Progressing
Disability
Services
for Children
& Young People

Working together to support children and families

National Guidance for Local Implementation Groups and Children's Disability Services on Family Forums 4.12.15

Introduction
Children's Disability Services exist to support children, young people and their families. The development and ongoing delivery of Children's Disability Services should be focussed on, accountable to and informed by service users and their families. It is essential that each area incorporates a family forum in their governance structure with explicit links to and from the governance group.

Background
The principles of the programme in relation to the engagement of service users and their families are as follows:
- ❖ Family centred services
- ❖ Interdisciplinary teams working in partnership with families
- ❖ Accountability of services for outcomes for children and their families
- ❖ Acceptance and appreciation of diversity

Governance of Children's Disability Services
Children's Disability Services must have a governance structure for oversight and accountability with clear roles, responsibilities, reporting relationships and decision-making processes.

The governance group in the defined geographic area must be inclusive of all key stakeholders. In accordance with the *Guidelines for local implementation groups on developing a governance structure and policies for children's disability services* the governance group should have a minimum of two family representative members.

The family representatives must have a mandate from the wider parent/service user body to represent their views. This mandate can be sourced and supported in the family forum from which the representatives are selected.

An example of a typical governance structure is in the Appendices.

The Family Forum
The primary purpose of the family forum is to provide the means to mandate and support parent/service user representatives on the children's disability services governance group and potentially on other relevant existing and emerging groups. The forum will also provide regular opportunities for families, including young people who are service

users, to find out about services in their area, current issues and general information and to influence and inform their local service development.

The family forum should not be regarded as a substitute for individual families engaging directly with their child's service provider on specific service issues, or as a conduit for individual concerns and complaints.

A family forum may include face to face meetings and online communication.

The family forum will have agreed terms of reference and standing orders. (See Sample in Appendices)

Range of supports for parents and other family members in setting up and joining a forum
- ❖ Sample documents such as Terms of Reference, constitution
- ❖ Guidance on concerns such as confidentiality
- ❖ Information on services and structures
- ❖ Training in how to organise a group and conduct a meeting
- ❖ Infrastructure – accommodation for meetings
- ❖ Transport – expenses for representatives and committee members in attending a meeting
- ❖ IT and other facilities such as photocopying

Possible sources of support for parents:

- ❖ Children's Disability Services
- ❖ Family Resource Centres
- ❖ DESSA (Disability Equality Specialist Support Agency)
- ❖ City and County Child Care Committees
- ❖ Children and Young People's Services Committees (CYPSC)
- ❖ National organisations e.g. National Federation of Voluntary Bodies, Inclusion Ireland etc.
- ❖ Other local sources of support e.g. partnership or development agencies in a local area

Relevant policies, guidance documents and other working groups

Interim Standards for Children's Disability Network Teams 2015
Standard 5.11 There is a regular opportunity for parents/carers and children/young people to express their opinions and experiences of the services they receive and make comments and suggestions on services (e.g. annual focus group)

Outcomes for Children and Their Families September 2013
Report on an Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Network Teams

Framework for Collaborative Working between Education and Health 2013
Recommendation 3 Education and Health Forums are established at local level under the direction of the National Education and Health Steering Group. The objectives of the local forums, which would include representatives of parents, health services and education partners, would be to facilitate networking, building relationships and to share information

Guidelines for local implementation groups on developing a governance structure and policies for children's disability services 2011
   ❖ Composition of governance group
      Members should include a minimum of two parent representatives and a balanced representation from all agencies involved
   ❖ Mechanisms by which parents and young people's views can be heard around service planning
         ▪ Parents' representative committee
         ▪ Parents group

National Strategy for Service User Involvement in the Irish Health Service Department of Health and Children and HSE 2008

The Independent Commission on Good Governance in Public Services (2004)
Core principles for good governance
      1. Good governance means focusing on the organisation's purpose and on outcomes for citizens and service users.

      6. Good governance means engaging stakeholders and making accountability real.

Transforming Lives – Programme for Implementing the VfM Policy Review of Disability Services in Ireland
Working Group 3 People with Disabilities and Community Involvement
An important focus of the work of this group will be to build on the existing national & local consultative processes so as to develop a model, which meets the changing needs of the Health Service and which will be fit for purpose to support the new model of service delivery envisaged in Future Health. The intention is to maximise the potential of local communities to support people with disabilities and their families within their own area and to develop both the informal and formal social networks which have the capacity to support the new service models.

Definitions
Forum: A place or meeting or online facility where a public discussion is held for the purposes of networking and sharing information

Sub-group: A group formed for a specific purpose which is subordinate to the main group

Representative: A person chosen to represent another or others or to take part in an assembly on their behalf

<u>Governance Group</u>: A group representing all key stakeholders with responsibility for oversight, monitoring, evaluation and strategic decision-making

Appendices

1. Sample Terms of Reference for a Family Forum

These are provided solely as a guide to assist a family forum in developing their own terms of reference.

<u>Membership</u>
The following will be invited to become members of the family forum:-
- Parents, carers and other family members of children aged from birth to eighteen years attending a Children's Disability Network Team (CDNT) in (name area).
- Service users attending a CDNT in (name area) as appropriate to their age and understanding.

<u>The Purpose of the Family Forum</u>
1. To provide for representation on the Children's Disability Services Governance Group. Representatives on (*name of Governance Group*) will be elected by the members of the family forum for a two year term.

2. To involve families in the development of children's disability services by:
- Expressing their views, concerns and suggestions for improvements
- Seeking clarifications from services on specific issues
- Contributing to service initiatives and progress

3. To share information on:
- Service provision, governance and access
- Community supports
- Rights of the child and the family
- Other relevant topics of interest

<u>Standing Orders</u>
The family forum will have a minimum of three meetings per year.

The quorum for decisions and elections will be one third of the membership plus one.

2. Sample management structure

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                    ┌─────────────────────┐
                    │     Community       │
                    │    Healthcare       │
                    │ Organisation Chief  │
                    │      Officer        │
                    └─────────────────────┘
                              ▲
                              │
┌─────────────────────────────────────────────────────┐
│      CHO Management and Governance Group             │
└─────────────────────────────────────────────────────┘
        ▲                    ▲
   Service                   │
   Arrangement               │
        ↘                    │
┌──────────────┐   ┌──────────────┐   ┌──────────────┐
│ Non Statutory│ → │   Children   │ ← │ Local Family │
│  HSE funded  │   │  Disability  │   │    Forum     │
│   agencies   │   │   Services   │   │              │
│              │   │  Governance  │   │              │
│              │   │     Group    │   │              │
└──────────────┘   └──────────────┘   └──────────────┘
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