



IRISH MEDICAL
ORGANISATION
Ceardchumann Dochtúirí na hÉireann

IMO
Position Paper on Disability
Ages 0 - 18 years

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OVERVIEW

Doctors, collectively and individually, consider their responsibility is to ensure the health and well-being of their patients. The aspirations of disabled children are vital parts of their sense of well-being and doctors are committed to helping everyone to reach their full potential.

Services for children with disability extend across the board from specific health interventions to community and hospital based therapies to preschool and school education.

It is vital that the family – or carer – of a child with disability has access to well coordinated, local and easily accessible services.

As diagnosticians, doctors have a key role in the management of disability but they are not the only professionals who make valuable contributions. The list of those upon whom doctors rely for help includes Occupational Therapists, Psychologists, Teachers, Teaching Assistants, Social Workers, and Physiotherapists.

Doctors want to play an active role as advocates within a team setting for the development of children to their full potential. Doctors in general practice, community health and primary care are ideally placed to advance the interests of the individual child, to advise parents and professionals of the clinical needs of children and the impact of availability and suitability of services on children's development.

Within the context of the implementation of the Disability Act 2005, the HSE has enunciated several key principles for the delivery of education services to the disabled child:

1. Easily accessible services
2. Individual Education Plans,
3. Resources co-ordinated to ensure a team-based approach,
4. Seamless transition between services
5. Accountability and responsibility for services
6. Flexible delivery of services
7. Evidence based delivery
8. Children and Parents active partners in all aspects of service provision.

These principles will underlie the provision of disabled children's health and education services. The IMO welcomes the commitment to key principles outlined above (accessibility, individual plans, seamless transition, accountability and responsibility, flexibility, evidenced based services and parental involvement.) These are aspects of service delivery which should be common to all services.

However, the IMO remains concerned that the HSE framework is aspirational as no specific resources or timeframes have been determined. Nor is there clear national leadership on the roll out of the disability act.



THE IMO Focus

The IMO has decided to focus its policy paper on the issue of provision of a seamless service to disabled children between the ages of 0 and 18 years. The IMO sees the provision of appropriate health and education services to those whom competent professionals define as in need of these services, and who would benefit from them, as the basis on which to proceed. Services, where possible, should be designed to fit around the child rather than the other way around.

The IMO has specific concerns regarding the model which is to be adopted as the framework for the provision of services to disabled children.

International Experience

The international experience from English speaking countries which have been surveyed by the National Disability Authority throws up some common points. Five English speaking jurisdictions were investigated which included Queensland (Australia), British Columbia (Canada), New Zealand, the United Kingdom, and the United States.

Certain common factors characterised the work of those seeking to provide Individual Education Plans for children with disabilities.

Personal Plan

Each jurisdiction devised a plan for the individual child. Children are not grouped together.

Individual Design

Each child had an individually crafted plan involving all appropriate health care professionals

Professional Assessments

Assessments need to be appropriate to the child and carried out by appropriate professionals. In the New Zealand assessment process good practice demands that no single assessment procedure be used. All the health and education professionals should be involved.

Learning Styles

The learning styles which best suited the children were taken into account in the devising

Collaborative

Some jurisdictions had formal teams others did not but all emphasised the requirement for a collaborative approach between all health professionals.

Cyclical Review

All plans are reviewed on a regular basis, in Queensland on a half yearly basis and elsewhere annually.

Measurable Outcomes

Each of the plans incorporated milestones by which the professionals could assess the child's progress.

Smooth Transitions

International experience suggests that transitions should be handled with special care. These important times of transition include transfer between classes, transfer to secondary or higher education, or exit from the education system.

Adequate Resources

All of the jurisdictions base their plans on the premise that there are adequate professional resources available.

THE IMO MODEL

Team Approach

Children with specific health needs associated with development have a right to the services of general practitioners, community paediatric specialists, community health doctors and allied health professionals. Children who miss out on the services of these professionals will not have their developmental needs assessed competently and will suffer poorer health and development outcomes.

Parents and Carers

The health of parents and family who care for children is intimately connected to the health status of the child for whom they are caring. Children whose care is poorly co-ordinated or whose health status is not managed by professional healthcare workers will suffer and this suffering will have a knock on effect on parents, siblings and carers. Parents and family members responsible for special needs children must be well supported by service to allow them continue the onerous task of caring for their child.

Assessment

Continuous clinical assessment forms the foundation of the healthy development of the child. Health problems missed or underestimated will hamper progress and lead to the inefficient use of resources.

Health Outcomes

Special needs children's health outcomes are linked closely to the advancement of their general development. Doctors and allied health professionals must have the decisive professional inputs into the management of the child's development

Outcomes

Clinicians must set personal quantitative and qualitative development goals for each child. These goals must be based the very best clinical assessments possible. They must be measured to insure that the optimum health and development outcome is reached for each child.



Review

The progress in children's development must be reviewed regularly and certainly no less than once a year. Reviews will be useless unless the multi-disciplinary team has the right to alter the provision of services for children.

