the extra needs of autism, perhaps our children find it difficult to sit still whilst eating; like flicking their food and experiencing it hitting the ceiling or distant wall; get up and run to look out of the window and food smeared hands (as they refuse to use cutlery) are smeared all over the glass — more cleaning.
4. I am up often into the small hours cleaning and tidying all those bits our loved autistics create which don't get seen because they are cleaned, such as they delight in emptying a cupboard and climbing into the space left and, whilst you sort this they are not getting attention, thus something else happens ... a vicious circle.
5. My daughter can go into fits of throwing things which are a visual distress to her; she went through a stage of flipping dishes from the sink (she is a kinetic learner, meaning things only excite or interest her if they make a noise or get a reaction from others). In an instant broken crockery which must be cleared from a danger point of view. My social work department informed me that I was unable to utilise my home care clearing my dishes. My daughter is on a gluten free, milk free, soya free diet, I cook absolutely everything — there are few convenience foods I can buy — the time this takes and the extra work load it creates is immense, I am only trying to be the best mother I can be by providing a healthy but restrictive diet, but was penalised for it. The stress to me of not having cleared my dishes, a necessity in my mind for me to be able to relax and do something productive with the children, rather than the vicious circle of not having enough time to clear all the damage and teach them (the autistic child) what is expected and needed from them in many situations which in the end of the day allow them to be a member of their own community.
6. In our experience we have been offered care but to social work department's requirements rather than our needs. Such as; the carers will take the child out separately "to give the family a break" but, in fact, the family does not want "a break", it wishes to achieve something enjoyable

TOGETHER, and to do this require support from people who are of a similar ilk. In other words, certain people will be suitable (fit in) with certain family types, such as a physically active family would suit a carer who was also interested in physical activity and, in that way, perhaps the whole family could go ice skating, horse riding or sailing; the “break” being achieved through a family's enjoyment with each other, where one child is not left out because of another's needs.

7. I find it shocking that social workers are not required to study psychology as part of their qualification, nor do they spend time necessarily with all sorts of different special needs categories. How can people like this effect our lives so disastrously by forcing completely loved children to live in residential homes rather than a system in place where as nurses.
8. There is a bank of carers, each able to work in various special needs areas. For example, in a family who could normally work well, if their child had an off day, or was up all night and the parent also needed to be awake or was not able to sleep due to the child's needs of supervision. In this situation, this parent could phone the “bank” and get the help they needed the following day so that they could catch up on sleep and thus continue to be an effective caring parent to all their children. It is often the cumulative effect of one bad night which then turns the whole week into disarray, caring for autism requires being flexible as the children can vary their needs from day to day, [night to night](#).
9. Care provided by social work was not allowed to “teach” yet the autistic child needs help to learn everything and it is possible to teach them.
10. Respite is great but only if the child is known to be enjoying the activity or outing, the parent does not relax if they know their child is unhappy. Often there needs to be a pass over, so that the carers work alongside the parent for several weeks before a complete break (respite) can be achieved. By working together, trust is built up between everyone who makes future events work so much more smoothly. Success is achieved gradually, but that success is profound and positive, the child does not come home self harming or stating their wishes not to go. For an almost non-verbal child, this should then be taken as a massive step forward in communication and thus should be respected, as in the child does not have to go where they are so obviously to the parent not wanting to be.
11. I have two children and the best care I have received is where the carer is not just fixed to the autistic child, which can then bring about jealousy in the typical child, but the carer is actually involved with both children and the day to day events, such as cooking and cleaning. The autistic child is helped (often extremely slowly as it is miniscule step by miniscule step, repetition being the key) and, in this way, the autistic child is constantly redirected by

more than one individual at different times to achieve a task of daily life, the act itself being consistent and the message and understanding of the task is achieved.

12. Siblings also gain from this way of working as they see an adult who is calm and caring not flaring up at every little mishap (because they are so over stretched already) but gently coercing correct behaviour, it encourages the sibling to also be helpful naturally by another's example.
13. I have been devastated by my daughter being forced to live away from home, her sibling also has suffered and we have been wholly unsupported as a family. Often not believed or respected, our children's behaviour arises due to their condition and lack of enough hours in the day, and definitely not enough sleep! WE WANTED TO BE A FAMILY TOGETHER: NOW WE LIVE WITH "LIVING BREAVEMENT". The more families are supported within their homes and local environment, the more autism can be accepted. One autistic woman told me she wanted the right to be supported in work, she matched socks, instead of living in a hostel and going to play bowling, she had care in her own home and enjoyed tasks which suited her, she feels a useful member of society.

Catriona Spink  
6 October 2010