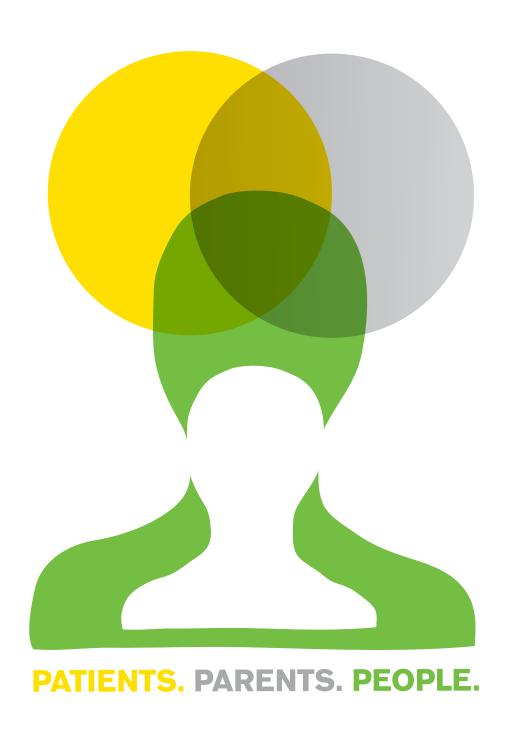
## Patients. Parents. People.

Towards integrated supports and services for families experiencing mental health difficulties.





This report was produced to accompany the Barnardos conference **Patients. Parents. People. Towards integrated supports and services for families experiencing mental health difficulties**, held in Croke Park on 19th June 2014 and opened by Minister of State with responsibility for Mental Health, Kathleen Lynch.



PATIENTS. PARENTS. PEOPLE.



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### **Executive summary**

In recent years pressures on parents have increased, with austerity budgets cutting child support payments and increasing costs. Barnardos has more than 40 services across the country and staff are reporting that poor mental health among parents is increasing in prevalence. Barnardos staff are also finding that when a parent experiences a mental health difficulty and they are not adequately supported or are receiving inappropriate treatment, their children can be affected.

These reports prompted Barnardos to examine the issue of mental health specifically in relation to parents to try and identify ways in which approaches and supports can be improved. In the majority of cases Barnardos encounters, parents are experiencing feelings of anxiety, stress and hopelessness. There is a proven link between poverty and poor mental health and often the parent's life circumstances are at the root of these feelings and exacerbating them. Staff also found that very few parents have adequate support for their mental health difficulty.

It is not possible to generalise the effects of parental mental health difficulties on families as it can depend on the severity and duration of the difficulty. In addition, other factors are frequently present such as poverty, addiction, overcrowding in housing, bereavement and domestic violence, all of which can have a huge impact on family life. It is important to note research has indicated that parental mental health difficulties alone present little risk of significant harm to children¹. But the absence of supports for both parents and children can compromise the child's ability to cope.

This can result in children's social and emotional development and their educational attainment being adversely affected. The impact can include inconsistency in parenting capacity, resulting in poor routines and sometimes patchy school attendance, lack of boundaries and children

presenting with poor hygiene and / or hungry. Other risks are that the child's self esteem is affected as they feel confused, isolated and unsure of what is happening to their parent and how it will affect their household. Children can internalise all their concerns and feelings and become socially withdrawn as they seek to hide their fears or begin to act out their frustration through engaging in damaging behaviour.

Often parents will put their children first, even if they are feeling under severe strain. They may also have a concern that asking for help could lead to questions being raised about their parenting capacity. So regardless of the cause, parents experiencing mental health difficulties must be supported in a sympathetic manner which takes into consideration these additional stresses they are carrying.

It is important to recognise the entrenched societal prejudice and discrimination against mental health<sup>2</sup> and seek to challenge poor attitudes that can act as a barrier for parents to access support. It is also important to listen to parents who have experienced mental health difficulties and hear their recommendations to ensure the supports and services in place meet the needs of those facing challenges.

Barnardos is a strong advocate for supporting families who are facing challenges in a holistic manner, where the needs of each family member are identified and supported. This report outlines how such an approach is not apparent in the current structures and systems, which too often treat adult mental health problems in isolation, without recognising patients as parents and tailoring treatment accordingly. Subsequently, services and responses to the family's needs are not coordinated. The dominance of the medical model in mental health treatment coupled with an isolated (and isolating) approach, makes the pursuit of a holistic familial approach even more difficult to achieve.

<sup>1</sup> Hansson, U, et al (2013) Maternal Mental Health and Poverty: The Impact on Children's Educational Outcomes, The Child and Youth Programme Reports, UNESCO- NUI & University of Ulster

<sup>2</sup> See Change (2012) Irish Attitudes Towards Mental Health Problems, www.seechange.ie

In fact, a key problem highlighted in this report is the over-reliance on medication as the treatment for parents experiencing mental health difficulties. Too often this is a short-cut solution that does not address the root cause of the emotional distress. The side effects of the medication can result in severe problems of their own, which can affect their parenting. Practitioners and parents must be supported to work together to find alternative solutions that will work in the long term. It would be extremely beneficial if the Government's mental health policy A Vision for Change was properly resourced and rolled out so that community mental health teams were fully staffed and available across the country.

Overall, Barnardos is calling for the present family, health and child support systems and structures to break away from their historically isolated perspective and instead see parents and their children in the context of their family. Such an approach demands more integrated inter-agency working, as any one family may be working with multiple agencies managed by separate structures at any one time. As well as recognising everyone lives multi-layered lives that cut across many sectors, coordination between the agencies should result in lower intensity intervention for parents and their children. The adoption of a family model approach to identifying needs and supporting recovery would lead to more effective joint working for professionals across all disciplines<sup>3</sup> and would also better support both parents with poor mental health and their children.

#### **Key Recommendations:**

Challenge mental health prejudice and discrimination: While some efforts are already being undertaken, more needs to be done to challenge public perceptions and promote the message that mental health difficulties can affect anyone and people can and do recover, given the right supports. In particular, parents must know they can access support without judgement on their parenting capacity.

Adopt a family model approach: Promote policies and improve practice across adult and children's systems that consider the needs of the whole family instead of seeing their service users in isolation. This would be a shift from the current siloed system, towards more holistic user

focused services. Far greater intra and interagency co-ordination between inpatient mental health services and primary care services and between community mental health teams and primary care services are desperately needed. Likewise improved information sharing involving community based services is required. Practical changes to improving service delivery across adult mental health and children's services interface can include co-ordinating workforce development training, having common questions about family life in screening and assessment templates, and considering whole family needs in care plans and identifying crossover with different agencies needed to implement the plan.

Talk to children: Children living with a parent experiencing mental health difficulties need to be informed and reassured in an age appropriate manner about what is happening to their parent and what to expect. All professionals working with the parent must understand the importance of talking to the children and be skilled accordingly. Likewise parents should be given the appropriate support so they can talk to their children about what they are experiencing and reassure them in an age appropriate manner.

**Expedite the roll out of community based services:** The ongoing delays in recruitment and service provision for fully staffed, multi-disciplinary community services as outlined in A Vision for Change are unacceptable. Their widespread availability will help challenge the dominance of the medical model and act as a preventative factor stemming some problems from escalating.

Consult with parents affected by poor mental health: Identify parents' preferred community based services that would make a positive difference to their lives and to their children. These services could include peer support groups (for parents and children), counselling services and family support services. The widespread availability of such practical supports would ease pressure on parents and reassure them they are not alone and can seek support without fear their parenting ability is being judged.

<sup>3</sup> Dr Falkov, A, (2012) The Family Model Handbook, Pavilion Publishing and Media, UK

#### 1 Introduction

'There is no health without mental health'. It is universally accepted that everyone's mental health needs to be supported and protected. Whether you are an adult or a child, having positive mental health gives you the tools to embrace, adapt and cope with life's opportunities and challenges. It helps build self-esteem and the ability to solve problems. In Ireland, there is still a sense that having poor mental health is somehow blameworthy. But the reality is that we all try to cope with the daily societal pressures that exist and all experience dips in our mental health at times. Feelings of guilt, inadequacy, shame and blame can undermine our ability to cope.

Barnardos, which works with more than 8,900 children and families annually, is aware that parents striving to do what is best for their children face a range of challenges on a daily basis. Frequently, parents' resilience is under threat due to a range of environmental and socio-economic factors including financial stress, addiction, poverty, inadequate public services and poor housing conditions. This can lead to feelings of hopelessness and despair which can affect their mental health and their entire family. Tackling these societal issues would go a long way to improving families' mental health and resilience and assist families to overcome the sense of hopelessness and despair that can become entrenched.

Presently the deep rooted prejudice and discrimination against poor mental health often prevents people seeking help. Parents experiencing mental health problems are often concerned about naming these difficulties because of the prevalent societal prejudices that erroneously assume such conditions are always long term and are a barrier to being a parent.

