

Citywide Family Support Network

'Supporting Grandparents ... Supporting Children'

report on the

Consultation with a number of Carers involved in Family Support groups in the Greater Dublin Area.

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Background

The Citywide Family Support Network

The Citywide Family Support Network was formed by CityWide Drugs Crisis Campaign in 1999 and consists of representatives of local Family Support Groups, individual family members and those working directly with families of drug users from Dublin and right across the island of Ireland. Over 50 support groups are affiliated at present. The Network is continually growing with new groups being set up.

Aims

The Family Support Network aims to:

- ▲ Raise awareness of family support work and its role in the community.
- ▲ Highlight the importance and value of work done by family support groups.
- ▲ Provide information to families and communities on existing services and supports.
- ▲ Highlight the extent of the drug problem and its effects on families and communities.
- ▲ Campaign for better services for drug users and their families.
- ▲ Support the involvement of the people most affected by the problem families of drug users and drug users [themselves] in the development and running of services and to ensure that adequate supports are put in place to enable this to happen
- ▲ Remember and commemorate those who have died as a result of drugs.
- ▲ Offer support to each other as members of the Network.

Advantages

Being part of the Network gives:

▲ Family Support Groups strength through contacts with similar groups and through the exchange of information.

▲ Family Support Groups and individuals a sense of security in knowing that problems do not have to be solved in isolation – that there is support available for families of drug users.

The work of the Network is facilitated by Citywide Drug Crisis Campaign, established in 1995 by Inner City Organisations Network (ICON), to bring together communities from across Dublin struggling with the heroin crisis. Citywide works to promote and support a Community development approach to the drugs problem – involving those who are most affected by the problem in dealing with the problem – drug users, their families and communities.

Carers

The Citywide Family Support Network, referred to as the Network throughout the document, has been involved on an ongoing basis in the active support of those grandparents or extended family members who take on the role of caring for the children of drug users. These drug users may have died. Others may still be involved in drug use and so can no longer care for their children. Some are affected by serious health matters such as Hepatitis C, HIV and AIDS; and therefore are not in a position to be able to care for them. Relatives, grandparents, brothers and sisters took on the care of these vulnerable children. These will be referred to throughout the document simply as carers.

Members of the Family Support Network had been in ongoing contact with various local networks. Through these contacts they became aware of the issues in relation to the above carers. Originally these local groups were in the greater Dublin area, but more recently this has included emerging networks and groups all over the island of Ireland.

There can be no doubt that there are a large number of carers in this position, both in Dublin and all over Ireland who are not in touch with the Network or any other services. Their isolation and need for support is an issue that needs to be further addressed.

Some of those involved in support groups were those who had been living with the devastating impact of drugs on themselves and their families but in addition were also put in the position of having to care for the children of their own sons and daughters. This was after raising their own families. Caring for the grandchildren presented a range of difficulties and issues that were particular to their situations. They required additional information. The support needs of both carers and children were very different. Also the children's needs included specific health, behavioural and other social difficulties. The Dundalk Conference focussed on identifying the variety of these issues and resultant needs.

Dundalk Conference

Citywide Family Support Networks organised a Conference in April 2002; "What do we all mean by Family Support?: Developing Partnerships." The Conference focussed on identifying these issues and resultant needs. The aims of the Conference included:

- ▲ To define what is meant by family support
- ▲ Identify the needs of Family Support Groups.
- ▲ Begin to develop a partnership between statutory agencies and family support groups to address the needs of drug users and their families.

Among the expected outcomes expected from the conference were to achieve:

- ▲ A greater awareness of the impact of the drug problem on families.
- ▲ A greater awareness of the work of family support groups and the value of that work.

The final recommendations included the call that 'professionals... listen to and respect the views of the experts – the families of drug users and drug users themselves.' This is to recognise the 'need of families to become partners in service development, service delivery and the policy making process.' (Conference Report p: 2004). This led to discussions as how best to get the perspective on these issues

from grandparents and carers themselves, in order for Citywide to develop policy and advocate for their needs with State and other agencies. Although there were some specific needs identified and discussed at the Dundalk conference, it was considered helpful to further consult with this group.

