Submission in relation to the National Carers’ Strategy Consultation

April 2008

The Children’s Rights Alliance is a coalition of over 80 non-governmental organisations (NGOs) working to secure the rights and needs of children in Ireland, by campaigning for the full implementation of the UN Convention on the Rights of the Child. It aims to improve the lives of all children under 18, through securing the necessary changes in Ireland’s laws, policies and services. The Alliance welcomes the opportunity to make a submission to the Inter-Departmental Working Group in relation to the development of the National Carers’ Strategy.

This submission will focus on issues relating to children as carers which the Alliance believes should be included in the National Carers’ Strategy. Although not explored in this submission the Alliance believes that the Strategy should also address the need to improve the level of support to families caring for children with illness and/or disability.

Child carers are defined as children under the age of 18 years, who are unpaid and the nature and extent of their caring responsibilities has a significant impact on their education, health, social and emotional life and longer-term life chances.[1] Some child carers may be as young as five years and may carry out tasks including:

- giving general care such as assisting with mobility and dispensing medication
- performing a range of intimate care tasks, such as toileting and bathing
- undertaking a range of domestic tasks and trying to provide emotional support.[2]

The Alliance raised its concerns about child carers with the United Nations Committee on the Rights of the Child in its 2006 second shadow report, *From Rhetoric to Rights*.[3] In its report, the Alliance highlighted two areas of concern, which remain relevant two years on.

Number of child carers. Little is known about children in Ireland caring for disabled or physically or mentally ill family members. Existing evidence suggests that a minimum of 3,000 children act as carers, but the figure could be much higher.[4]

Support needs. There is a clear link between child carers and the broader issue of inadequate service provision and care supports for families living with disability and illness.

Summary of recommendations

1. Commit to a set of principles to underline the National Carers’ Strategy
2. Invest in research and data collection on child carers
3. Identify child carers and invest in support services for them and their family

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[1] University College Cork presentation (2007), *Hidden Young Carers in Cork: an exploratory study*, Department of Applied Social Studies, University College Cork

[2] Disability Federation of Ireland (2006), *Pre-Budget Submission 2007: Significant Commitments Demand Significant Delivery.* http://www.disability-federation.ie/documents/prebudgetsubmission2007.htm#a22.

[3] Children’s Rights Alliance (2006) *From Rhetoric to Rights: Second Shadow Report to the United Nations Committee on the Rights of the Child*, Dublin: Children’s Rights Alliance.

[4] Halpenny, A.M. and Gilligan, R. (2004), *Caring before their time: Research and policy perspectives on young carers*, Dublin: Barnardo’s National Children’s Resource Centre and Children’s Research Centre, Trinity College Dublin.

Principles to underline the National Carers' Strategy

Compliance with the UN Convention on the Rights of the Child

The current policy approach to child carers does not reflect Ireland's obligations under the UN Convention on the Rights of the Child, which Ireland ratified in 1992.[5] The lack of an adequate response to the issue of child carers is in breach of the Convention by denying child carers the right to the highest attainable standard of health (Article 24), to a standard of living adequate for the child's physical, mental, spiritual, moral and social development (Article 27), the right to education (Article 28), and the right to rest, leisure, play and recreational activities (Article 31).

Recommendation

- The Strategy should commit to uphold and further the implementation of the UN Convention in Ireland.

No child should be burdened with inappropriate caring responsibilities

Caring responsibilities are a natural aspect of being part of a family. The Alliance believes, however, that no child should be overburdened by his or her caring responsibilities. The specific circumstances of a family, coupled with an absence of external support, may lead to children finding themselves taking on inappropriate caring roles which impact negatively on their childhood.

Recommendation

- The Strategy should adopt the principle that no child should be overburdened with caring responsibilities. Furthermore, the Strategy should recognise the existence of child carers in Ireland and include a specific section addressing the specific rights and needs of such child carers and provide detailed policy responses and commitments to address those rights and needs effectively.

Best interests of the Child

Article 3 of the UN Convention on the Rights of the Child states that: "in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration." But, for young carers, this is not the case. In its *Concluding Observations* to the Irish Government in September 2006, the UN Committee on the Rights of the Child recommended that the general principle of the best interests of the child be fully integrated into all legislation relevant to children, and that it is applied in all political, judicial and administrative decisions, as well as projects, programmes and services that have an impact on children. The 'best interests' principle is not new to Irish domestic law: it has operated as part of child and family law since the 1960s.[6]

Recommendation

- The Strategy should include a provision that the principle of the best interests of the child be the primary consideration in all decisions taken in relation to child carers.