Unfortunately due to the dominance of the medical model with regard to treatment and recovery, the current availability of supports and services to help those with poor mental health are very siloed and can reinforce these societal attitudes. They can be rigid in their rules and perspective. Rarely is the individual seen in their family context but instead too often seen only as a patient in isolation not a parent.

But no one lives in isolation. A more holistic system is needed; one with the availability of practical supports for parents to look after their children, free from the fear of losing parental responsibility. Research from the UK found children and young people want relevant information about their parent's mental health difficulty, someone to talk to about their experiences and a chance to make and see friends4. The ability and desire for systems and society to move away from a medical oriented model towards a more holistic family approach will form a central part of this report. Only through such a shift will it allow families who are living with mental health challenges to thrive without being judged, and improve outcomes for parents and their children.

This report is a result of desk research and discussion with parents, carers, mental health experts and professionals to examine different ways to better support parents experiencing difficulties and improve outcomes for their children.

<sup>4</sup> Social Care Institute of Excellence (2012) Think Child, Think Parent, Think Family: Final Evaluation Report, www.scie.org.uk

#### 2 Prevalence of poor mental health

It is always hard to establish prevalence rates for poor mental health for a number of reasons and subsequently figures are often conservative and should be read with caution<sup>5</sup>. The reasons include:

- Societal prejudices and associated reluctance to reveal mental health problems for fear of being judged unfairly. There is often an air of suspicion on parents who seek help and once parents are labelled as having a mental health difficulty the label can stick indefinitely;
- The individual being unaware they have a mental health difficulty;
- Poor patient uptake of services;
- Conditions are often short term so don't lend themselves to large scale studies;
- The wide range of difficulties and severity that can be described under the banner of poor mental health.

The World Health Organisation estimate up to one in four people will experience a mental health or neurological problem in their lifetime<sup>6</sup>. The most common issues treated by GPs, public health nurses and other non-specialist settings are depression, anxiety and substance abuse with a smaller proportion in need of specialist mental heath services such as psychiatry.

It is harder to systematically identify patients as parents as often there is an incomplete systemic recording of patients as parents by professionals. Recording structures vary between professionals and services with some recording family details and others not. Internationally, approximately 30% of users of mental health services are parents with dependent children<sup>7</sup>.

However, smaller studies can reveal the scale of the issue. For instance Growing Up in Ireland found that 9.3% of mothers and 4.1% of fathers were experiencing depression while 14% of mothers and 6% of fathers had previously been treated for depression<sup>8</sup>.

Barnardos' experience of working with children is that having a parent experiencing mental health difficulties is very common. In the majority of cases this means parents experiencing feelings of anxiety, stress and hopelessness. Often the parent's life circumstances are at the root of these feelings and exacerbating them, especially when there is a proven link between poverty and poor mental health. Monteith (2008) found that parents living in poverty had poorer mental health and that mothers living in persistent poverty (three out of four years) had the worst scores regarding poor mental health9. Barnardos has worked with parents who are under significant stress when coping with a child with special needs and the inadequate supports available for their child. This correlates with the Growing Up in Ireland research, which found higher levels of depression among parents with children who had learning disabilities such as autism and ADHD, speech and language difficulties and dyslexia compared with parents whose children did not have these conditions.

#### 3 Potential impact on family

Given that every family circumstance is different, the impact, if any, of poor parental mental health also varies significantly. There is a real danger of over generalising the impact of parental mental health difficulties on families as it can depend on the severity and duration of the difficulty. Other factors are frequently present such as poverty, addiction, overcrowding in housing, bereavement and domestic violence, all of which can have a huge impact on family life. It is important to note research has indicated that parental mental health difficulties alone present little risk of significant harm to children¹0.

<sup>5</sup> Hansson, U, et al (2013) Maternal Mental Health and Poverty: The Impact on Children's Educational Outcomes, The Child and Youth Programme Reports, UNESCO- NUI and University of Ulster

<sup>6</sup> World Health Organisation (2001) The World Health Report 2001 – Mental Health: New Understanding, New Hope available at www.who.int

<sup>7</sup> Fowler, R, et al (2009) Improving Opportunities and Outcomes for Parents with Mental Health Needs and their Children, Barnardo's UK

<sup>8</sup> Nixon, E, et al (2012) Parenting and Infant Development, Growing Up in Ireland Infant Cohort Report, ESRI, Trinity College Dublin and Department of Children and Youth Affairs

<sup>9</sup> Monteith, M, et al. (2008) Taking a Closer Look: Child Poverty and Disability. Belfast, ARK, Family Fund and Save the Children

<sup>10</sup> Hansson, U, et al (2013) Maternal Mental Health and Poverty: The Impact on Children's Educational Outcomes, The Child and Youth Programme Reports, UNESCO- NUI & University of Ulster

The Child Care Law Reporting Project does identify poor parental mental health as a main reason for seeking a care order or a child already being in care, but again it is often in tandem with alcohol / drug addiction and domestic violence<sup>11</sup>. This finding suggests there is insufficient support available – or support is inaccessible – for parents experiencing mental health difficulties, with devastating consequences for families.

A child's development is strongly influenced by the quality of the parent child relationships. Forming strong attachments and being able to discuss their feelings and experiences is important in developing children's own resilience and effective coping mechanisms. For those living with a parent experiencing a mental health difficulty, often the presence of another caring parent, being informed of what is happening, availability of supports in schools and community and their own established social network can offset some potential impact<sup>12</sup>. It is essential that these protective factors be available to all children in this situation. Unfortunately, this is not always the case and the absence of these supports for both parents and children can compromise the child's ability to cope and reinforce feelings of isolation and hopelessness being passed on between generations, especially when living in areas of disadvantage. Therefore as research and Barnardos own experience indicates, some children experience poor transitions into adulthood while others enter adulthood with no long lasting effects<sup>13</sup>.

Former child carer: "Lack of communication with children is a huge problem. As a child you are quite black and white, so you think someone must be to blame, as everything must have a cause."

#### 3.1 Developmental effects

At an emotional level, a child can feel confused and anxious about what is happening to their parent and how to manage it, especially if no other family member or professional has spoken directly with them. This anxiety can be heightened

11 Coulter, C (2013) Interim Report, Child Care Law Reporting Project www.childlawproject.ie

when their parent is under additional stress, has to return to the doctor or has to go into hospital. For those being raised by a lone parent having to move to relatives or be taken into care while their parent is an inpatient can be overwhelming. Decisions about their future and whether they can visit their parent are often made with little or no regard to the child's views and wishes. The lack of communication with the child about the care their parent needs continues to fuel the child's anxiety. This is even harder when the child may have already been involved in a caring role. Also not having the vocabulary or the language to talk about how they are feeling or to understand what their parent is experiencing can add to a child's feeling of isolation.

Being unsure and apprehensive of how their parent will react or what is waiting for them at home can greatly unsettle children. Scared of being separated from their family by being taken into care and uncertainty about their future is a common feeling. There can also be feelings of blame and concern about whether it was something they did to make their parent feel unwell. The parent may not be emotionally available to the child due to their poor mental health which in some cases can lead to intermittent parenting, unpredictable behaviour, over-reliance on medication and being socially withdrawn. For parents who are taking benzodiazepines regularly they can experience drowsiness, slower reflexes and reactions and this can mean they are unable to react in time when a child falls or calls for assistance which can result in injury. Parents on this type of medication may also be too sleepy to undertake domestic duties such as preparing meals or lunches for schools, which can leave children going hungry or trying to prepare food for themselves and their siblings. All of these factors can in turn damage the strong emotionally secure attachments between the parent and child, which are central to enabling the child build their own self esteem and resilience. These attachments shape the child's cognitive and emotional development and influence all present and future relationships.

Parent: "I wasn't focusing on my kids' needs or listening to them because I was too relaxed on my Xanax. The kids could be doing anything; putting themselves into danger and I wouldn't be aware of it. Now I know how dangerous they [benzodiazepines] are."

<sup>12</sup> Cooklin, A (2010) Living Upside Down: Being a Young Carer of a Parent with Mental Illness. Advances in Psychiatric Treatment, vol 16, 141-146

<sup>13</sup> Aldridge, J, (2011) Children Living with Parents with Mental Illness, Scottish Child Care and Protection Network

The child could internalise all their concerns and feelings and become socially withdrawn as they seek to hide their fears partly out of loyalty to their parent but also out of fear they'll be taken away. Unfortunately, children and young people are acutely aware of the prejudice surrounding mental health difficulties and how they could be judged unfairly so they can be reluctant to share exactly what their home life experience is like and subsequently it is hard for them to make and keep friends.

Conversely, children can act out their frustration in the situation through inappropriate, violent or other self destructive behaviour. Halpenny (2004) found the most frequent problems presented by children with parents with mental health difficulties were behavioural problems, although the mental health difficulties in isolation were not the sole reason, with other factors at play too, such as greater prevalence of parental separation and marital conflict, and poverty and housing problems<sup>14</sup>. Similarly, children's own tendency to experience mental health difficulties themselves is heightened when other environmental factors are included. Again this would support Barnardos' experience where families are coping with a range of complex issues which collectively affect the child.

