



Response

Public Health Agency Infant Mental Health Framework and Action Plan 2015-2018

May 2015

Introduction

Children in Northern Ireland (CiNI) is the regional umbrella organisation for the children's sector across Northern Ireland. CiNI provides information, policy, training, participation and advocacy services to support our 160 members in their direct work with and for children and young people. Our membership is drawn from across the voluntary, statutory and independent children's sector. We are increasingly working in partnership with the statutory children's sector, recognising that the best outcomes for children and young people are achieved through partnership working. As part of our commitment to partnership working we represent the sector on a number of cross-sectoral, multi-agency bodies, most notably the Children and Young People's Strategic Partnership and the Safeguarding Board for Northern Ireland.

CiNI and Disability Action jointly chair the Children with Disabilities Strategic Alliance (CDSA) which brings together organisations from across the children's sector and the disability sector. CDSA wants to ensure that policy impacting on the lives of children and young people with disabilities is informed by their needs and circumstances. CDSA has produced a 'Children with Disabilities Manifesto' endorsed by almost 50 organisations.

We also jointly chair the Early Years Strategic Alliance (EYSA), together with the Women's Resource & Development Agency, which brings together organisations from the child care and women's sector. EYSA seeks to inform and influence early years, child care and family support policy. It seeks to ensure equal access to high quality, child-centred support and services that meet the holistic needs of younger children and their families. In 2012 EYSA updated its Early Years Manifesto outlining some of the key elements for an early year's strategy.

The issues addressed by the Manifestos outlined above have helped to inform our response to this consultation.

General Comments

Children and young people with disabilities are at a higher risk of developing mental ill-health than other children and young people. The Bamford Review Report noted that children and adolescents with a significant learning disability are 3-4 times more likely to experience mental health problems. Yet despite the higher risk they experience great difficulty in accessing services. Young people with mental health or learning disability have frequently been accommodated in adult wards.

We have continually called for more early intervention and preventative approaches to enhance the emotional health and well-being of disabled children and young people and provide support to their families. We have also called for equal access to universal services for children and young people with disabilities as well as targeted approaches where there is need. We would advocate that the specific needs and circumstances of children and young people with disabilities are addressed in the development of this service framework, currently that need has not been addressed.

CiNI warmly welcomes the recognition of the need for explicit standards for infant mental health that are evidence informed.

We are keen to support and inform the ongoing development of standards for services across health and social care. However, we recognise the challenges inherent in this process, given that so much of what the population expects in its interaction with services is a joined up and comprehensive response to meeting their needs and circumstances in a holistic way. For those who rely on access to public services across the spectrum their expectation of these services is that there will be a joined up approach to meeting their needs in a holistic manner, yet the manner in which services are organised does not lend itself to meeting that expectation and desire. This is an issue which must be tackled; we would like to see a more comprehensive framework that shows how the PHA can work collaboratively to establish standards for infant mental health.

Having considered the entire framework we are disappointed at the lack of vision and aspiration for the future of infant mental health for **all** children. There is very limited emphasis on enhancing and improving the standard of provision for

specific groups of children i.e. children with disabilities, newcomer children, children from the travelling community.

We do not consider the action plan to be an effective plan – a well-designed plan will consist of actions that you will be doing NOT what has already been done. The plan is scant in detail and actions and omits many programmes and services offered by the voluntary and community children’s sector. How will you know if you have achieved what the Framework has set out to do if you have no goals, outcomes, timescales or completion dates within the action plan?

In responding to this consultation our over-arching concern is to highlight and emphasise that standards for infant mental health must be developed with due regard to Government’s international obligations to respect and promote the rights of vulnerable populations.

We would highlight in particular both the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of People with Disabilities. Both of which have been ratified by the UK Government and, therefore, must subsequently be implemented and delivered on.

In respect of standards for the provision of infant mental health services we would highlight that these services must be grounded in a child-rights framework. The setting of standards for such provision must be underpinned by the four core principles of the UNCRC namely non-discrimination (article 2), best interests of the child (article 3); survival and development (article 6) and respect for the views of the child (article 12).

These four core principles underpin all of the other specific provisions of the Convention. In respect of infant mental health of children, including children with disabilities, we would highlight:

Article 23

States parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.

