Health and Social Care Research & Development Division

Implementing Bamford: Knowledge from Research

Background:

The 2007 Bamford Review of Mental Health and Learning Disabilities ("Bamford") indicated a considerable number of areas of research need. These recommendations for research were further developed in the Bamford Action Plan launched by the Minister for Health, Social Services and Public Safety in 2009.

The Health & Social Care Research and Development Division of the Public Health Agency (HSC R&D Division) worked with users of research (policy-makers, practitioners and commissioners) and with researchers to determine the main priority areas from among the Bamford recommendations. Patients, clients and carers were also consulted as part of that determination process.

The HSC R&D Division then commissioned a series of rapid reviews in five priority research areas to consider the available literature, identify policy implications, examine specified sub-themes and determine key research questions that would address current knowledge gaps.

This document presents a summary of the rapid reviews in each of the priority areas. We trust that this will be suitable for use by policy-makers, practitioners and commissioners. Furthermore it focuses the scope of forthcoming calls for research proposals.

The document is an important initial output to support the implementation of the Bamford recommendations and can be disseminated freely and shared with patients, clients and carers. The full Rapid Reviews are available through the HSC R&D website: www.publichealth.hscni.net/directorate-public-health/hsc-research-and-development

HSC R&D Division
Public Health Agency
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Ministerial Foreword

I am pleased to commend to you these Research Reviews that form a series focussing on priorities identified through the Action Plan that supports the Executive's response to the Bamford Review Recommendations. The Bamford Action Plan (2009-2011) is driving much-needed change in how we care for people affected by mental health or intellectual disabilities. One in six of our population has a mental health need at any one time, and it is estimated that between 1-2% of our population, that is around 24,000 people, have an intellectual disability. In addition, there are many others who have or will develop dementia in the future.

Our highly committed staff who deliver health and social care services have expertise and skills that must be supported by the best up-to-date knowledge. Through research, new knowledge is created. But it is now recognised that, for a variety of reasons, essential knowledge does not always reach the people who most need to use it. The knowledge can vary from better understanding of the causes of poor mental health or intellectual disabilities through to evidence on which services bring about the greatest improvements to the lives of people or their carers. To bring together this knowledge we have commissioned five Research Reviews.

Each Review was written by a team of experts in academia, clinical services and care who have collected the most up-to-date evidence from research done locally or globally. All of the review teams were based in Northern Ireland so we know that the Reviews are relevant to our local situation. The quality of each Review has also been assured through input from experts who are based in other parts of the UK or internationally.

The priority areas addressed by the Reviews are:

- Children & Young People including early interventions, the needs of looked-after children and the development of resilience;
- Patient Outcomes including the measurement of recovery and the capture of patient feedback;
- Intellectual Disability including the management of challenging behaviours;
- Psychological Therapies including how to embed these in services for children and adults across the lifespan and including those with intellectual disability and severe mental health problems;
- Primary Care including aspects important to the prevention, recognition and management of mental health in the community.

As well as providing accessible knowledge and information, each Review has highlighted gaps in our knowledge. We will commission new research projects aiming to fill those gaps.

My final acknowledgement is of contributions made by local people, patients and their carers who assisted in the selection of the priority areas covered by the Reviews and provided extremely helpful feedback to the review teams. Some of those people also serve through their membership of our Bamford Monitoring Group.

I dedicate these Reviews to the people who are affected by mental health or intellectual disabilities. I urge our health and social care staff, education professionals, members of voluntary organisations and others to use these Reviews so that all members of our community may receive the best possible support to live their lives with dignity.

Edwin Poots MLA
Minister for Health, Social Services and Public Safety

Supporting People with Intellectual Disabilities who Challenge or who are Ageing in Northern Ireland.

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Methodology

- Systematic review of literature from the past decade.

Key Findings

- Current policy is to shift away from a treatment model directed at grouping of patients to one of supporting people to maintain or regain a good quality of life within their natural environments and with equality of access to generic and specialist services. However, current implementation lags behind the policy.

- Based on conservative estimates, across all settings in Northern Ireland (NI), 2,228 people with an intellectual disability (ID) (958 children and 1,270 adults) are likely to have behaviours that challenge. These people require significant input from services to maintain them in their own homes.

- Of 16,720 people with ID who are known to services, almost 90% live in their family or a community home; the others live in congregated settings. Studies indicate the longevity in most developed countries has increased for this population dramatically and is now in the range of 60-70 years on average and over the next 30-50 years, more people with ID will live longer – into their seventh and or eighth decades. This places an onus on statutory services to plan for allowing these people to remain in their own homes while taking account of their possibly complex needs for out-of-home placements.