Consultation with Grandparents Group

CityWide Family Support Network who were in contact with individuals affected by these issues, became aware of a number of common issues and difficulties that emerged on a regular basis. These included:

- ▲ What were the actual entitlements of those caring for grandchildren etc?
- ▲ What was the difference between The Orphan's Allowance and payments for Health Board sanctioned foster parents?
- ▲ What was the role of Social Worker and other Health Board services in relation to their own and the children's support needs?
- ▲ Could grandparents apply, in their own right, to foster under Health Board regulations? (under Section 36 of the Child Care Act 1991).
- ▲ Where could this group get the advice and support they required in their own areas?
- ▲ Why was getting support and help so complicated and hard to find?

It was proposed to further explore the issue of supporting those groups of grandparents or extended family members who were or had been carers — *the experts*. The aim of the consultation was to explore their experiences by identifying:

- ▲ What had or had not helped?
- ▲ What are the key agencies?
- ▲ What specific information did they require?

This was to inform the ongoing work of the Network by identifying a number of practical steps that would enable it:

- ▲ To provide initial practical information and support.
- ▲ To identify and refer to the appropriate local Family Support Group.
- ▲ To encourage local groups to identify the local service providers especially those who are familiar with the issue and refer on.

▲ To work with the service providers in influencing policy to address the above issues and issues that will arise from the consultation process.

Patsy Moran (SWAHB) and Dave Little (NAHB) Community Development Workers were asked to conduct this consultation in partnership with the Network.

Aims of Consultation

- ▲ To *enhance* the information that has been identified previously in relation to this group i.e. from Dundalk Conference and Network members etc.
- ▲ To consult with a range of grandparents and other relevant carers ('the experts') around their own needs what services have been helpful, not helpful, gaps etc.
- ▲ To use *information* to further inform Citywide policy as well as contributing to local Drug Task force and local Health Board policy.
- ▲ To *inform other Network actions* and initiatives (such as Resource Pack content, possible further research etc.).

Objectives

- ▲ To meet with a number of Network affiliated/representative groups in the Greater Dublin Area.
- ▲ To utilise techniques to encourage participation and qualitative information.

Methods

Qualitative research - Focus Groups in a number of locations in the Dublin area. It was decided to use Participatory Appraisal (PA) techniques.

Venues and groups

These were to be arranged between the Network and Patsy Moran.

Time frames

The consultation would take place during 2003.

What is PA?

Participatory Appraisal (PA) is a growing set of approaches and methods to enable local people to:

- ▲ Share, enhance and analyse their knowledge of life and conditions.
- ▲ Plan, act, monitor and evaluate.

Chambers, R. 1997, Who's Reality Counts?

The methods used usually involve local people creating and analysing shared visual representation e.g. maps, models, ranking lists of their life and conditions. PA methods are an alternative to questionnaires and surveys, which are generally based on the view of those who draw them up. Techniques help people focus on their own lived experiences. Its informality and visual nature made it very suitable for working with groups where literacy is a potential barrier to participation. It enables people to share their ideas and knowledge about life and local conditions.

These techniques had been used in the North East Inner City by Community Development practitioners, as a method that Statutory agencies and Community Groups could utilise in consulting and accessing feedback from service users/clients in the development, planning and evaluation of their services.

It was decided to use a number of simple PA exercises with the Groups.

- 1 Brainstorm Exercise
- 2 Mapping exercise
- 3 Ranking exercise actions

Each group would also be given an opportunity to identify key agencies/groups and rank/prioritise actions necessary.

Consultations

Four consultations with four focus groups in a number of Drug Task Force Areas.