Developmentally, children's health may be at risk if parents miss key appointments with public health nurses, speech and language therapists or dentists due to being overwhelmed by their mental health difficulty and there is a lack of support and / or transport to assist them in these parenting duties. With many HSE services operating on a 'two strikes and you're out' approach, the long-term impact of a couple of missed appointments on the child can have huge implications.

#### 3.2 Impact on education

In general terms, children's concentration levels on school work can be affected by worry for their parent and what is happening at home and this can affect their educational experience, including attainment. Aligned to this, a parent experiencing poor mental health may be less able to assist with homework or be involved in the child's education. In cases where parents are unable to get their children ready for school, an older child may assume a caring role within the family, which can in turn affect their school attendance and participation in school activities.

Depending on each individual circumstance, some children see school as a place of refuge where teachers are supportive and empathic and encourage their involvement in key supports such as homework clubs. Other children, however, may be reluctant to inform teachers or friends of their challenges for fear of the prejudice associated with having a parent with poor mental health.

With regard to specific disorders, research by Somers (2006) found that children whose parents had schizophrenia experience more problems at school compared with children whose parents had no mental health difficulty<sup>15</sup>. While the ESRI found that children living with a mother who was depressed had an increased likelihood of having a poor attendance record<sup>16</sup>.

#### 3.3 Children as carers

It is hard to calculate the numbers of young carers as they often don't see themselves as carers and there are few studies to examine this issue, particularly focusing on younger children. Those who are in a caring capacity due to their parent experiencing a mental health difficulty are even harder to identify. The information available through Census 2011 regarding children as carers in general show that 8,472 young people under 19 years were engaged in providing care to others. Of these 1,838 were under nine years of age. The majority of all these carers were regularly providing up to two hours of unpaid care per day in addition to school attendance and homework, with some doing longer hours<sup>17</sup>. The range of caring tasks undertaken include domestic tasks such as cooking, cleaning etc, giving medication, emotional support, intimate care and childcare for siblings.

Children who are active carers can feel frustrated and overlooked when not consulted with or involved in their parent's treatment process. They have first-hand experience of how their parent is feeling and how it is affecting their home life but they are often ignored by professionals. They want more information and advice as to how they could best help<sup>18</sup>.

<sup>14</sup> Halpenny, A, et al (2004) Caring Before Their Time? Research and Policy Perspective on Young Carers, Barnardos and Children's Research Centre

<sup>15</sup> Somers, V, (2006) Schizophrenia: The Impact of Parental Mental Health on Children. British Journal of Social Work, 37(8), p 1319-1324

<sup>16</sup> Thornton, M. et al (2013), "Persistent Absenteeism Among Irish Primary School Pupils" Educational Review, ESRI

<sup>17</sup> Census (2011) Profile 8 Our Bill of Health – Health, Disability and Carers in Ireland, Central Statistics Office

<sup>18</sup> Somers, V, (2006) Schizophrenia: The Impact of Parental Mental Health on Children. British Journal of Social Work, 37(8), p 1319-1334

In a school setting, as mentioned, young carers often experience difficulties with punctuality, attendance and are unable to participate in afterschool opportunities due to their caring commitments. There can be feelings of resentment, a sense of isolation, anxiety and worry about the person they are caring for and difficulties developing or maintaining friendship and family relationships<sup>19</sup>. While much of the research focuses on the negative aspects of being a young carer, caring, when it is not too onerous, can be a positive experience and can contribute to self esteem and the maturing process. The absence of widespread availability of community based family support programmes can mean young carers shoulder more than they should for their age, which can have an effect on their own personal development.

Former child carer: "There should be better information and communication with children, especially in relation to care plans. What support does the person need to live a full life? If they have children that has to come into it."

#### 3.4 Impact of poor maternal mental health

All parents with mental health problems worry about the effect it may have on their children especially when they are feeling isolated and socially withdrawn or if they have to go to hospital. These feelings can be further heightened in lone parent households where there are often fewer family supports. While there is a confirmed relationship between poor maternal mental health and the wellbeing of children, it is important to be aware that a lot of the research done on mothers and mental health portrays them in a damaging light, which is not the case. The World Health Organisation has given it special consideration due to mothers predominately and traditionally undertaking the main carer role. Depression in particular has been associated with restricting the development of positive emotional attachments due to maternal withdrawal, lack of involvement and negative emotional responses towards the child<sup>20</sup>. Similarly, Barnardos found more than a third of mothers with a medical card show signs of lacking hope and have difficulty finding either 'the will or the way' to address the challenges which they face<sup>21</sup>.

Again depending on the severity and duration of the mental health difficulty, children may experience a mother's mood fluctuations, chaotic lifestyles, poor interpersonal functioning and low self esteem which can affect her parenting style<sup>22</sup>. This can put her child at risk of developing emotional, behavioural and mental health difficulties in later life<sup>23</sup>. However, poor maternal mental health rarely occurs in isolation. As mentioned earlier, there are often other environmental and socio-economic factors contributing to the situation. Where mothers are supported by a partner, other family members or services, there is a protective factor for both mother and child.

Parent: "My life was out of control. I was losing everything in my life; my kids were gone from me, my parents and family were worried about me. I was taking Xanax to block out the domestic violence I was going through. But I did not want to be this person any more. I wanted my life to change."

#### 4 Barnardos experience

Families are presenting to Barnardos with a range of different needs, however a common thread is that these families are facing multiple challenges which can lead to feelings of hopelessness and despair or other mental health difficulties. Often problems of poverty, unemployment, poor housing conditions, inadequate public services and isolation due to lack of transport co-exist and make it impossible for some parents to break free from the intergenerational cycle that can trap them. Also challenges such as addiction, domestic violence, debt and ill-health can erode parents' and children's resilience to cope with the multitude of factors. Subsequently, the majority of all parents referred to Barnardos do have mental health difficulties and many staff have also encountered suicide or attempted suicide during the course of their work with families.

<sup>19</sup> Halpenny, A et al (2004) Caring Before Their Time? Research and Policy Perspective on Young Carers, Barnardos and Children's Research Centre

<sup>20</sup> Dix, T and Meuriner, L (2009) Depressive Symptoms and Parenting Competence: An Analysis of 13 Regulatory Processes. Developmental Review 29(1) p.45-68

<sup>21</sup> McKeown, K and Trutz, H (2007) Understanding the Needs of Limerick: A Study of Needs and their Determinants in Limerick and Thurles, Barnardos

<sup>22</sup> Bifulco, A et al (2002) Adult Attachment style: Its Relationship to Clinical Depression. Social Psychiatry and Psychiatric Epidemiology, (37), p50-59

<sup>23</sup> Giallo, R et al (2013) Maternal Postnatal Mental Health and Later Emotional-Behavioural Development of Children: the Mediating Role of Parenting Behaviour. Child Care Health Dev. 2013, Jan 2013

Barnardos' experience of working with families where there is an insufficiently supported parental mental health difficulty echoes much of the research in this area. It includes inconsistency in parenting capacity such as poor routines, lack of boundaries and children presenting with poor hygiene and / or hungry. The reliance of parents on medication is a common issue. Staff also highlight that parent's moods can dictate children's moods, with children often anxious about what is waiting for them at home. Sometimes, children are referred to Barnardos because of their behavioural difficulties and their inability to regulate their emotions out of fear and concern for their parent. This can affect their social and emotional development and ability to make friends and develop their own sense of resilience. Schools have also referred children out of concern that they can be frequently late, caring for other siblings and socially withdrawn.

Barnardos knows that all parents love and want the best for their children and strive to achieve it. However it can be particularly challenging when parents do not recognise they have a mental health problem or are unaware of the impact their behaviour is having on their children. For instance it can be challenging if a child working with Barnardos begins to understand and improve their ability to talk about their feelings but their parent is unwilling or unable to do likewise.

### 4.1 Challenges facing families

#### 4.1.1 Discrimination

Barnardos always adopts a strengths based approach when working with parents as it capitalises on their capabilities. However, when faced with the engrained societal attitudes towards mental health it is difficult for parents to see their own strengths. The reality is that once a parent is diagnosed as having a mental health difficulty it is a label that is hard to shift even when such difficulties are episodic and are an often understandable reaction to the pressures they are under.

Subsequently, there is a real fear for parents that their children could be taken away from them or that they are being judged as bad parents if they seek help. Only through eliminating this perception and shifting the emphasis towards supports, as is the case with all other types of health difficulty, will parents freely seek and access the support they need at the time they require it.

#### 4.1.2 Impact of recession and State policy

The current recession and effects of seven austerity budgets is leaving a lasting legacy on many of the families with whom Barnardos works. The combination of cutbacks to services and reductions in social welfare support compound the sense of hopelessness among families. The regular cuts to Child Benefit and the reform of the One Parent Family Payment are pushing more families into debt and poverty. The increases in energy costs and healthcare costs stretch these limited household budgets to breaking point. Also the reduction of discretion available to the Community Welfare Officer is adding to this financial stress on families as unexpected bills go unpaid. The medical card debacle, including the current debate about discretionary cards, also adds to this stress. The criteria people have to match to avail of State supports are increasingly specific. This coupled with the activation tactics to move people back into the labour market can be disempowering and reinforce a person's sense of low self-esteem.

