Childhood Disability and Health and Social Services Policy in Northern Ireland

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Introduction

The recent policy and planning developments such as the implementation of the 1995 Children (NI) Order, children’s service planning, and the Health and Well-Being Investment planning have the potential to increase the inclusion of children with disabilities and their families into planning processes and service provision, but as yet none of them have been explicitly dedicated to increasing the quantum of public services available to disabled children. Research to date has shown that the provision of social services to disabled children and their families has been limited, piecemeal and fragmented. The Children (NI) Order brought some re-organisation of these services, alongside some additional funding, but there still remains considerable unmet need.

Policy Context

The primary policy planning and legislative changes that have occurred since the 1990 PPRU Disability Surveys are the introduction of:

* The 1995 Children (NI) Order
* From 1998 the Children’s Services Planning system at Health and Social Services Board level
* From 2000 Health and Well-Being Investment planning at both Board and Trust levels.

The 1995 Children (NI) Order provides a legal framework for the provision of social care services for children with disabilities and other children in need. It requires Trusts to open and maintain a register of disabled children in their area and to provide services to them which are designed to give them opportunities to lead their lives to their full potential.

Since 1998 Health and Social Services Boards have been required to establish and to lead multi-agency area children’s committees which produce children's service plans. These plans should in future contain explicit reference to the needs of and provision for disabled children.

The Health and Well-Being Investment Plans at both Board and Trust level are intended to ensure that the strategic directions and goals set by the Department of Health, Social Services and Public Safety are met. The Department’s 2002-2004 Corporate Plan aims to enable those with a disability to be fully integrated within society (aim 3) and to promote the welfare of children (aim 4). Aim 3 includes a commitment to improve services and support for children with disabilities by March 2004, while aim 4 includes a commitment to inspect services for disabled children by December 2002.
The Social Services Response to Disabled Children and their Families in 1990 – Key Facts

This data is taken from the 1990 Disability Surveys undertaken by the Policy Planning and Research Unit (PPRU).

* 9% of disabled children living in private households in Northern Ireland in 1990 had access to the services of a social worker in the last 12 months. Disabled children in lone parent families (11%) were slightly more likely to have received services from a social worker.

* Families in Great Britain with disabled children (11%) were more likely to have contact with a social worker than those in Northern Ireland (9%).

* Children with a consciousness disability were more likely to have access to a social worker (12%).

* Almost all disabled children living in communal establishments (96%) had access to a social worker.

* One-sixth of parents (16%) thought that they needed help from health and social services. This help included access to a social worker (13%), provision of a night sitting service (10%), a home help (7%), a visiting service (4%), and a voluntary worker (2%).

* Only 4% of families with a disabled child had received respite or short term care for their child in the last 12 months.

* Only 19% of children with the most severe category of disability had access to respite care.

* Lone parents with a disabled child (8%) were more likely to have obtained respite care compared to two parent families (4%).

* Families of disabled children living in owner occupied housing (6%) were more likely to receive respite care than those living in public sector housing (4%).

* Similar proportions of disabled children in Great Britain and Northern Ireland were using special aids and equipment (33%).

* 38% of aids or equipment used by disabled children were paid for by health and social services and 32% were paid for by parents or carers.
Children’s Views in 2001 on Health and Social Services Provision

Most of the children’s discussion with the researcher about this area involved talking about trips to or stays in the hospital, although one girl mentioned her social worker whom she liked. Some children were matter of fact about hospital visits and said the doctors and nurses were “okay”, “good”, “nice”, or “funny” and did not discuss it in great detail. However, other children visited hospital more often and stayed for two or three weeks at a time and they discussed their visits in more depth. One child who said that the doctors and nurses were “good” then went on to talk about one particular nurse who had hurt him:

“one nurse hurt me…she put my medicine, she put my fingers up my throat…she just said take the medicine…mummy had to tell her off…she said she was sorry, not to me, to my mum…”

Several disabled children talked about their medical or technological equipment. Some made regular trips to hospital and had made friends with others when staying there. One child talked about a friend she had made in hospital who had died “cause she was very ill…she’s up in a good place now”. She also referred to having to travel to Belfast for treatment as her local hospital “doesn’t even know what cystic fibrosis means – anything that is wrong with me they don’t even have a clue”. Another child who also had a naso-gastric tube talked about having to go to hospital “every couple of months…[it] doesn’t bother me really”, and talked about friends there:

“…normally whenever you’re in there’s always about two or three people you know, ‘cause you’re always there anyway, just get to know people”.