- ▲ Clondalkin Drug Task Force Area 28th May 2003
- ▲ Ballyfermot Drug Task Force Area 10th June 2003
- ▲ North East Drug Task Force Area 24th September 2003
- ▲ Dublin 12/Canal Communities Drug Task Force Area 21st October 2003

Difficulties with the Consultation

There were practical difficulties in organising meetings with carers, such as arranging childcare, clash of work and voluntary commitment. This, compounded by isolation and stress, meant that certain carers could not always attend. There also was a perception that despite being involved in numerous discussions and consultations nothing had happened or changed. It was sometimes necessary to 'get behind' negativity, anger and hopelessness in order to explore positives. There was obvious anger with specific agencies, especially Health Boards and Social Welfare. There was an unwillingness to seek help from Social Workers for fear that the children would be taken in to care. This fear was heightened by the stigma of drug use. There was a lack of support, which resulted in a lack of hope. People's personal stories abounded often with harrowing detail and grossly unfair and arbitrary treatment by professionals. Negative feelings often obscured the positive help and support people were receiving or had received.

One aspect, which is both positive and negative, is that PA and similar methods do generate an awful lot of material!

Conclusions / Findings

General

- ▲ There was a general sense of helplessness and isolation for carers.
- ▲ Those participating in the consultation reported a marked variety of experiences between the various geographic areas regarding information on and access to entitlements and services.
- ▲ Service provision and practice also varied significantly between the various areas and service providers.
- ▲ Legal issues and difficulties especially re custody or guardianship were commonly cited.
- ▲ Often the contentious nature of such issues was compounded by a lack of legal information and advice at local level.
- ▲ People often needed practical support and information but were unaware of where this was available.
- ▲ All groups identified the support that they received from others in their immediate Support Groups and local networks as the most important.
- ▲ It was noted that having an advocate for individuals was seen as being of great personal value and importance.

Services

People noted a contrast between the Health Board role of child protection and an inability or unwillingness to offer more general support, which they perceived to be a role of Social Work. For example one carer had actively sought support from the Social Work team. This was not forthcoming. Years later a Social Worker materialised due to a related matter, and an assessment was suggested – '[Up to that]... I could have been anyone, minding the child!'

Services in general were reported as being unresponsive with some notable exceptions. For example one worker was named and identified as being helpful however it was not known what agency she worked for! Those service providers, where supportive, were identified as being a good source of information and contacts. These included individual Community Welfare Officers, Social Workers, Public Health Nurses and local voluntary community based services. The attitude and conduct of the individual service provider interacting was often valued where respectful and scorned where disrespectful.

Individuals identified the availability of Child-care and after school clubs as of great help to them in their daily lives — it offered both respite to them and support to the children themselves.

There was not always a good knowledge of what general information and advice services were available in their locality (i.e. Comhairle, legal advice). When such services were tapped into they were deemed as being very helpful.

Community Welfare Services

Entitlements

- ▲ Lack of clarity about what people were entitled to this varied drastically between the different areas.
- ▲ The entitlement of carers to apply for the Orphan's Allowance has only been made known in recent years.
- ▲ The lack of access to back to school allowances was deemed arbitrary and unfair and placed a huge burden on carers.
- ▲ Discrepancy between fostering rates and Orphans allowance was perceived as unfair.

- ▲ Often carers were simply not made aware about what their entitlements were.
- ▲ Service providers varied between areas in the actual delivery of services, which ranged from rudeness to courtesy and 'taking the time to help'.
- ▲ In the areas where it had developed having a designated link-person within a specific service provider was very helpful.

Social Work Departments

There was a perception that Social Work Teams focussed on the task of child protection and crises and so the needs of carers were considered low priority. Staffing shortages have impacted seriously on the needs of this group – the issues for carers may not be seen as emergency and hence not prioritised and allocated to specific Social Workers.

Their 'cases' were not allocated to a Specific Social Worker but dealt with by a rotating duty system by 'younger', 'inexperienced' Social Workers who didn't always know the full details. For that reason they constantly had to retell their story to a different worker each time – which rendered them vulnerable and frustrated.