The continued absence of a nationwide outof-hours social work service means there are inadequate supports available for families coping with a crisis and children are left at risk of danger for longer. Preventative supports such as family support, public health nurses home visits and early intervention social work teams have all been affected by cutbacks, often leaving families to fend for themselves. These are areas which have always been underfunded and cuts on top of the long term underinvestment in these areas are having serious consequences for families. The reduction in the availability of a range of therapeutic and community supports for both parents and young people has also had negative consequences on families relying on these services. The loss or ongoing absence of vital supports has an impact on an individual's ability to sufficiently cope and adds significant stress and anxiety on families already living with adversity.

### 4.1.3 Reliance on medication long term

Barnardos staff consistently highlight the ongoing issue of large numbers of parents who are on medication to cope with their anxiety or stress. The dominance of the medical model to treat such symptoms means many GPs automatically revert to medication as opposed to exploring other options with their patients. While medicines are valuable, it is Barnardos' view that too often the medication is treating the symptom but not the cause. There are very few referrals to Barnardos services from

GPs which raises the question of whether GPs are fully aware of the different community services, although limited, available in their area and which could assist the patient. Hence it is essential that such supports be resourced so medication is not the first and only route when treating anxiety, depression, etc. Also given the limited consultation time available to the GP, are they aware that the patient is a parent and what consequences such medication could have on functioning family life? Benzodiazepines can numb parents from the harshness of their daily lives but can impair their parenting ability by being too drowsy or detached from the needs of their children.

Parents can be on benzodiazepines for a lengthy duration and once they are prescribed, anecdotal evidence suggests that repeat prescriptions are given out regularly. They are frequently taken in tandem with other drugs such as non-prescription painkillers, methadone or alcohol. A Barnardos study in 2007 found that up to 25% of mothers with a medical card showed clinical signs of depression, more than three times the rate among mothers without a medical card. Possibly as a consequence of this and other contributory issues such as poverty, 20% of mothers with a medical card are on sedatives, tranquilisers and anti-depressants, which is five times higher than the national average<sup>24</sup>.

From our experience, parents taking benzodiazepines are not being adequately assessed to check its efficacy or whether it is still a suitable treatment. Parents can develop a dependency on them and a tolerance of them which can affect their parenting ability. Also there can be significant withdrawal symptoms when ending the prescription.

Parent: "Knowing what I know about this type of medication and what effect it can have and the torment of coming off it I would never have taken them. In my opinion Xanax is a deadly drug and should be taken off the market. People who are parenting should not take them as you are not focusing on your child's needs."

#### 4.1.4 Children's school experience

An ongoing downside to the compartmentalised nature of public support services is that often many professionals can be working with one family without sharing information between them. This is often the case when adult services such as GPs, addiction or mental health services are dealing with a parent but do not engage with children's services such as education services or public health nurses. Notwithstanding the importance of client confidentiality and the challenges presented by data protection, Barnardos believes there are times when sharing information between professionals would alleviate the isolation and pressure that some children can feel.

In our experience, schools have varied significantly in how they support children living with a parent with poor mental health. Some are totally unaware unless the child or parent has informed them, while other schools have referred the child to specific supports such as homework clubs to give the child additional tuition or breakfast clubs to ensure they are not hungry starting their school day. Other schools have punished the child for being frequently late or having disruptive behaviour in the class without enquiring why this is the case. Admittedly the recent cutbacks to educational supports and increase in class sizes have also affected this as the teacher is coping with more children with fewer supports. The cuts to guidance counsellors and homework clubs are also having an adverse effect.

Barnardos sees the daily struggles parents with poor mental health have and how it can affect their children. Unfortunately, the present structures of policy and support services can hinder more than help these parents as they have not been developed in a holistic, family-focused manner.

Parent: "I wasn't able to get out and physically collect my children from school. I had neighbours who did it for me. It's the human connection that pulls you through."

### 5 Current policy and supports

Barnardos is a strong advocate for supporting families facing challenges in a holistic manner, where the needs of each family member are identified and supported. This is a far cry from the present structures and systems dealing with adult issues where the individual is seen in isolation and not as a parent. Subsequently

<sup>24</sup> McKeown, K and Trutz, H (2007) Understanding the Needs of Limerick: A study of needs and their determinants in Limerick and Thurles, Barnardos

services and responses to the family's needs are not coordinated. This is particularly true for adult mental health services where the services are designed to meet the needs of the patient only, leaving the needs of the family and children overlooked<sup>25</sup>. The dominance of this siloed approach coupled with the continued adoption of the medical model to treat mental health difficulties by prescribing medicines makes the pursuit of a holistic familial approach harder to attain.

#### 2.1 Primary care

As with most health challenges, for the majority of people who experience a mental health difficulty, their first port of call for professional support will be their local GP. They treat and care for 90% of mental health difficulties in Ireland<sup>26</sup>. The most common issues treated by GPs are depression, anxiety and substance abuse<sup>27</sup>. A small proportion of patients (about 10%) upon a referral from a GP will require mental health services delivered by specialist mental health professionals such as a psychiatrist, psychologist, mental health nurse, counsellor, social worker or therapist.

When a patient presents to the GP, there is no set guidance for the GP to identify if that patient is a parent and the implications this may have on any treatment or support being offered. However there has been a growing awareness of the need to adopt a more 'whole family' approach, and a recognition of the need to identify protective factors such as presence of a well parent and family support structures. In practice though it is still inconsistent. In some cases, the GP will have a long established relationship with the patient and will know their family circumstances but in other 'drop-in' type settings this information is harder to establish. Also, given the time constraints for a GP consultation it is often too short to explore any concerns broader than the immediate situation the patient presents.

During Mental Health Reform's 2011 consultation with users of mental health services and their family members, a number of key issues affecting their care in a primary care setting were identified<sup>28</sup>. These included the dominance of medication as often the only option offered and the lack of access to counselling. In this context, the new service Counselling in Primary Care (discussed below) is a welcome development. It was also felt GPs are not explaining the risks and benefits of medication that they are prescribing to their patients. In 2012, the HSE acknowledged there were "significant gaps in provision and access to psychological therapies in Ireland with an over reliance on medication"<sup>29</sup>.

As mentioned earlier the widespread use of benzodiazepines among parents is a concern for Barnardos. There is a perception because it is a legal drug it is less harmful, but this needs to be challenged by both GPs and wider society. Ireland is eighth highest in EU in benzodiazepine usage<sup>30</sup>. Particularly worrying is the usage of benzodiazepines along with other drugs such as methadone or alcohol, with poly drug use common among those attending drug treatment programmes.

The Department of Health issued the draft Misuse of Drugs Regulation (Amendment) 2013 for public consultation in August 2013. The Heads of the Bill are now being drafted and when enacted will impose much stricter rules and conditions on GPs when prescribing, and pharmacists when dispensing, benzodiazepines. They will no longer be seen as medicinal drugs and the quantity and duration of their usage will be limited. These proposed legislative changes were broadly welcomed by medical professionals including GPs as there is a growing awareness they can be overused.

Parent: "My doctor did really explain the side effects to me [of taking benzodiazepines] but I just wanted to take them to block out everything I was going through, instead of looking for other support. But I don't think people really see how dangerous Valium can be and how it affects you being a parent."

<sup>25</sup> Somers, V (1997) The Experiences of Children Living with a Parent with Schizophrenia, Unpublished M.Ltt Thesis, Trinity College, Dublin

<sup>26</sup> Mental Health Reform (2013) Mental Health in Primary Care in Ireland: A Briefing Paper, Dublin

<sup>27</sup> World Health Organisation (2001) The World Health Report 2001 – Mental Health: New Understanding, New Hope available at www.who.int

<sup>28</sup> Mental Health Reform (2013) Mental Health in Primary Care in Ireland: A Briefing Paper, Dublin

<sup>29</sup> Health Service Executive Primary Care and Mental Health Group (2012) Advancing the Shared Care Approach between Primary Care and Specialist Mental Health Services: A Guidance Paper, Naas, Office of the Assistant National Director Mental Health, HSE

<sup>30</sup> International Narcotics Control Board (2009) www.incb.org

While medicines have their uses, other options must be available when treating poor mental health. GPs need to be informed of what services are in the community that can help their patients but in turn these services need to be resourced, available and affordable<sup>31</sup>. These can include counselling, peer support groups and family support services.

Other gaps identified in the current provision of primary care mental health services include after-hours and follow-up services. The after-hours primary care services such as CareDoc often do not pick up on people with mental health difficulties, instead referring them directly to A&E services. On the other hand, GPs don't always get the information they need from mental health services to be able to provide adequate follow-up following discharge from hospital<sup>32</sup>.