Practice Implications

- Services should be evidence-based and subject to ongoing evaluation. Although a number of interventions (such as behavioural approaches) have a strong evidence base, they are not widely applied in practice.
- Early intervention should be a guiding principle to prevent behaviours becoming long-standing and difficult to treat.
- A functional analysis should always be undertaken to determine the cause(s) of behaviour(s) that challenge and its function for the client.
- Specialist mental health teams for people with ID might be developed and staff trained in understanding the mental health needs of these people.
- Medicines should be used to supplement other interventions rather than as stand-alone treatments.
- Annual health checks that include cognitive and behavioural assessments should be provided for people with ID from as early as 35 years old in addition to the promotion of healthier lifestyles and surveillance of health risks.
- Succession planning should start early; have clear communication and information strategies, identified databases of ageing family carers and older people with ID, identifying those people with ID not known to ID services early.
- Development of high quality older person day-care, respite and recreational services for older people with ID within both ID services and mainstream older people‘s services should be put in place and used.

Policy Implications

- Enhanced education is required for staff and for lay care-givers, perhaps jointly, e.g. on evidence-informed approaches.
- A more flexible range of community-based services, including short term respite breaks, should be available. Day opportunities should be expanded to include education, vocational training, work and social activities.
- Greater co-ordination is required between ID services and mainstream older people's services, including in voluntary and private sectors.
- Specialist nursing facilities are required to manage older people with ID particularly at the mid and end stages of dementia.
- Specialised treatment and assessment units should not be used for long-term care. The development of small-scale, locally-based facilities should be considered.
- Specialist community challenging behaviour teams should be developed across NI with service users and families being seen by agencies as partners in care planning and delivery.
- The same range of psychotherapeutic interventions for mental health that is available to the general population should also be available for people with ID. Attention needs to be paid to service transition between childhood and adulthood.

Evidence Gaps

- How do the differently structured community support teams across the five HSC Trusts compare regarding efficiency and effectiveness for people with behaviours that challenge?
- What alternative innovative day opportunities for people who challenge are offered elsewhere that might most effectively be used in NI?
- How do the experiences of people with ID who use mainstream mental health services compare with the experiences of other people using the same services?
- What are the precursors of behaviours that challenge and mental health problems and how might early interventions prevent or ameliorate their occurrence?
- How and when do older people with ID retire in NI from day centres and employment? What would they like to do when they retire? How might older people with ID and dementia be supported to utilise day facilities?
- Could an effective hybrid support model be developed to address the needs of the older person with ID and their ageing family carers?
- Could health screening instruments be developed for older people with ID to identify the early signs of physical and mental illness and dementia?
- What parental education / support programmes would best support future planning as family carers age?

Advancing Psychological Therapies Research in Northern Ireland.

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Methodology

- Systematic review of literature over the past decade including NICE Guidelines, practice and research recommendations.

- A regional survey of the current provision of psychological therapies being delivered, and research programmes evident, across statutory and third sector services in NI.

Key Findings

- The regional review of psychological therapies research in Northern Ireland identified two overarching clusters of published research related to psychological therapies for children and adults with both mental and physical health presentations (1) psychological interventions in chronic illness and disability in child and adulthood and (2) trauma and mental illness. The research was embedded in partnerships between clinical services and the universities. Better coordination of psychological therapies research would ensure a significant source of expert guidance to inform policy and strategic initiatives.

- NICE guidance and other evidence have established the case for the utility of psychological interventions for both mental and physical health presentations. DHSSPS has committed to improving access to psychological therapies across a range of prioritised populations and groups. Benefits have been recognised for the individual’s quality of life and for the health of the nation through enhanced life expectancy, educational achievement, employability, productivity and savings on healthcare and disability costs.

- A wide range of evidence-based psychological therapies is available in both the statutory and third sectors. Therapies delivered were mapped to patient populations and were largely consistent with evidence-based guidance. The requirement for an outcomes framework for mental health and learning disability services is assuming increasing policy significance and the review emphasised the importance of also commissioning and supporting good quality “practice based” research to serve this strategic need.

Policy and Practice Implications

- There is significant evidence, which continues to expand and become refined, for the utility of psychological therapies not just for mental (e.g. depression, anxiety, psychosis, Attention Deficit Hyperactivity Disorder (ADHD), conduct disorder) but for physical health presentations (e.g. cancer, heart disease, paediatric chronic illness, diabetes). Often these are distilled in NICE guidance. These should be embedded within service developments and care pathways.