Article 24

State parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

Article 25

State Parties recognise the right of a child who has been placed by the competent authorities for the purposes of care, protection or treatment of his or her physical or mental health, to a periodic review of the treatment provided to the child and all other circumstances relevant to his or her placement.

The UN Committee on the Rights of the Child has given particular consideration to the issue of the mental health of children. In 2002 the Committee called upon government to strengthen its mental health and counselling services and ensure that these are both appropriate for, and accessible to, young people.

Most recently in 2008 the Committee noted its concerns that many children with a diagnosable mental health problem do not have access to the required treatment and care and that children may still be treated in adult psychiatric wards. In relation to Northern Ireland the Committee noted that due to the legacy of the conflict the situation of children with mental health problems is *'particularly delicate'*.

The Committee recommended that *'additional resources and improved capacities are employed to meet the needs of children with mental health problems throughout the country, with particular attention to those at greater risk, including children deprived of parental care, children affected by the conflict, children living in poverty, and those in conflict with the law'*¹.

It is our strong view that standards for infant mental health provision must aim to address the Committee on the Rights of the Child concluding observations and recommendations, as part of a process of delivering on the guiding principles and relevant provisions of the Convention.

¹ UN Committee on the Rights of the Child (2008) Concluding Observations: UK GB and NI CRC/C/GBR/CO/4 para 56 and 57

Dissemination and Communication

CiNI has particular concerns regarding how user friendly this Framework will be. We would strongly recommend that there is a robust dissemination and communication strategy to raise awareness, knowledge and understanding of the Framework. This should include an explicit 'how to use' guide, with a separate guide developed for parents. It will be critical to ensure the Framework is constantly monitored and reviewed to ensure these remain up to date in line with policy and practice developments. Ultimately the objective of a set of actions must be focused on continuous improvement in the quality of service provision to meet the needs of users.

CiNI is also concerned that there is no consideration within the consultation given to how the Framework will be monitored, that is, how will we know that the action is making a difference, there must be explicit mechanisms to ensure the effective monitoring of the Framework. This may require further mechanisms being put in place to monitor the difference being made.

Affordability

Given the historic levels of under investment in mental health provision we believe there is a need for considerable investment to bring all mental health provision to a level and standard that is acceptable and desirable in terms of meeting the specific needs of children. We would strongly recommend that costings are made in relation to the investment required and would advocate that services receive an equitable and proportionate share of the overall mental health budget. Consideration must also be given to how cost effective programmes are and how they are improving outcomes for all children and young people.

Development of the Infant Mental Health Framework

CiNI understands that the Infant Mental Health Framework has gone through several development stages already. We are interested in exploring precisely how this framework will integrate with other frameworks in the interest of ensuring the production of a suite of standards for services that are accessible and easy to use. We are concerned that with so many frameworks emerging,

encompassing such a vast array, these will simply not be accessible to users, particularly those whose experience multiple barriers in accessing provision.

We would also like to know what work the PHA has done in consulting with parents on this Infant Mental Health Framework to determine their views on both universal services and targeted services.

Multi-disciplinary & multi-agency working

The best outcomes for children and young people can only be achieved through cooperation, coordination and collaboration among government departments and agencies. The challenges faced by children and young people, and particularly our most vulnerable children and young people, are complex. Their needs straddle the areas of responsibility of multiple government agencies and therefore require a holistic and combined approach.

Such cross-departmental working involves integrated planning of programmes and services for children and young people and pooling departmental budgets and resources to achieve shared objectives and key outcomes. Integrated planning helps ensure that all relevant organisations and agencies work closely together towards the same goals, that resources are maximized and services are delivered efficiently, that investment of public funds is focused on impact, and that, most importantly, better outcomes are achieved for children and young people.

It has become apparent that within current political configurations, the commitment to work jointly and collaboratively on issues affecting children and young people remains sporadic and isolated, and is unlikely to develop as standard without an explicit obligation.

It is welcome and important that multi-disciplinary team working and multi-agency working is considered within the Framework, we particularly welcome the involvement of all stakeholders as outlined in the Support path for development.

However, we are disappointed and concerned to see no link made to existing mental health services for children within the voluntary and community sector, particularly Sure Starts.

We would also highlight the need to have clear links to, with regard to provision for children, the regional arrangements for Children's Services Planning which operate as a cross-sectoral and multi-agency approach through the Children and Young People's Strategic Partnership which led by the Health and Social Care Board.