Parent: "When a person goes to their doctor and they are looking for Valium maybe the doctor could offer them a different option, maybe hand that person leaflets and say look, it has a number on it for a support group and maybe you could try the support group for two weeks and see how you get on and come back to me."

#### 5.2 Mental health policy

A Vision for Change is the national blueprint for reform of mental health services in Ireland. Launched in 2006, it places a huge emphasis on moving away from residential care provision to accessing appropriate supports and services in the community. It outlines detailed targets to shift resources in this direction. Despite significant buyin by all stakeholders in the plan and a commitment to challenge underlying cultural barriers, its implementation has been extremely slow.

Mental health services continue to be underfunded. The gross mental health budget of €765m as a percentage of the overall health budget is 6.2% in 2014, a slight rise from 6.1% in 2013 but still far short of the 8.4% recommended in A Vision for Change, which itself is low when compared to international figures<sup>33</sup>.

The number of acute inpatient beds has fallen, in line with the recommendation of A Vision for Change, however the expansion of community based services has not seen the necessary development, due to ongoing delays in recruitment of personnel or non-replacement of staff who have retired or who are on leave. Although €70m was allocated for 900 new posts to strengthen community mental health teams (CMHT) as part of Budget 2012 and 2013, not all these posts have been filled. Factors such as availability of qualified candidates and geographic location are significantly impeding the recruitment process. A further €20m was allocated in Budget 2014³⁴.

The effect of incomplete CMHT means waiting lists build up and patients have to continue without appropriate supports, or situations escalate and the patients present to A&E for assistance. Delays in accessing CMHT are common for both adult services and Child and Adolescent Mental Health Teams. The general adult community mental health teams had received 38,887 referrals up to the end of November 2013 and 68% of referrals were seen within eight weeks or less, with the remaining 32% waiting various lengths of time<sup>35</sup>.

However the most important continuing gap is the lack of a national approach to coordination between mental health and primary care services. The HSE's Guidance Paper on a 'shared care approach between primary care and mental health services' falls short of being a national policy, although it provides valuable corporate support for shared care. There is a need for leadership from the Director for Mental Health to drive national implementation of this guidance<sup>36</sup>.

A Vision for Change also states that CMHT should collaborate with primary care services in establishing protocols for coordinated care. This is especially important to facilitate referrals to mental health services and discharge from inpatient units back into the community. Again there has been very slow progress on this<sup>37</sup>.

<sup>31</sup> Whitford, D et al (2005) 'General Practice in Ireland: Are we equipped to manage mental health?', Irish Journal of Psychological Medicine, 2:2:40-41.

<sup>32</sup> Mental Health Reform (2013) Mental Health in Primary Care in Ireland: A Briefing Paper, Dublin

<sup>33</sup> HSE Mental Health Divisional Operational Plan (2014) www.hse.ie

<sup>34</sup> Parliamentary Question 335-337 16th January 2014

<sup>35</sup> Irish Medical Times 19th February 2014

<sup>36</sup> Mental Health Reform (2013) Mental Health in Primary Care in Ireland: A Briefing Paper, Dublin

<sup>37</sup> Ibid

Former child carer: "It is upsetting to see your mother unwell. She was admitted [to a mental health inpatient unit] four times during my childhood and each time there was a lack of communication. I remember looking for family therapy and being told 'that is not available'."

## 5.3 Mental health services working with parents

Availability of counselling services is limited, especially for those on low incomes, therefore Barnardos strongly welcomed the national roll out of the Counselling in Primary Care (CIPC) service in July 2013. It offers all adult medical card holders the potential to access free short-term counselling based on their identified needs. The service is geared towards mild and moderate mental health difficulties including depression, anxiety, loss/bereavement, stress, etc. It is not intended as a crisis intervention service or to assist those with an enduring mental health difficulty. The service is also not intended for people with addiction issues.

A patient is referred by their GP to one of the ten CIPC co-ordinators who then undertake an assessment with the patient. This assessment is returned to the GP with a recommendation for what type of counselling is needed. The GP approaches the counselling service in question and the patient avails of the service. A total of €7.5m has been allocated to this service and counselling services are bought on a contract basis. The service is already proving successful as over 5,000 referrals were received up to the end of December 2013 and 188 of these were waiting between one and three months, with a further 40 waiting longer than three months<sup>38</sup>. The increasing demand for this service is proof it is needed. Unfortunately, there are few options for those on low income but who do not have a medical card.

However it also appears there is a need to have better information and pro-active promotion of this treatment as parents can be reticent to avail of counselling even if it was offered free of charge. It would be beneficial if further research was undertaken to investigate the causes of this reluctance so those barriers can be overcome.

As already highlighted, a frequent critique of present mental health services and supports is the tendency to treat the patient in isolation rather

than seeing them as a parent and identifying their specific needs in this respect. There is a lack of attention on family focused practice both in training and in practice among professionals. This would help form partnerships with parents and in turn support children<sup>39</sup>. In fact there appears to be reticence on the part of mental health professionals to approach parenting issues because of the possible impact on their relationship with the patient and the stigma attached to mental health and seeking support<sup>40</sup>. The increasing use of the Wellness Recovery Action Plan (WRAP) is an encouraging development as it is a patient led recovery plan that also considers the wellness of their children and identifies actions that can be undertaken to strengthen their wellness. Evaluation reports suggest it can be very effective<sup>41</sup>.

There is also reluctance for adult mental health services to engage with children's services such as social workers, teachers and public health nurses. While Barnardos recognises the inherent challenges associated with interagency working, some inroads have been made to connect adult addiction services with children's services, to ensure the needs of the entire family are considered and supported. However this synergy needs to be further developed in adult mental health services, although Ireland is not alone in having this gap.

A recent Ofsted (2013) report in the UK examining the extent to which adult and children's services worked effectively together found the quality of joint working was much stronger between children's social care and drug and alcohol services than between children's social care and adult mental health services<sup>42</sup>. Thinking about the impact of parents' difficulties on children was more strongly embedded in drug and alcohol services than in adult mental health services. This stronger

<sup>39</sup> Anne Grant (2014) Registered Psychiatric Nurses' Practice With Parents Who Have Mental Illness, Their Children And Families In General Adult Mental Health Services in Ireland. (Unpublished Doctoral dissertation). Monash University. Melbourne. Australia

<sup>40</sup> McDonald, G et al (2011) Improving the Mental Health of Northern Ireland's Children and Young People, Belfast, Institute of Child Care Research.

<sup>41</sup> Higgins, A et al (2010) Evaluation of the Mental Health Recovery and WRAP Education Programme, Report to the Irish Mental Health and Recovery Education Consortium. Trinity College Dublin, http://www.nursing-midwifery.tcd.ie/assets/research/pdf/TCD-Evaluation-Report.pdf

<sup>42</sup> Ofsted (2013) What about the Children? Joint Working Between Adult and Children's Services when Parents or Carers have Mental III Health and/or Drug and Alcohol Problems. www.ofsted.gov.uk

<sup>38</sup> HSE letter 7th February 2014

focus on children by drug and alcohol services has been driven by the requirement for local areas to gather information on the number of adults with children and report on this to the National Treatment Agency for Substance Abuse. Within adult mental health services, while it is expected that the care programme approach considers safeguarding of children, there are no national requirements to gather information and report on the number of parents who have serious mental health difficulties. Therefore, in the absence of any national drivers there is limited scrutiny of this issue within mental health services generally<sup>43</sup>.

This lack of a coordinated response also has an impact on which professionals engage with and inform the child of their parent's poor mental health, and by extension, what it could mean for their household. While mental health staff are often best placed to talk to the child because they know what the parent is experiencing, they may claim they are ill-equipped in terms of both time and expertise to talk to children. Whereas social workers, if they are informed, are often hard-pressed to respond to even the serious and obvious cases of child abuse. As children living with parents experiencing mental health difficulties are commonly not obvious, they can often be missed. Furthermore, many social workers will have had only minimal training in mental health and will feel ill-equipped to offer any explanation to a child44. Parents too need to be supported on how to talk to their child providing them with the emotional language in age appropriate formats for them to discuss what is happening.

Former child carer: "I would have to stay with family members when my mum was in hospital and I would worry I was a burden so I would have been very quiet. My brother would have stayed with another family member, so we were separated. I never asked [about what was happening] and they didn't bring it up."

#### 5.4 Children's services

From a legislative perspective, under Children First: National Guidance for the Protection and Welfare of Children (2011) there is now a legal requirement to ensure that services working with

43 Ibid

adults consider the impact of adult's behaviour on the child and act in the child's best interests.

At a policy level both within the Department of Children and Youth Affairs and in the newly established Child and Family Agency there is an understanding and recognition of the multidimensional nature of children's lives. Their lives and needs do not fit into clearly delineated departmental lines. There is a strong emphasis on enhancing interagency co-operation so that services of varied agencies and departments that are core to child and family supports must operate in a singular unified fashion<sup>45</sup> (DCYA, 2012). A Joint Protocol for Inter-Agency Collaboration is a formal agreement between the Child and Family Agency and the HSE to ensure a consistent national approach to service delivery where the delivery of two or more services is involved in the same case.