There was a varying inconsistency between Health Board Community Care areas regarding service delivery and levels of support to carers – it was acknowledged that it often depended on staffing resources.

Formal Health Board assessments can often happen years after the events. This may be despite the fact that the child may have been in their care for those intervening years and known to the Social Work team.

If and when they happen the standard assessments, which are conducted with all prospective foster parents, can be perceived as obtrusive and crude by carers.



In general, with only one noted exception, support and advice was not freely available to carers from Social work Departments.

Local Support

- ▲ All participants in the consultation primarily valued the support of the local Family Support Groups and Networks.
- ▲ These groups need adequate resources and support to function, and this was not always available. Those consulted often relied on other community groups whose resources were limited themselves.
- ▲ All participants in the consultation appreciated highly the work of the Network and specifically the staff themselves in terms of personal support, support to the local support group, information and practical help.
- ▲ Financial Support to the various local support groups depended on the geographical situation and the development of services locally and ranged from non-existent to having access to paid support staff and projects.
- ▲ Having paid support workers in a locality was considered an advantage.
- ▲ Local support groups also identified specific designated support workers paid or unpaid, as being helpful and supportive
- ▲ Advocacy, by a local support worker whether in a voluntary or paid capacity, CityWide Family Support Network and/or other designated Projects, helps people feel supported and get better information and access to services.
- ▲ There were mixed experiences of local Task Force Areas in relation to addressing the needs of families in general but those of carers specifically.
- ▲ Carers having representatives on or clear links into Task Forces were considered of value people felt their voice could be heard.

Recommendations

These recommendations are relevant to CityWide Drugs Crisis Campaign and the Family Support Network, the Local and Regional Drug Task Forces, National Drug Strategy Team, Area Health Boards, Family Support Agency and National Advisory Committee on Drugs.

- Having access to designated (paid) specialised support staff necessary for this
 group is key. These can be employed through specialised local services such
 as Community Drugs Team, Family Resource Centres etc. where they exist or
 by providing the appropriate training to the more general health board family
 support services.
- 2. Local Community Welfare services must be open and transparent to these groups specific links with Community Welfare services recommended.
- 3. Local Drug Task Forces (LDTF's) are key to move the needs of carers forward. They can advocate that the need of carers are fully represented on LDTF's—a place at the table often is an indicator of the availability of specific support services available in that LDTF Area. It is crucial that LDTF's should ensure representation for carers or their representatives in their structures.
- 4. Integration and real partnership between Statutory and community groups such as the partnership developed between the Network and the Departments of Justice, Equality and Law Reform and Health and Children on the issue of the recording of drug related deaths at local level is imperative in order for this group to be adequately supported.
- 5. The availability of groups and activities in designated Projects are of great benefit to children and gives 'time out' and support to carers (e.g. residential holidays, afterschool clubs etc.).
- 6. Similar to the above, priority of access to high quality childcare and crèche places must be available for carers where necessary.

- 7. Information Services it would help to make Groups more aware of where information and specific advice centres are situated i.e. Legal Advice, Welfare Rights and Entitlements etc. Specific support staff for carers would help provide links but also outreach by information services themselves would be of benefit.
- 8. Both carers and children need support Having specific local services for carers and children better again (a good example is Cumas Project in Clondalkin)
- Social Work services need to be more responsive and stop problems arising at earlier stages in order to maximise its preventative and early intervention role under the Children's Act 1991.
- 10. Social Work assessments for Grandparents and carers must be sensitive and appropriate not a generalised assessment. This is especially as children may have already been in their care for a long time. (It was acknowledged by carers that assessment was important to ensure the child would receive adequate care and protection).
- 11. Advocacy is a key role in supporting carers
- 12. Local Support Groups should be adequately resourced.
- 13. Adequate resourcing for Citywide Family Support Network, which would help local Support Groups and encourage mutual support among Groups.
- 14. Family Support Network as a general source of info to local groups of great value (including Information Packs etc.) however priorities should be focussed on how best to develop strategies to disseminate information at local level.

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