It is also essential that there are clear and explicit linkages, and as relevant, integration, of all service frameworks processes and children's services planning.

CiNI would advocate that there is a need for an explicit action in relation to collaborative working, those accessing and relying on services are entitled to expect that agencies and departments will work together around a framework of common/shared outcomes.

Data Collection

We would like to know the source and date where key statistics within the consultation originated to ensure that the information used is based upon the most up to date data. CiNI wishes to also draw your attention to the gap in availability of data and information. This is an issue which does require urgent attention to underpin the framework to ensure that performance against actions can be robustly measured. With regard to data collection we would highlight the recommendations from the UN Committee on the Rights of the Child. The Committee, in its Concluding Observations on implementation of the Convention in 2002, voiced its concern at the absence of a nationwide mechanism to collect and analyse data on the areas covered by the Convention.

'The Committee recommends that the State party establish a nationwide system whereby disaggregated data are collected on all persons under 18 years for all areas covered by the Convention, including the most vulnerable groups, and that these data are used to assess progress and design policies to implement the Convention. The Committee encourages the development of regular reports in England, Northern Ireland, Scotland and Wales and for the whole State party and the promotion of wide public and parliamentary debate on them in the

*United Kingdom and Scottish Parliaments and in the National Assemblies for Northern Ireland and Wales*².

In addressing information gaps and establishing appropriate data gathering systems it is crucial that data is appropriately disaggregated to allow for identification of possible inequalities and to monitor the position of those groups at particular risk of mental health problems including children with disabilities.

Performance Indicators & Outcomes

What is missing from the Framework is an instrumental tool to implement and deliver the actions. It is important that the framework does not have a narrow or reductionist approach to outcomes or limits actions which only improve outcomes for a select number of children. We need outcomes that help ***ALL*** children with ***TARGETED*** services to intervene for children with additional support needs. There is also a danger that the naming of a limited number of targeted programmes will also narrow the types of services delivered and commissioned for all children, some of which are locally developed and are evidence informed.

There needs to be a commitment to Outcomes Based Accountability to ensure programmes are making a difference in the lives of children. Ellen Taylor-Powell, an expert in Outcomes Based Accountability and Evaluation proffers starting where people are at, to build on existing knowledge and experience as well as ensuring relevance.³ The document is very limited in drawing upon the knowledge, experience and evidence informed practice and work undertaken by the children's sector, including those working with families who have children with disabilities and those working in high levels of deprivation such as Sure Starts. This seems to be a fundamental flaw in the Framework that it limits prior learning and practice and fails to build on what already exists in terms of evidence informed programmes and practice.

² UN Committee on the Rights of the Child (2002) Concluding Observations: UK GB and NI CRC/C/15/ Add. 188

³ <http://aea365.org/blog/ellen-taylor-powell-on-teaching-and-learning-materials-for-evaluation-capacity-building/>

It is our view that the framework should be strengthened and further developed by linking the priorities to specific outcomes. We believe this would greatly assist in being able to use the framework and to report on whether it is working. The link from the framework to Departments' priorities and action plans including OFMDFM Disability Strategy, Child Poverty Strategy, 10 year Children's Strategy, DE Learning to Learn Strategy etc. is crucially important and must be presented in a coherent manner.

Specific Comments on Priorities

Evidence and Policy

It is not clear nor is it explicit within this priority how the PHA will work in co-operation with other Departments, agencies, sectors and academia institutions with responsibility for legislation, guidance/regulations and policy/programme formulation and research in order to further develop the framework.

In the development of a 'local plan in each Health & Social Care Trust' it is not articulated how PHA will work in partnership with the Children and Young People's Strategic Partnership who are responsible for commissioning services and developing local action plans. Nor is there any information on how the local plan will link in with Community Planning and the associated plans from this process.

CiNI welcomes the focus on dissemination of information on key infant mental health issues however we would remind PHA that this is not something that can be achieved by PHA working alone. CiNI believes it is critical that the framework reflects the vital role and contribution of the voluntary and community sector, particularly those in the children's sector. The children's sector is particularly skilled and uniquely placed to support some of the most vulnerable and marginalised families in Northern Ireland. Again we would advocate that there is a need for an explicit commitment in relation to collaborative working within this section of the document.