The intention to wrap the services around the child is being pursued with the aim of identifying the needs of children early on and providing appropriate support for them. This prevention and early intervention approach complements a family strengths-based approach as it aids the building of resilience and trust, and is more likely to keep the family unit together.

Unfortunately, implementation and adherence to this plan remains fragmented and subsequently services delivered to children are not as coordinated or even as available as hoped. There continues to be different protocols, understanding and practices among a range of professionals working with children and their parents<sup>46</sup>. Due to staff shortages and cutbacks to services, social work services are often forced to deal with crisis child protection cases only, leaving the child welfare cases insufficiently dealt with. For public health nurses, their caseloads have increased in line with the population resulting in delays in routine assessments and fewer home visits, which are a vital form of early diagnosis of child or family issues. Also (as outlined earlier) there remains a gulf between systemic interagency cooperation between children's services such as social work services and adult mental health services, and this also applies to broader children's services too such as the education, pre-school and youth sectors.

<sup>44</sup> Cooklin, A (2010) Living Upside Down: Being a Young Carer of a Parent with Mental Illness. Advances in Psychiatric Treatment, vol 16, 141-146

<sup>45</sup> Department of Children and Youth Affairs (2012) Report on the Taskforce on the Child and Family Support Agency, Dublin. The Stationery Office

<sup>46</sup> Darlington, Y (2005) Interagency Collaboration between Child Protection and Mental Health Services: Practices, Attitudes and Barriers. Child Abuse and Neglect, 29, p1085-1098

Parent: "It would have helped me in leaps and bounds ... if there had have been support groups for parents of kids with disabilities; other parents linking in together instead of thinking they were on their own. I wouldn't have been as stressed and probably wouldn't have needed the anti-depressants I ended up on if I'd had the support I needed."

#### 5.5 Pre-school and education sectors

A pre-school setting can play a vital role in helping the social and emotional wellbeing of the child and picking up on any worrying cues as to what could be impeding the child's development. Being more relaxed than a school setting, it allows for relationships between staff and parents to form more organically. However, staff receive little training on the importance of building relationships with parents and due to the limited non-contact time there is little opportunity to discuss any concerns with the parent.

Within the school system, there is clear guidance that underlines the unique position of schools to recognise and address wider child welfare issues that may negatively affect educational progress<sup>47</sup>. As a continuum of support, the guidance is based on early intervention and individual needs of any child experiencing difficulties and the particular circumstances of maternal mental health is highlighted in these guidelines.

However in reality the response of schools can be varied and depend largely on the teacher and their ability to point towards internal school supports (if such supports are available). How supportive and empathetic a school or teacher can be significantly influences the experience of the child and their overall attainment and participation in school. More supports are available in DEIS schools including the Home School Community Liaison scheme which is designed to forge links between the school and the child's home. This operates in both primary and secondary schools. Again, in Barnardos' experience, this scheme has worked well in identifying and obtaining supports for children who have a parent with poor mental health in some areas and not in others. There are fewer options

to those teachers in non-DEIS schools who may have a concern regarding a child. Often their only recourse is to social work services even though there is no child protection concern. Teachers can be reluctant to refer to these services for fear of jeopardising their own relationship with the parent, over-exaggerating the issue or due to the sensitivity and prejudice surrounding mental health difficulties.

#### 6 Model for reform

Barnardos is strongly advocating for the present systems and structures to break away from their historically siloed perspective and instead see parents in the context of their family and all the interconnected pieces that overlap within this unit. The adoption of a family model approach to identifying needs and supporting recovery will aid both parents with poor mental health and their children. Families and supporters are an integral part of the support system<sup>48</sup>. It will also lead to more effective joint working for professionals across all disciplines<sup>49</sup>. The increased availability of accessible peer support groups for parents connected with empathetic and supportive services would also be of significant benefit.

#### 6.1 Think Child Think Parent Think Family

The adoption of the family model to service planning and delivery is being advanced in a number of local authorities in England and across Northern Ireland. The origins for this stems largely from the Social Exclusion Unit (2004) report which addressed the social and economic costs of mental health problems and the impact of mental health difficulties on family wellbeing and child development<sup>50</sup>. Part of its recommended Action Plan was to achieve change by working across adult and children's systems to promote policies and practice that consider the needs of the whole family rather than regarding their service users solely as people with individual difficulties and needs that exist in a vacuum<sup>51</sup>.

In July 2009 the Social Care Institute of Excellence (SCIE) published the national practice guidelines

<sup>47</sup> Department of Education and Skills, Health Service Executive and Department of Health (2013) Guidelines for Mental Health Promotion and Suicide Prevention http://www.education.ie/en/Publications/Education-Reports/Well\_Being\_PP\_Schools\_Guidelines\_Summary.pdf

<sup>48</sup> Shine (2014) Guidelines for Realising a Family Friendly Mental Health Service

<sup>49</sup> Dr. Falkov, A, (2012) The Family Model Handbook, Pavilion Publishing and Media, UK

<sup>50</sup> Social Exclusion Unit (2004) Mental Health and Social Exclusion, Office of the Deputy Prime Minister, UK

<sup>51</sup> Fowler, R, et al (2009) Improving Opportunities and Outcomes for Parents with Mental Health Needs and their Children, Barnardos UK

entitled Think Child, Think Parent, Think Family: A Guide to Parental Mental Health and Child Welfare to help services improve their response to parents with mental health problems and their families. It is an evidence-based resource for improving outcomes for the whole family and raising standards among professionals.

A 'think child, think parent, think family' approach means that adult mental health practitioners need to have a basic understanding of child development, safeguarding and the parenting task, to ensure the needs of all family members are identified and appropriately supported.

The family model stresses a systems and ecological approach to screening, assessment and intervention. It tries to convey a more dynamic understanding of how multiple factors within and between individuals and their environments interact over time. It encourages services to examine the risks, stressors and influences that can exacerbate the condition along with the protective factors and available resources. Risk of negative effects will vary from person to person. For example, people with the same mental health difficulty can experience very different symptoms and behave in different ways. Therefore relying on a diagnosis is not sufficient to assess levels of need or risk.

Key messages for implementing the Think Child, Think Parent, Think Family approach:

- Staff in all settings should routinely and reliably ask the right questions to identify families with a parent with a mental health problem. They should also explore the impact of any mental health problem on parenting and the child and then put parents in touch with the right services.
- 2 Staff in all settings should develop a working knowledge and confidence in how other services operate, what they have to offer and how to refer to them.
- 3 Staff in all settings should reassure parents that identifying a need for support is a way of avoiding rather than precipitating child protection measures.
- 4 Staff in all settings should be proactive in developing good working relationships with their counterparts in other agencies, so as to facilitate joint working and shared case management.

- 5 Develop new systems and tools (or customise existing ones) to routinely collect information about families and record the data for future use.
- 6 Develop a communications strategy to tackle the stigma and fears that parents and children have about approaching and receiving services. This should be a priority.
- 7 Be very clear about what information can be shared and with whom, also seeking parents' and children's permission for information sharing where possible.
- 8 Be better informed about what forms of mental health problems and their symptoms and associated behaviours could pose a risk of harm to children.
- 9 Care planning needs to take a holistic approach to include appropriate care plans for each individual family member as well as the family as a whole. These plans should aim to increase resilience, reduce stressors and respond appropriately to risks.
- 10 Commissioning, funding and management processes need to ensure that services meet the full spectrum of needs of parents with mental health problems and their children.
- 11 Reviews need to consider changes in family circumstances over time, include both individual and family goals and involve children and carers in the process.

Between September 2009 and September 2011, SCIE worked with five local authority areas in England and the five health and social care trust areas in Northern Ireland to implement the recommendations in the guide. The Northern Ireland project concluded in March 2012.

#### 6.2 Think Family project in Northern Ireland

Unlike the five local authority areas in England, the Northern Ireland project was led by the Department of Health, Social Services and Public Safety which enabled it to have region-wide impact. Two project managers were employed to manage the development of the component parts of the 'think child, think parent, think family' recommendations. It had buy-in from across the region, sectors and professionals. Parents, children and carers were also involved from the outset in discussing their experiences through a Family Experience Survey

and giving their opinions on reform. The roll-out of the recommendations spanned the following areas.

#### 6.2.1 Communication

A communication strategy was developed which aimed to co-ordinate communication with both staff across a range of settings and the families with whom they work. These were implemented in a variety of ways including regular updates via the website and newsletters, information about the website sent out with staff payslips and development of posters and aide memoires for staff and service users to raise awareness about 'think family' issues.

#### 6.2.2 Workforce development

Given the diversity of the sectors involved in working with families where a parent has poor mental health, attempts were made to co-ordinate workforce development in relation to 'think family' issues. These set out plans for embedding 'think family' in existing training such as staff inductions and safeguarding training, and rolling out new relevant training opportunities. Also a knowledge and skills framework was developed which aimed to structure planning, commissioning and delivery of training to meet the learning and development needs of staff working across the mental health and children's services interface.