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[5] *United Nations Convention on the Rights of the Child* (1989) http://www.ohchr.org/english/law/crc.htm.

[6] Under Section 3 of the Guardianship of Infants Act, 1964, a court is obliged to regard the welfare of the child as the first and paramount consideration in any proceedings before it, including the custody, guardianship and upbringing of an infant. Section 3 of the Child Care Act, 1991 (as amended) provides that, in the performance of its functions, the Health Service Executive "having regard to the rights and duties of parents, whether under the Constitution or otherwise shall regard the welfare of the child as the first and paramount consideration". In addition, Section 24 provides that in any court proceedings under this Act in relation to the care and protection of a child, the court shall regard the 'welfare' of the child as the first and paramount consideration.

Commitments to be included in the National Carers' Strategy

1. Invest in research and data collection on child carers

There has been significant international research around the issue of child carers, most notably in Australia and the UK. In Ireland, however, there remains a lack of systematic and comprehensive data on children, resulting in a lack of information about child carers, low policy awareness and insufficient service provision. The invisibility of child carers in Ireland emphasises the complexity of the challenges they face. Research and data collection is required in order to identify and respond to the particular needs of child carers in Ireland.

Recent research by University College Cork showed that being a child carer has a significant, and usually negative, impact on the lives of the children involved. The impacts are multi-dimensional, affecting child carers' physical and mental health, social life, education, work/career, poverty, life chances and choices.[7] The research indicates that children fear professional intervention and the possibility of being removed from their homes, and are concerned about labeling and the stigma associated with their role. The study outlined the supports child carers require; they include:

- access to adequate and age appropriate information
- professional engagement and external support
- adequate home help and respite care to ease pressure on child carers
- networks and support groups to facilitate contact between child carers and help to combat isolation.[8]

Towards 2016, the ten year framework social partnership agreement, commits to commissioning a study of the extent to which children undertake inappropriate care roles (with the involvement of relevant departments) in order to establish "the extent and degree to which this issue arises and the levels of impact it has on the lives of children concerned."[9] The Agreement further commits that, based on the outcome of this study and an analysis of the issues identified, a programme of in-home supports will be developed to alleviate specific problem areas identified for children.

As a first step to complying with the *Towards 2016* commitment, a study has been put out to tender by The Office of the Minister for Children (OMC). The aims of the research are to examine mechanisms through which young carers can be identified, to identify the impact of caring on their lives and to make recommendations for ways in which they can be assisted.

Recommendation

- The Strategy should acknowledge the OMC study and commit to implementing its recommendations.
- The Strategy should commit to establishing adequate research and data collection systems which track child carers with a view to developing necessary supports. These should include:
  - qualitative research to capture the experience of child carers
  - quantitative research to track the numbers of child carers, their ages, socio-economic background, urban or rural location, hours caring, duration of care, nature of care, education levels and additional employment
  - solution-focused research to identify the support needs of child carers, so that appropriate policy and home-based services and supports may be made available to them and to their families.

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[7] University College Cork (UCC) presentation (2007), *Hidden Young Carers in Cork: an exploratory study*, Department of Applied Social Studies, UCC, see http://www.cpa.ie/research/seminars/presentations/2007-03-28_CathalOConnellEtAl.pdf accessed 11/04/08

[8] See http://www.youngcarers.net for a UK example of an online forum for child carers

[9] Department of the Taoiseach (2006), *Towards 2016: Ten-Year framework Social Partnership Agreement 2006-2015*, http://www.taoiseach.gov.ie/attached_files/Pdf%20files/Towards2016PartnershipAgreement.pdf, p. 46 accessed 11/04/08

2. Identify child carers and invest in support services

Despite the reported number of child carers and the impact on the child, the issue of child carers has been overlooked in the past across a range of government policy documents. The *National Children's Strategy* (2000-2010) outlines a vision of an Ireland where children are respected as young citizens with a valued contribution to make and a voice of their own, where all children are cherished and supported by family and the wider society, where they enjoy a fulfilling childhood and realise their potential.[10] For child carers, this vision is far from the reality of everyday life.

Currently, mechanisms to identify and support child carers in the community are lacking. Often children caring for ill or disabled parents or relatives are isolated and unsure where to go for support and advice. The full spectrum of child carers' needs must be met, including those around education, mental health, counselling and social support.