- Although there is evidence of *efficacy* of a wide number of psychological therapies, evidence of *effectiveness* when translated into multifarious service contexts (e.g. therapists skilled to different standards; therapies combined for co-morbid presentations) is poor. Current evaluations of treatment effectiveness in NI use disparate outcomes models. An outcomes framework is required to enable standardised judgements and comparisons.

- Increasing longer-term follow-up in psychological therapies research and outcomes monitoring is important. Most recently the importance of follow-up was highlighted when NICE guidance on pharmacological and behavioural interventions for ADHD changed significantly as a direct result of new evidence on the long-term consequences of pharmacology-only treatments.

Evidence Gaps

- There are influential and informative programmes of research into psychological processes which bear directly on the onset and course of psychological adjustment across conditions. There are fewer trials of translating these into consequent psychological interventions.

- Can practice-based research, focussing on psychological therapies outcomes, inform the development of an outcome measure framework for mental health services?

- How can Cognitive Behavioural Therapy (CBT) be adapted for effective use in cases other than adult presentations?

- Can effective research trials of psychological interventions be extended beyond rarefied research contexts, where the aspects of ecological validity for clinical services (e.g. co-morbidity, patient diversity, sub-threshold diagnoses etc.) are often excluded? This could transform traditional service evaluation research into work of generalisable research significance that is translatable into practice.

Improving the Mental Health of Northern Ireland's Children and Young People: Priorities for research.

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Methodology

- Review of systematic reviews.

Key Findings

- The impact of the Troubles may have contributed to poor mental health within Northern Ireland and may limit the generalisability of existing prevalence studies of child and adolescent mental health.
- Stigma and embarrassment, worries about confidentiality and the response they might receive are the most important barriers to health-seeking behaviours in children and young people.
- The most effective models of service which promote resilience in looked after and maltreated children and in children who self harm have still to be identified.
- There are a number of barriers to effective practice by mental health workers, including lack of policy and practice guidelines; inadequate resource allocation; lack of clarity around role boundaries, and concern about undermining their relationship with a patient by raising issues regarding their parenting.

Practice Implications

- Services should ensure they are accessible to young people by making them flexible, affordable, relevant and responsive to their needs.
- Young people should be involved in the development, implementation and evaluation of services and programmes.
- Professionals working with young people should receive adequate and ongoing professional development, supervision and support.
- More services should be provided for maltreated children particularly those interventions based on learning theory e.g. cognitive behavioural therapy.
- Anti-bullying programmes are most effective when they are school based but the timing and duration of these are important to ensure lasting impact.
- Practitioners should use a recognised theory when developing interventions for children of parents with mental health problems, and should link programme components to identified risk factors for this target group identified from a range of strategies and involving multi-agencies.

Policy Implications

- Policies aimed at improving mental health among young people should address young people's wish for self-reliance.
- Anti-stigma campaigns should be targeted with methods appropriate to the needs of different groups.
- There is no 'one size fits all solution' to the prevention of self harm or suicide given the complexity of the topic.
- Screening tools should be rigorously evaluated before implementation in service frameworks.

Evidence gaps

- How many young people in Northern Ireland suffer from moderate or severe mental health problems?
- What are the most effective interventions for helping parents, professionals and communities to identify help-seeking behaviour and overcome the barriers which prevent help-seeking behaviours?
- What are the most effective components of interventions such as anti-bullying, parenting or programmes for children with autistic spectrum disorders, their long-term impact and their cost benefits?
- What interventions would address the impact and prevention of child physical abuse and severe neglect in high risk populations not covered by the Nurse Family Partnership?
- What interventions are the most effective in promoting multi-agency and multi-disciplinary practice aimed particularly at mentally ill young people?
- What works in promoting, sustaining and rebuilding resilience including the applicability and effectiveness of the Penn Resilience Programme in the UK and Northern Ireland?
- What are the challenges facing children and young people who are gay, lesbian, bisexual and transgendered and what are the most effective and appropriate interventions?
- What are the most effective interventions for preventing suicide and reducing self harm in young people?
- What is the prevalence of parental mental health problems in Northern Ireland and what are the particular needs of fathers? What treatments for parental mental health determine differential effects on children?
- What services have the best outcomes for children and young people regarding their experiences and differences they make to their lives?

Patient Outcomes in Northern Ireland: The best methods for measuring recovery from mental illness and capturing feed-back from patients to inform service improvement.

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Methodology

- Rapid reviews and a systematic review of literature.

Key Findings

- Recovery involves more than the absence of mental illness.
- Recovery is a personal experience – it cannot be 'done to' a person.
- The routine assessment and collection of recovery outcome data is necessary to support recovery.
- A recovery orientation needs to be a permeating organisational value.

