

I am an Occupational therapist working in a Regional special school with Cerebral Palsy Children and their families.

Current provision of wheelchairs, disability equipment and building alterations are all very variable.

## Housing

### Case 1

Girl aged 12, weighing 41.6 kg is carried up a steep open staircase, Mum who did not work lived with a partner with financial support to provide for his first family, applied for DFG approximately 5 years ago and asked for payment of first ?27,000 on the private terraced house. Couple have now married, two more children to support, used various legislation with Social Services, who eventually two years ago gave some money which has provided suitable showering and bathroom facilities that can be used with minimal carer assistance. The family need approximately ?6,000 for a vertical lift, major health and safety risk, uncomfortable etc. etc. If accident occurred Step Dad unable to work, no finance, this would then be provided!!!!

### Case 2

Family of six, girl with CP, 3 brothers, live in housing association 3 bedroomed house. Not wanting to move, spent a lot of money, decoration, double glazing etc. Need ground floor extension, suitable for future as an adult in wheelchair, bedroom and shower facilities, told waiting list 4 to 5 years. Girl sleeps in the same bedroom as parents, aged 10. Inappropriate and stairs again a continuing issue.

### Case 3

Mum and two sons, one with Cerebral Palsy. Son now 11, on Council/Housing Association list shortly after birth, in rented accommodation, (from frustration moved to rented accommodation in Durham for a short time then returned, Council say a form was not completed so lost space off housing list. Have maximum disability points, maximum social points, Mum off work almost a year through ill health. Had fight to get name added to a house list as well as bungalow list. Got added, available 3 bedroomed property (not viewed), tried getting but homeless have a higher priority, the rent was increased at this time on rented property, so tried also getting 'homeless' status, this was subsequently gained, however Council would not wait, allocated to a single person. Mum carrying son upstairs. Made ramp for assess of power chair. Child is being disabled not enabled - all cases.

### Case 4

Parents, son with CP and a daughter. Moved to a three bedroomed bungalow after a lot of pressure, knew bungalow became available, sent professional letters, used councillors and MP. Housing still asking all OTs in Social Services is there not another family! Eventually moved Hoisting equipment now in, Environmental control system in, doors widened, major damp proof work. Shower due to be installed soon. Outstanding issue is the old wheelchair level kitchen which was in for over ten years, but agreed not to change the first financial year. Been in property 2 1/2 years. Kitchen has one small double cupboard and one set of three drawers, the kitchen is in a poor general state. Various

professionals contacted housing re kitchen including the family, told no family told they signed a disclaimer, Family have no knowledge of this. Photographs and letter resent to Council, (first not received!). Current situation Council still not wanting to provide, suggesting moving the family for a disabled person to go in. The kitchen needs re-doing anyway, also we requested an adjustable height section for the 12 year old to use in his wheelchair to develop life skills. If the Council wish by the provision of an adjustable height sink unit, some 'normal' height units with suitable pull out baskets, turntables, the kitchen could be suitable for both ambulant and wheelchair users.

Some services tend to find it easier to say 'no' to many situations, even when there is obviously major issues.

This is really just a few sample cases!!!!

Parents respond to the stresses in various ways but many do suffer from both physical and mental health issues. The pressure created on parents relationships, from dealing with the many Different Services and where to go for what, along with the various different outcomes dependent on both the professional individuals, and the local services standards. Parents do communicate between them selves and get frustrated with the variability.

Some articulate parents get services with little difficulty, others can be labelled nice and that they keep coping and will keep managing, by Social workers not wanting to fund respite, whilst non coping and parents with low cognitive ability get their cases closed due to failing to return a letter. Being unable to make contact with a family should RAISE concern over the child care and safety and not cause a case closure or removal from a list.

Equipment provision via District Home Loan Departments - again so variable. Some recognise school therapists special role and allow us to prescribe for home off their budget, other services make children wait on a waiting list for re assessment. Now have 6 children waiting in one District, one waiting over 15months, has issues over a hoist sling-wrong size (poor prescription and no follow up by the therapist for handover) therefore moving and handling issue, Sleepsystem - Child in pain wakes through night disrupts rest of family, Therapist has copy of my assessment of need and will not process. Writtern to Acting manager who passed letter back to therapist - not addressing question about what action they are taking with regard to the waiting list. Therapist involved does not want Percy Hedley children to get preferential treatment, rather than viewing it as lightening their loads and addressing need. Salaries are expensive and therefore could be better used. Their letter suggests a 12month wait for non urgent! Already 15months, Prioritising therefore poor, Child had hip surgery therefore support needed to protect work puts surgery at high risk of failure.

Service changes

I believe parents should not be funding their disabled child's needs.

If funding provided to parents of children - there are vast differences in childrens level of disability - who assesses? would it be realistic? organising a system to police the funds to maximise use of money with professional input and by who and which service, which specialist, Parenting skills are very variable along with parents cognitive and reasoning skills. Technology is contiuing to develop therefore expenses constantly increasing and raising expectations.

Gone on long enough. Sorry but alot of my time is being spent trying to access services for frustrated parents and to help prevent family breakdown, my main job should be improving the child's function, independence and skills for becoming an adult in society. Services are disabling children in many ways, it is a constant battle and this is very sad in today's society.

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