We would also emphasise the critical importance of the establishment of a robust action requiring the production of accessible information, which is critical in supporting and enabling informed decision making. In relation to information CDSA has highlighted that children with disabilities and their families

consistently report great difficulties in getting the information they need, including information about available support services. CDSA also identified that children and young people with disabilities and their families need independent, timely, relevant and accessible information at key times, for example, at the point of diagnosis and at other major transition points to enable them to make genuinely informed choices.

Moreover, in order to provide user friendly information and up to date evidence for practitioners, parents and the wider population, PHA cannot do this alone, other partners should be involved in this particularly to ensure the information is accessible for parents.

Workforce Development

CiNI welcomes the proposed actions in relation to workforce development. However, we would add that there needs to be an acknowledgement that some additional support and assistance will be needed to further develop the skills of those working within the community and voluntary sector. We would like to see a clear action relating to the development of a workforce strategy to ensure entry, progression and professional development is established and consideration is given to a bursary scheme.

Service Development

CiNI welcomes the proposed key actions which are both based on improving universal services and targeted services. However, there is considerable work to be done to ensure equality of access of universal services. The necessary resources must be identified urgently to ensure that children and their families have timely access to appropriate provision.

There is a need for an action that addresses the need for timely access to appropriate early intervention and preventative services that can reduce the likelihood of crisis situations arising. Children and their families should have access to consistently high quality service provision regardless of the area in which they live.

We also have concerns regarding the omission of local evidence informed programmes from the document, particularly the contribution of programmes developed and run by Sure Starts. From the document PHA is suggesting that if programmes are not done in a certain way or if they have not evaluated to a specific standard then it doesn't count. Taking the example of Randomised Control Trials (RCT), these contribute to the problem of a one size fits all mentality and the ascertainment that a programme which has been developed in another country can be lifted and placed in a society which is different to where it originated. RCT trial participants typically don't represent the population as a whole therefore results from RCTs may not apply more generally to other populations and indeed other countries. The PHA must embrace locally developed programmes and assist organisations in capturing data that evidences that these programmes are making a difference.

It is our view that the PHA should consider conducting focus groups to gain an understanding directly from parents of how universal services are operating, it is only then that a baseline can be established from which to establish actions on what targeted services are needed. The focus groups must take in to consideration the services offered by the likes of Sure Starts. To account for the whole population of Northern Ireland, PHA must engage significantly with parents and mothers to be as a matter of urgency. Evidence informed policy should rely on a very broad diverse base of evidence and views.

Conclusion

CiNI welcomes the recognition of the need for timely and effective provision for children and their families.

It is of concern that baselines have yet to be established in respect of the actions contained within the framework and therefore performance levels cannot be established. Clearly performance levels in respect of actions are a fundamental consideration in determining whether this Framework has improved outcomes. An action plan is about setting goals yet some of what the PHA wanted to action has already been done – why is it still in an action plan out for consultation?

We believe there is a need to include performance indicators in this Framework which are quantitative in nature and would reveal how the Framework is performing from the perspective of children and families. We would also highlight that the views of families are *the* litmus in relation to performance of services. Therefore quantitative indicators must be complemented within the framework indicators. For example a performance indicator must go much further than simply measuring the percentage of infants using a service or number of families who received information; it must also measure the outcomes, by way of determining their effectiveness in improving the lives of infants and their families.

CiNI would highlight that there is one area where a specific action in relation to collaborative working would be particularly welcome to ensure collaborative working particularly between health and education.

CiNI believes it is also essential that the framework is based on evidence informed practice and programmes. We would strongly advocate that a comprehensive review and collation of evidence-informed programmes is carried out. At present it would appear that the PHA is in favour of particular programmes while omitting programmes which can also offer evidence that they are making a difference in the lives of children and families. CiNI would welcome a commitment to a comprehensive review of ALL programmes.

Finally we trust that our submission can usefully inform the ongoing development of the framework. We look forward to receiving a summary of the responses to the consultation and feedback on how this submission has been used to inform work on the framework going forward. We are keen to engage with the PHA on its work to develop an Infant Mental Health Strategy. Again we would emphasize the urgency of ensuring appropriate linkages are made with all those who are working to ensure the best outcomes for children and young people.