Practice Implications

- Three measures of personal recovery are recommended for consideration for use: The Questionnaire on the Process of Recovery (QPR); the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS); the Mental Health Recovery Star (MHRS).
- Two measures of recovery orientation are recommended for consideration for use: INSPIRE and the Recovery Context Inventory (RCI).
- No family member-rated measures of recovery orientation are suitable for recommendation.
- No mental health professional-rated measures of recovery orientation are suitable for recommendation.

Policy Implications

- Each person who uses mental health services should assess routinely their experience of personal recovery in order to identify how much they are recovering and to what extent they are experiencing factors such as social inclusion and well-being.

- The recovery orientation of a mental health service should be judged by service users and this information should be used to inform action planning with users as well as driving service developments.

- Routine collection of recovery outcome data must be prioritized, resourced and informed by approaches, experiences and lessons from other countries.

- Organisational transformation is required in order to develop a recovery orientation.

Evidence Gaps

- How can information from recovery outcome measures be used to increase and improve service support for recovery?

- How might effective feedback delivery systems be implemented cost-effectively into routine practice?

- What is the relationship between recovery outcomes and traditional clinical outcomes?

- What measures of recovery orientation from the perspective of a family member and a mental health professional respectively might be recommended unreservedly for routine use in Northern Ireland?

Mental Health in Primary Care: What aspects of primary care are effective in the prevention, recognition and management of mental health issues across the lifespan; for whom do they work, in what circumstances and why?

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Methodology

- Realist Synthesis Approach to identify and evaluate the literature pertaining to primary care and mental health.

Key Findings

- Mental health disorders in NI are highly prevalent, lying at the upper end of prevalence estimates from other countries around the world. Age-at-onset information suggests that young children and adolescents should be the main priority for policy and interventions.
- There is considerable variation in practices relevant to particular psychiatric conditions and across client groups despite the existence of a variety of tools and processes for mental health assessment.
- There is a need for the development of targeted strategies which reduce stigma associated with mental disorders with the aim of increasing public awareness, treatment seeking behaviours and prevention.
- Increased GP awareness of prevalent mental health issues is required including those associated with the Troubles and suicide trends.

Practice Implications

- Mental health screening using validated tools including those for suicide ideation, dementia, depression and alcohol abuse, should be more widely considered and employed in primary care.
- Interventions with an established evidence base which can be implemented at a primary care level across all age groups include guided-self help, Computerized Cognitive Behavioural Therapy (CCBT) and Cognitive Behavioural Therapy (CBT) to reduce the symptoms of depression.
- There is support for the development of 'case management' and 'collaborative care' models for the management of mental health disorders in primary care.
- GPs and 'high risk' groups should be furnished with information detailing the risk factors associated with mental health disorders to aid early detection.
- Given the clear associations between mental illness and poor physical health, it is imperative that primary care professionals recognize physical healthcare needs in their approach to the management of treatment for individuals with mental health problems.

Policy Implications

- Primary care services should provide comprehensive targeted assessments based on standardised criteria that are focused on maximising treatment options and minimising risks.
- Mental health diagnoses should be based on comprehensive assessment that has followed standardised criteria.
- Primary care services should build on and work with the local authority community services, with colleagues in secondary specialised services, and services in the non-statutory sector, in order to ensure continuity of care across all phases of care and service delivery.
- Primary care teams should work in partnership with carers.
- Services for adults with mental health needs should work with service users and others significant to them in a way that ensures their wishes, decisions and treatment options are facilitated in an atmosphere of trust and respect.
- Opportunities for mental health promotion should be taken and integrated into the role functions of all members of the primary health care team.

Evidence Gaps

- More research is needed into the available skills in primary care teams, including the effectiveness of GPs in delivering treatment and appropriate tools for use to improve detection and treatment within primary care settings.
- Research studies that compare and contrast the effectiveness of different models of care for General Anxiety Disorder are recommended and should include consideration of the co-morbidity with physical and mental health problems and the cost-effectiveness of low and high intensity interventions and their impact; in particular to explore the further potential of CBT.
- Further research should be undertaken into the effectiveness of primary care led preventive work with high risk children and young people (e.g. children with chronic illness).
- More work is needed to standardise approaches to the measurement of mental health outcomes.
- There is a need for greater understanding of partnership-interventions that enable service users/carer participation in decision making and the resulting care outcomes.
- Additional research is required to determine the level and effectiveness of GP training strategies in mental health in a Northern Ireland setting.

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