The training raised key issues that professionals need to be mindful of, including that children may experience adverse consequences of living with a parent with poor mental health, but they may also develop resilience, and support should be provided by these professionals to both parents and children to help develop individual resilience. Children require interventions that take into account their own needs as well as the needs of the whole family. Children should be listened to and direct consultation should take place between professionals and children and young people themselves. Children need age appropriate information about mental health and this should be geared towards their own particular circumstances and needs.

#### 6.2.3 Screening and identification of parents

Improving the process of identifying patients as parents was a key aspect of the 'think child, think parent, think family' guidance. At one level it meant providing tools to assist workers to ask the right questions. In Northern Ireland, services collaborated to develop a standardised form

of words for workers to use when gathering information from parents with mental health problems. A range of services were asked to review their current screening and assessment templates, including addictions, maternity, health visiting, A&E, mental health, children's social work services and voluntary organisations, and involved inpatient and community services. This exercise highlighted the diversity of practice in operation and examples of good practice were identified and shared. Subsequently a shared form of words was then developed and disseminated and is being used by the range of professionals in their screening and assessment procedures.

Also Northern Ireland amended its UNOCINI (Understanding the Needs of Children In Northern Ireland) assessment tool which is used largely by social workers as the basis for referrals to statutory children's services to identify the needs of children, based on 12 domains. A review of the UNOCINI guidance highlighted that parental mental health was not explicitly covered. The guidance did not provide for the detailed elements of parental mental health that staff need to consider when completing a parental assessment. Nor did it consider the factors such as nature of the difficulty, treatment being accessed, frequency of difficulty, insight into condition, insight into children's needs, support that is available to the family and so on. In consultation with key stakeholders including front line workers, changes were made to the tool embedding cues for staff to consider parental mental health in their assessments and this continues to be used.

### 6.2.4 Care planning and review

Effective care planning and review of treatment is vital to a patient's recovery. This is greatly enhanced when the whole family's needs are considered in such plans and crossover with different agencies is needed to successfully achieve the plan. Therefore, having a good understanding of other agencies and strong relationships with other professionals underpins good joint care planning and review. A protocol for interagency working was produced in Northern Ireland, making explicit reference to the 'think child, think parent, think family' guide. It had a wide target audience including adult services (acute hospitals and community health and social care services), learning and physical disability, sensory impairment, maternity services, primary health care services, children's services including CAMHS,

substance misuse services including statutory community and voluntary services and voluntary and community groups.

Key aspects to the joint protocol include; the need for an initial joint planning meeting attended by all agencies and the family, changes to circumstances that will affect current care plans must be communicated to staff or services involved in the family's care and the case must not be closed unless all agencies/services are in agreement.

Other improvements leading to enhanced joint working across agencies was the decision to embed specialist workers in another setting. For example, providing mental health support in family support settings or providing family support via the community mental health teams.

Barnardos believes key lessons and practical strategies can be learnt from the experience of the sites that implemented the 'think child, think parent, think family' guidance especially Northern Ireland who achieved systemic change across the professions within the region. Such suggestions do not have to cost too much but do require leadership to challenge the professional boundaries that exist so that a more holistic perspective in assisting parents with poor mental health is pursued.

### 6.3 Peer support programmes

For the parent with poor mental health and their child to know they are not alone dealing with their difficulties is hugely powerful as feelings of isolation can be all encompassing. Much can be garnered through meeting, listening and learning from other parents who have shared similar experiences. Although some peer support groups do exist they are not widely available and rarely are they connected with specific support services that may help the parent through their current difficulty.

For the child, forming positive friendship groups may be a challenge, as they can be socially withdrawn, engage in disruptive behaviour or have caring responsibilities that prevent them from participating in social activities. Although there is no specific peer support group for children living with a parent with poor mental health, programmes such as Big Brother, Big Sister run through Foroige has proven to improve the social and emotional development of children. This programme offers one-to-one peer support by matching an adult volunteer with a young person facing adversity.

Participants in the programme have described themselves as more hopeful and happier as a result of their involvement. Boys who had been hyperactive were described as calmer and more in control of their behaviour while girls had greater confidence<sup>52</sup>.

Internationally other peer support programmes designed specifically for children with parents with poor mental health exist. These include CHAMPS which aims to build resilience skills among children with parents with poor mental health in settings such as after school clubs and holiday programmes. An evaluation of the programme found that it had contributed to improvements in self-esteem and coping, strengthened family connections and reduced relationship problems<sup>53</sup>.

Similarly, SMILES actively works with children of parents with mental health problems to build self-confidence and resilience, gain better understanding of their parents' mental health problems and reduce feelings of isolation. The programme also incorporates joint sessions with parents to develop their parenting skills and improve relationships with their children. Evaluations of the Australian SMILES Programme identified positive outcomes for children and parents alike. It provided children with a better understanding of their parents and improved their confidence and resilience and enabled parents to talk openly to their child about their mental health<sup>54</sup>.

#### 7 Recommendations

As this report has continuously highlighted, Barnardos is concerned there is insufficient awareness of the potential impact of parental mental health on children and inadequate supports available to help parents and children with the challenges. In our view, the present structures providing support for those with poor mental health are too firmly embedded in the medical model. The individual is regarded as a patient to be given the appropriate medicines and treatments with little regard to their family context or needs. The system

<sup>52</sup> Brady, B et al (2011) Big Brothers, Big Sisters of Ireland: Evaluation Study, Summary Report. Child and Family Research Centre, Galway

<sup>53</sup> Goodyear et al (2009) CHAMPS: A Peer Support Program for Children of Parents with a Mental Illness. Austrialian e-Journal for the Advancement of Mental Health, Vol 8, No.3, p296-304

<sup>54</sup> Baldwin, P and Glogovic,C (2010) Providing S.M.I.L.E.S to children of the Waterloo region whose care gives has a mental health diagnosis. Ontario Association of Children's Aid Societies Journal, 55(1).

fails to offer a range of supports that could alleviate their mental health difficulties and assist their entire family. It also fails to recognise and address the reality that poor mental health very often co-exists with (or indeed can stem from) a range of other factors such as poverty, addiction, unemployment, housing conditions and poor public services.

Barnardos believes any reform of service delivery must be accompanied by a societal commitment to tackle the prejudice and discrimination that surrounds poor mental health. Just because a parent is experiencing a mental health problem it does not mean their parenting ability will automatically be affected. However, if additional supports are needed, they must be available. Public perception and services must be sympathetic and empathetic in their design and execution, as they are with other types of health problems, particularly cancer. This involves extensive public awareness and education to debunk all the myths that surround mental health. Some efforts are already being undertaken and the public sharing of poor mental health experiences by more people helps to normalise it as an episodic condition, from which most people can and do recover, given the right supports. This needs to continue at a pace as failure to do this will result in parents being constantly viewed with suspicion as regards their parenting ability.

## 7.1 Adopting the *Think Child, Think Parent, Think Family* approach

Incorporating the 'think child, think parent, think family' approach to service planning and delivery across all disciplines and professionals would guarantee more holistic user focused services. It requires a commitment by professionals to see beyond their own professional boundaries and instead see the patient as a parent and the child as a component of the family unit which could be under strain. It is a departure from the present silos that exist, to offer individual support for specific ailments and instead attempts to join up the dots between all the professionals and services working with families, whose parent has a mental health difficulty. Adopting a family model approach would have an impact on adult mental health services, adult and child community mental health services, education services, pre-school services and children's social care services, etc. Significant practical guidance has already been published to aid the adoption and roll out of this model.

#### Recommendation:

 Department of Health and Tusla, the Child and Family Agency should adopt 'think child, think parent, think family' approach across all its relevant services when working with parents who have mental health difficulties.

# 7.2 Identifying patients as parents in screening and assessment procedures

A crucial element to being more holistic is the need to identify which patients are parents and what their needs are, as well as their children's needs. It is vital the recording, screening and assessment procedures for all GP, adult mental health services and addiction services enquire at the very start whether the client is a parent. Coupled with this they must be up-skilled with the tools to ask the right questions to establish the full impact, if any, of the mental health difficulty on their home life, so appropriate supports can be quickly identified.

#### Recommendations:

- Systematic guidance is required to ensure all medical professionals record and consider the patient's family circumstances in assessments.
- Department of Health with assistance from Tusla, the Child and Family Agency, must compile guidelines for professionals to ensure the right questions are asked so to paint an accurate picture of home life.

### 7.3 Professional training

Professionals working with adults must have a greater understanding how the parent's difficulty may be affecting their child's needs and develop a care plan with these considerations in mind. The potential impact of medication on parenting ability must also be considered. Accordingly, professional training must include modules on child development and safeguarding children. The ability to undertake joint training sessions for staff across a range of professions will aid a greater understanding of the different perspectives and lead to improved interagency co-operation.