A number of disabled children discussed having to use a nebuliser and doing physiotherapy every day. Some also had physiotherapy sessions in school. One girl talked about having to get out of “dinners” to do her physiotherapy which took 15-20 minutes. She missed eating with her friends and playing.

Other children mentioned their mobility aids to the interviewer, including wheelchairs, hoists, seats for the bath/shower, and walking aids. One teenage girl had particularly strong views about the design of aids and thought that they should be child appropriate (bright and funky). The walking sticks she was issued with were boring and old fashioned and as she said:

“kids like to be modern. Lots of kids ask me where I got mine [walking aids] and ask their mums and dads, can I have some too? I wish someone would start up a company and make sticks and callipers that are modern”.

Similarly wheelchairs were heavy and dull and several parents had to pay privately for lightweight wheelchairs to make it easier for their disabled child to get about.
While many disabled children seemed to cope well with regular trips to the hospital, some did not like this and one young boy viewed himself in a negative light because he had to attend the hospital.

“I hate going to the hospital- it’s more like I’m weak… you know the way strong people play act like I’m not going to the hospital…they’re just saying that because they don’t want to go..that’s what I’d be like, but I have to go – because of my eyesight”.

Several disabled children talked about their personal care needs, the need to be helped to go to the toilet, or take a bath or shower. One teenage girl talked about going to the toilet and “somebody has to come and give me help” and went on to discuss having her ‘period’. As children get older, dealing with personal care needs become more sensitive, as this example of the teenage girl having to deal with her menstruation indicates. Managing personal care needs and developing personal autonomy as the disabled young person grows up is an important issue both for families and for those providing education and social services.

Parents Views in 2001 on Social Services Provision

In addition to the children’s own views, some important additional points were raised by their parents:

* Several parents indicated the need for lighter wheelchairs which would make access for their child easier.

* One third of parents said there were aids and equipment that their child currently needed but did not have access to.

* One third of parents said their child was not currently receiving a respite care service but needed to do so.

Policy Recommendations

* Policy makers and service providers need to actively involve parents and children in the planning process and to listen to and take on board their views. User participation needs to be fully and wholeheartedly implemented so that these public services meet the needs of those to whom they are targeted.

* Financial assistance with aids and equipment should be made more widely available.

* Young people should be more actively involved in the design of aids and equipment.

* The reduction of the high proportion of severely disabled young adults living in communal establishments should be speeded up. This has
been a long standing policy goal but time has moved on and too many of the 10-15 year olds who were in communal establishments in 1990 are now young adults in communal establishments who should and could instead be supported in independent living.

* The inspection of services for disabled children to be carried out in 2002 should explicitly audit social work practice to ensure that inappropriate and unnecessary institutionalism is no longer a part of contemporary social care practice in Northern Ireland.

* Trusts and Boards need to be alerted to the evidence that Northern Ireland family support services appear to be at a lower level for disabled children and their families than is provided by Local Authorities for the same group in Great Britain. A re-profiling of resources between Programmes of Care at Board and Trust levels is required to correct this.

* In developing family support services, Boards and Trusts should note that parents are likely to want practical domestic and care help as well as the help of a social worker. In addition, Boards and Trusts should ensure that the types of services offered maintain a focus on the child or young person and are acceptable to them as well as to their parents, while recognising the additional needs of parents and siblings.

* The availability and suitability of respite provision needs to be reviewed across Northern Ireland and addressed.

* Social work support needs to be retargeted in keeping with New Targeting Social Need (NTSN) principles as low-income families have had less access to this support than have others.

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