Support for the Family

The issue of child carers is inextricably linked to the broader issue of inadequate service provision and care supports for families living with disability and illness. Children are forced to undertake inappropriate care roles when state health care services are inadequate. The first step in addressing the issue of child carers is to provide adequate support and services to families that need them. Failure on the part of the state to support families experiencing illness or disability should not put a child at greater risk of being separated from his or her family and taken into the state care system

Recommendations

The Strategy should commit to the following:

- *Families must be appropriately supported*: Appropriate policy, adequate support and service provision, including community and home-based support, should be developed to meet the needs of families living with illness or disability.

- *Children should be supported to remain with their families:* The Strategy should adopt the principle that all possible steps be taken to ensure that children remain with their families, and that a child should only be taken into state care as a measure of last resort.

- *Assessment of need should include children:* An assessment of need should be undertaken in allocating community based health services and in-home supports; this assessment should take into consideration the needs of the whole family including the needs of the children in the family.

Support for the Child

There is no clear and comprehensive assessment procedure for child carers. Risk assessments should be undertaken with child carers in order to establish whether the responsibility placed on the child is too much, and/or whether the nature of care is inappropriate. Some children provide round the clock care to parents, which has a deep affect on their own education, health and social life.

Where the burden of care is deemed to be too much, professionals should work with the young carer to identify support appropriate to their particular case. The child must be made aware that the specific circumstances of their case will be recognised and appreciated, and that the process is guided by their best interests. The child should also undertake a needs assessment, in partnership with a professional, in order to identify their particular needs and how they can be met within the context of caring.

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[10] *Our Children: Their Lives, The National Children's Strategy* (2000) Dublin: Stationery Office.

Recommendations
The Strategy should commit to:

- Developing comprehensive, child centred, risk assessment processes for child carers
- Providing adequate support and service provision to child carers
- Developing a policy on child carers which includes providing:
    - access to adequate and age appropriate information
    - professional engagement and external support
    - adequate home help and respite care for child carers
    - networks and support groups to facilitate contact between child carers and help to combat isolation.

Established support structures for child carers in Ireland are almost non-existent. Glasgow, a city of just over half a million people, has 22 young carer co-ordinators. Ireland has none. Western Australia has developed local area coordinators to support people with learning and physical disabilities in their families and communities.[11] Both of these are potential models of support for child carers. Where support is available, whether through a local coordinator, GP, community nurse or youth worker, child carers must be made aware of and encouraged to access support.

Recommendations
The Strategy should commit to:

- Introducing a single point of coordination with responsible for support services and the delivery of support programmes to child carers
- Extending social work services to provide 24-hour, seven day support to child carers.

Systems change

*Co-ordination***:** Child carers face challenges that breach departmental silos; however, current responsibility for support programmes and the delivery of support services is allocated to different governmental authorities and lacks a single point of coordination.

Recommendations
The Strategy should commit to:

- Undertake, as a matter of urgency, a review of support services provided to child carers under different government departments
- Carry out a programme of awareness-raising among relevant departments and health professionals.

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[11] See http://www.disability.wa.gov.au/DSC:STANDARD:1855760681:pc=L7C5C2C1 for more information. Accessed 11/04/08

Children's Rights Alliance

The Children's Rights Alliance is a coalition of over 80 non-governmental organisations (NGOs) working to secure the rights and needs of children in Ireland, by campaigning for the full implementation of the UN Convention on the Rights of the Child. It aims to improve the lives of all children under 18, through securing the necessary changes in Ireland's laws, policies and services.

Our Membership

The Alliance was formally established in March 1995. Our membership, from which Board Members are elected at the Alliance's AGM, consists of a diverse range of groups, including child welfare agencies and service providers; child protection groups; academics; youth organisations; family support groups; human rights organisations; disability organisations; parent representative organisations; community groups and others interested in children's rights. The Alliance's policies, projects and activities are developed through ongoing collaboration and consultation with our member organisations.

Our Aims

- Bringing about a shared vision that will realise and protect children's rights in Ireland
- Securing legislative and policy changes to give meaningful effect to the UN Convention on the Rights of the Child
- Securing the effective implementation of Government policies relating to children.

Our Experience

- The Alliance is recognised for its participation in the international monitoring and reporting process of the UN Convention on the Rights of the Child, including the publication of two shadow reports critically evaluating progress made by the Irish State to implement the Convention's provisions into domestic law, policies and services
- In 2006, the Alliance was the sole Irish NGO commentator reporting to the UN Committee on the Rights of the Child
- The Alliance is a designated Social Partner within the Community and Voluntary Pillar
- The Alliance has played an important role in influencing the development of several key initiatives for children, including the publication of a National Children's Strategy; the establishment of the Office for the Ombudsman for Children; and the inclusion of children's rights in the EU Charter of Fundamental Rights.

The Children's Rights Alliance is a registered charity – CHY No. 11541

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