Likewise, those working with children in all settings including pre-school crèches, schools, social work services and youth clubs must be cognisant of a child's behaviour and consider the full range of reasons behind it. The benefits of building up relationships between staff and parents in these settings cannot be overestimated. However, staff must be appropriately trained and be given the

opportunity to forge these relationships through the availability of paid non-contact time.

#### Recommendations:

- Enhance pre-service and in-service training for adult mental health professionals to always consider the needs of the family when developing a care plan for a parent.
- Organise regular joint training sessions across a range of professionals spanning the adult mental health and children services interface.

#### 7.4 Importance of talking to the child

Children living with a parent with poor mental health need to be informed and reassured in an age appropriate manner about what is happening to their parent and what to expect. Parents should be given the appropriate support so they can talk to their children about what they are experiencing and reassure them. Feelings of isolation, blame and confusion are common as professionals and other family members fail to talk to or reassure children. Decisions are being made about their lives with little regard to their needs or wishes, and research shows this is especially true when a parent needs to be hospitalised. For those in lone parent households it means moving in with relatives or being taken into care temporarily. Children who are acting as carers know a lot about their parent's condition but are often overlooked when care plans are being discussed. All professionals working with the parent must understand the importance of talking to the children and be skilled accordingly. Likewise, parents themselves must be supported to know what to say and how to reassure their children in an age-appropriate manner.

#### Recommendation:

- As per the Brighter Futures, Better Outcomes: National Policy Framework for Children and Young People, the Department of Children and Youth Affairs will be enhancing their parenting supports across the country. A component of this must be to up-skill parents in providing them with the emotional language required to talk to and reassure their child of their own mental health difficulty.
- Guidance needs to be given to all professionals on how to listen to the views of children affected and consider their opinions and offer them reassurance in the circumstances.
- Children who have been acting in a carer role must receive the recognition by professionals

of the responsibilities they have undertaken and the knowledge they have gathered while caring for their parent and this must be adopted into any care plan for their parent.

## 7.5 Statutory services – mental health services and children's services

The slow roll out of A Vision for Change is seriously affecting the recovery of many adults and children experiencing poor mental health. The shift in emphasis toward community based services is long overdue and will contribute to lessening the prejudice surrounding mental health. The ongoing delays in recruitment and service provision in community services is unacceptable and reinforces the lack of trust that exists in mental health services being user focused. The development of comprehensive community based services including the availability of a peer advocate connected with each team would not only improve access to essential services but also assist in reassuring parents they are not alone and subsequently normalise the services on par with other community based medical services.

The current deficiencies in the community based services also affect the development of improved co-ordination between the different aspects of the health service dealing with the patient. Primarily, greater co-ordination between inpatient mental health services and primary care services, and between community mental health teams and primary care services are desperately needed. This would ensure all information regarding a person is shared between the services and all would be aware of any changes in treatment or condition without a person being constantly pushed between services. The HSE Guidance Paper on Shared Care goes someway to advance this but much more needs to be done on it.

HIQA monitors the quality standards in all inpatient and outpatient services in either a hospital or community setting. These standards must be reviewed to provide oversight on the extent to which the individual care plan took the needs of their family and children into account.

Within Tusla, the Child and Family Agency, stronger links are required between services such as social work services, public health nurses and education welfare officers and adult mental health professionals. Greater synergy and common language used across these professionals will enhance the trust in the system and permit the responses to be more user focused, coordinated and empathetic rather than parents afraid of being judged for seeking help.

#### Recommendations:

- Raise the budget allocated for mental health services to ensure speedy implementation of the strategy across community based and hospital based services.
- Expedite the development of shared protocols between inpatient mental health and community mental health services and primary care services. All these are within the remit of the HSE but effectively operate separately. The Guidance Paper on Shared Care needs to be expanded on and fully implemented to enhance greater coordination and user focused care.
- Introduce shared information and coordinating protocols between agencies serving children and young people and adult focused addiction, domestic violence and mental health as committed to under Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People, 2014-2020 to enhance effective interagency working. The interagency protocol developed under the 'think family' actions in Northern Ireland provides a useful starting point as it spans a wide range of professional disciplines.
- Review HIQA standards to capture the 'think family' principles.

## 7.6 Community services for parents and children

While there is a dearth of services available through the community mental health teams there is also an absence of community preventative supports that could ease pressure on parents at times when they feel particularly stressed. These services include peer support groups (for parents and children), counselling services and family support services. Present provision is patchy and often restricted to specific times yet getting support early on, even with practical parenting tasks, can reduce or even entirely mitigate the impact of the difficulty on both the parent and child. These services need to be resourced, available and affordable.

They also must be widely publicised so that GPs in particular can refer families to them as opposed to automatically prescribing medicines. However, public health nurses, teachers and pre-school staff

should also be sufficiently informed of the range of services available in their locality which could offer help where needed.

The limitations under data protection legislation in sharing of information between professionals even where they are working with the same family are a recurring obstacle. It is difficult to overcome between statutory agencies but even more so between statutory, NGO and community services which are supporting the family to reduce the risk of further harm. In the interests of a more coordinated, effective response and reducing duplication of supports to the same family and without jeopardising trust and confidentiality there is a need for joint working protocols to be in operation between services.

#### Recommendations:

- Consult widely with parents affected by poor mental health identifying their preferred community based services that would make a positive difference to their lives and of their children.
- Audit and evaluate the current range of community services that are supporting parents with mental health difficulties and their children and continue to resource and extend those that are proven to be effective.
- Seek the advice of the Data Commissioner in the development of joint working protocols to be established between community based and statutory services.

## 7.7 Misuse of Drugs Regulations (Amendment) 2013

Barnardos calls for the Misuse of Drugs Regulations (Amendment) Bill 2013 to be published and introduced into the Oireachtas promptly. This will bring about the much needed changes in the prescribing, dispensing and taking of benzodiazepines.

#### Recommendation:

 Swiftly publish and progress the Misuse of Drugs Regulations (Amendment) Bill 2013 through the Oireachtas.

#### 7.8 Education systems

The school system is an ideal place to start talking to and informing young people about mental health. It can promote positive self-esteem, coping tools and build resilience. These debates in the classroom can help break down the persistent prejudice that surrounds mental health. It also provides an opportunity for children affected by poor parental mental health to discuss their own challenges and feelings if they feel the teacher and school is supportive of their situation. Guidelines already exist for secondary schools and the Department of Education plan to introduce complementary guidelines for primary schools in autumn 2014.

Teachers and principals should have a greater awareness of the potential impact of parental mental health on children and be adequately trained to pick up on any worrying cues the child may present. Connected to this is the need for available supports such as breakfast clubs, homework clubs and some flexibility from the school regarding issues of punctuality or homework undone. The need for interagency protocols of sharing of information must also extend to schools so they don't have to rely on the child to disclose or explain their situation.

#### Recommendation:

- Greater use of the Guidelines for Mental Health Promotion and Suicide Prevention in all classes in secondary school.
- At primary level, in addition to finalising national guidelines there should be more widespread roll out of evidence based programmes such as Roots of Empathy which are proven to improve the social and emotional development of the child
- Forge greater links between education services (teachers and pre-school staff) and children's services in the interests of assisting children early on before situations escalate into full child protection concerns. This could include joint training sessions and having shared language and terminology.

#### 8 Conclusion

As this report has highlighted, the support available for parents experiencing mental health problems is falling short. This is not just affecting parents, but having a knock-on effect for children too. As Barnardos has seen first-hand in its services, children of parents with unsupported or inappropriately supported mental health difficulties can experience physical and emotional neglect.

A key barrier for parents accessing appropriate support is the entrenched societal prejudicial and discriminatory attitudes towards mental health. There is a very real fear that once a parent says they have a mental health problem they will be shouldering a huge level of suspicion in relation to their parenting capacity – even if it is having no impact whatsoever. This fear is compounded by a mental health service that is seen as being a punitive, rather than a supportive structure.

We must break down this prejudice and develop coordinated, supportive structures for parents and children. These must cover health related and wider, more practical, community-based supports. The recommendations in this report outline how mental health supports need to recognise a parent experiencing mental health difficulties as a rounded person; part of a family and a community. Support should not just be medication, but a range of supports that allow parents to live full lives in their families and their communities. And these solutions must include children.

An important protective factor for children is providing them with information and including them in the process of recovery. Often what children imagine and are worrying about if their parent is experiencing mental health problems is far worse than the reality. They also need to be reassured it is not their fault and that they are not on their own. As has been highlighted in this report, being able to be a support for a parent can be a hugely beneficial experience for a child. Conversely, by neglecting them in recovery plans and not equipping them with emotional literacy and resilience, there is a risk of perpetuating emotional distress in another generation.

A key recommendation in this report is to consult with parents and children to find out what supports would help them. Parents have consistently highlighted the need for practical, peer support. To know they are not alone experiencing life's challenges and to be in a totally non-judgemental environment.

Put simply, by failing to properly support parents we are failing our children. But there is hope as the reverse can also be true. By taking the steps recommended in this report we can ensure that parents and their children are better supported.







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