Transitions

As children develop they go through important points of transition which include entry to education, entry to second level education, or entry to specialist residential care. It is vital that these transitions are handled sensitively and with the best interest of the child in mind. The family and carers of the child must be included in the planning of the transition

Resources

Children with special needs are owed a special duty of care by society. It is unacceptable that children who require extra help should be penalised because of that need. The resources clinical, financial and infrastructural must be made available to them.

RATIONALE FOR THE IMO MODEL

1. It is absolutely necessary that all planning in this area be focused on the needs of the child. Services must in all cases be tailored to suit the child.
2. Leadership of the multi-disciplinary teams assigned to each child must be clear and well structured. Doctors and teachers must not be placed in the onerous position of reporting to the Department of Education and Science, Health and Children and the Health Service Executive separately and individually.
3. The Department of Education and Science must develop appropriate liaison mechanisms with the medical profession so that the maximum benefit of medical knowledge and insight can be employed by the department in framing policy regarding the education of the disabled child.
4. The inclusion of the special needs child in mainstream education must, where appropriate, be the desired educational outcome. However it is the welfare of the individual child which is the paramount goal. Sufficient special needs education facilities must be provided for children for whom the mainstream schools do not prove a good educational environment. One size does not fit all.
5. Professional input from the first assessment of the child is an unquestionable right of each child. At all times and at every stage of development the child should have access to medical, educational, and allied health professionals.

DEFICITS IN THE HEALTH SERVICE FOR DISABLED CHILDREN

As already stated, the IMO welcomes the initiatives proposed – with caveats on the model – and wishes to draw attention to the serious deficits currently in the provision of health services to disabled children. The IMO has identified a series of deficits in the provision of services for disabled children.

- Deficits in early intervention for children.
 - Developmental tests. In 2006 35,000 children in Ireland were waiting for or had never received a 9 month check of development
 - General community screening- as below, therapy services all have W/L s .in the under 18 age group
 - 458 (6%) children are waiting lists for speech therapy, 143 (2%) for Occupational Therapy and 113 (1.2%) for psychology. Many more are awaiting assessment for these services -1165(16.6%) for Psychology , 995(13.6%) for Occupational Therapy
 - Specialised paediatric services- many areas have none or insufficient community paediatric medical services and child and adolescent psychiatrist services.
 - General community screening- as below, therapy services all have waiting lists
 - Insufficient therapists including
 - Speech Therapists
 - Physiotherapists
 - Occupational Therapists (see above)
- Deficits in access to support services
 - Inadequate supports for disabled children and their carers; gaps in services from home help, personal assistants and home care assistants
 - Inadequate provision of respite services: 1313 (18.7%) have requested day summer camp service, 462(6.6%) holiday respite.
 - Requirement for implementation and monitoring of standards for residential services
- Deficits in educational services



In an effort to address some of the deficits, the following need to be implemented:

AREAS OF CONCERN / DISABILITY ACT 2004

1. Clear leadership is not apparent nationally on the implementation of the recommendations of the disability act. A forum for feedback by professionals on the day to day issues arising from the introduction of assessment officers needs to be put in place.
2. There are still unanswered questions on the provision of services once the statement of need is issued. At present, early intervention teams assess and carry out treatment of children with disability and monitor progress at regular team meetings. It is not clear how a child with disability will receive specialised therapy through the primary care networks. If a generic therapist with no skill in paediatrics is delivering a programme as prescribed by a specialist, who supervises and monitors the therapy? Line management of, supervision of therapists in the network is not clear.
3. In some parts of the country, a child has to be seen by the assessment officer before referral can be made to the early intervention team or to specialised hospital services. In other areas the early intervention team sees the child first and the assessment officer then draws up a statement of needs. Waiting for the assessment officer can cause a delay in diagnosis and treatment for a child. It also highlights that already different practices are emerging instead of a uniform approach to assessment process
4. Specialists in the area of disability are concerned about the process of diagnosing a child with disability. Who has the right of diagnosis? Assessment officers do not have the necessary skills to diagnose.
5. The statement of need for a child with disability outlines all services a child should receive. If resources are not in place, it is hoped the statement of need can be used to ensure services are put in place. However, it is not clear where extra services will be in primary care or elsewhere and who will manage and supervise them.

RECOMMENDATIONS

1. All planning in this area must be focused on the needs of the child. Services must in all cases be tailored to suit the child. Therefore, the model outlined by the IMO should be adopted for immediate implementation of the HSE framework.
2. A National Implementation process is required to ensure that implementation of the recommendations of the Disability Act and the EPSSEN Act are introduced in a nationally standardised way and that a forum for feedback from parents and professionals is provided.
3. The HSE framework should be costed and the Department of Health and Children should clearly allocate the multi-annual, ring-fenced budget for disability with associated timeframes against the framework developed by the HSE.
4. A comprehensive service, free at the point of access, should be provided for both the mentally and physically disabled of this country regardless of parents' income
5. Gaps and inadequacies in diagnostic and treatment services must be addressed so that all children are seen and have access to treatment as early as possible
6. Immediate provision of extended care facilities for young chronically disabled patients should be funded and provided.
7. The inadequacy of care assistance and tax relief provided by the State for the disabled and the mentally handicapped should be urgently addressed.

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