problem of surveillance the WHO/Bangui definition has been useful, but the time has come for its reappraisal.

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Parent support groups

Doctors should work closely with them

Being told that your child has special needs and disabilities is probably one of the most painful experiences that a parent may have to go through.¹ No matter how carefully the problems and the prognosis are explained, this may not be enough—as this week's personal view shows (p 1208).² Many families will be devastated and feel very isolated.

Contact with other families with similarly affected children may be comforting—firstly, because they have shared similar experiences and, secondly, because they are not professionals, who are often perceived as too busy or intimidating. Finding these other parents may be difficult, and many parent support groups have been set up to facilitate this. Now the charity Contact a Family has published a directory of specific conditions and rare syndromes in children together with their support networks.³ This is an invaluable source of information for all those looking after children with chronic disorders. All families should at least have the opportunity of establishing contact with other families—even if they do not want to take it up. Some of those who do will be upset and confused by well intended support, a problem that those who run the groups will need to recognise.

The value of parent support groups extends far beyond just providing support for families. Many parents want to help advance the understanding of their child's condition, and support groups may provide substantial funds for research. They can also provide information for all those caring for affected children. Some families are eager for more information, which health professionals may also find useful. Helpful

practical advice about all aspects of management can be compiled.

Support groups may have a role in improving medical care, although this has not yet been fully recognised. Many parent support groups hold meetings for all parties concerned to discuss problems. Speakers may include parents or patients talking about their own experiences and views in their own terms. I doubt if there is a doctor who could not learn from listening to such a talk. Having to sit through the talk of a parent who has lost children under your care can be a chastening experience. This is an important form of audit. The potential value of a coordinated voice of patients and parents to improve all aspects of care should not be underestimated. With the emphasis on the patient's voice it may not be so easy for managers and the government to ignore issues of underfunding, poor service, and inadequate facilities.

Doctors tend to be suspicious of parent (or patient) power, but they should recognise the importance of these groups. They have a valuable contribution to make, and we should all work closely with them.

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