Response from the All Party Parliamentary Group on Complex Needs and Dual Diagnosis to the NHS Future Forum as part of the second consultation
November 2011

Integration and people with complex needs and dual diagnosis

Introduction
This submission is made on behalf of the All Party Parliamentary Group on Complex Needs and Dual Diagnosis (APPG), Co-Chaired by David Burrowes MP and Lord Victor Adebowale CBE, a member of the NHS Future Forum.

Lord Adebowale circulated a call for information amongst the Group’s supporters in regards to the latest Future Forum consultation on integration. He asked supporters to feed in the top 5 challenges, barriers and solutions in regards to integration as it does or could apply to people with complex needs and dual diagnosis.

This response cannot be taken as the views of each member of the Group but draws from the shared experience of the experts working in the field of dual diagnosis who regularly attend the APPG meetings and the specific submissions made to the Group by representatives from:
- NHS South West
- The Centre for Mental Health
- The University of Southampton
- Hereford PCT
- Hertfordshire County Council
- Revolving Doors Agency
- Devon and Cornwall Police
- Northumberland Tyne & Wear NHS Foundation Trust
- Academic Services for Public Management and
- Turning Point, which is the secretariat for the group.

People with complex needs and Dual Diagnosis
The group of people the APPG, and our submission, focuses on are those loosely defined by their chaotic lifestyle, complexity of need and co-morbidity of a range of conditions including; mental health, learning disability, substance misuse, physical disability, homelessness and/or long term conditions. They pose a challenge to commissioners and providers of services across a number of agencies for reasons including:\1;:
- Reluctance to engage with mainstream services
- Risk of offending.
- Potential cost of identifying and meeting their health, social care, housing, benefit and debt, education and rehabilitation needs.
- Low demographic prevalence but high cost.
- A workforce lacking the required skill set to cope with the complexity of need
- The need to increase access to appropriate services – often specialist, non-statutory services
- The realisation that one agency alone cannot address all the presenting issues

\1 List based on one provided by NHS South West
Our response
The Group’s response does not take each question in turn. Rather we outline the current barriers to integration and a number of solutions that address these barriers to ensure integration is the norm not the exception. This includes the perspective of health, social care and the criminal justice system.

Making integration work
The current system is failing people with complex needs due to a lack of understanding; a lack of integrated services; and a culture amongst health professionals which is ambiguous towards the needs of people who come under this category. This means they experience unnecessary exclusion; confusion; do not access services they need; and have escalating needs that when they do present to services are more complex and costly to address.

Although the new structures, as set out in the Health and Social Care Bill, are embedded in a desire to achieve greater efficiencies and collaborative working between professionals and patients, they could potentially fragment a system already lacking integration. There remain fundamental gaps in ethos, action and appropriate incentives which threaten to undermine any attempts to integrate the future health and social care system beyond its current state.

If the future system is to really improve health outcomes and reduce inequalities it needs to start with those furthest away from the centre who often only use health services in a crisis, and take action to ensure the Government’s pledge to ‘improve the health of the poorest the fastest’. It can only do this by breaking down the barriers that inhibit integration from being an integral part of business as usual.

The challenges
As previously stated there are a number of challenges that continue to be addressed in pursuit of an integrated system of service delivery.

For this response we have focused on challenges that broadly fall into three areas:

1. Service delivery (including commissioning)
2. Workforce
3. Systems

1. Service delivery
Integration is integral to good, high quality service delivery. To achieve ‘good’ requires services to be flexible, to take a coordinated approach to funding, commissioning, staff training and to work across boundaries that have for too long restricted teams from working together.

- **Flexibility:** There is currently a severe lack of flexible services on offer due to a range of reasons including the way services are commissioned; paid for and the outcomes this is linked to; delivered; designed and limited by too specific outcomes.

  For the individual, flexible services support the person to get on with their life with ‘support that responds to their current needs regardless of what organisation is providing them; that change as their needs change; and that mean they do not have to go from place to place seeking support or explaining their situation to a succession of different people and agencies.’

- **Commissioning:** This has one of the most fundamental impacts on whether or not services are integrated or not. In areas where joint commissioning arrangements are in place, service users experience more seamless care between agencies because there is...
an understanding, and practical application, of how they need to interact ‘based on a common framework for understanding needs’. In most areas, however, the commissioning structure in the eyes of many is not fit for purpose and people fall through the gaps in service provision because of a lack of commissioning that addresses the whole needs of the individual.

Some specific examples of where this lack of coordinated commissioning is most evident are:

- People with a dual diagnosis of substance misuse and mental health issues
- People with mental health conditions and long term conditions
- Offenders with mental health issues and/or a learning disability

Although it can be potentially expensive to establish, integrated care pathways have been proven to save a significant amount of money, particularly for people who have multiple needs. They also improve individuals’ experience, navigation between services and the outcomes they ultimately achieve, either in terms of improved health or ability to manage their own care and support needs effectively.

The role of commissioning therefore is central to breaking down the barriers that continue to exist within service design and delivery. The new structures being developed, particularly Health and Wellbeing Boards and the clinical networks that will offer expertise to Clinical Commissioning Groups on specific conditions, offer a huge potential to ensure that different commissioners are bought together to share, understand and support the needs of a community. It is upon this understanding that a common definition of commissioning could be based to ensure a more consistent approach not only between different types of services but across the country.

The definition of commissioning Turning Point supports is one where commissioning is ‘the means by which you understand the needs of an individual and/or a community such that you can build a platform for procurement.’ Based on this understanding, services should then be commissioned, or decommissioned where appropriate, to provide interventions and/or support that meets this need.

- **Early intervention:** The other significant contribution commissioning can make to integrating services is by focusing, and committing resource to early intervention.

The commitment to early intervention supports a more integrated approach by considering the range of support an individual requires to meet their needs and to stop them escalating further. One example where this could bring clear benefit is where someone is homeless. ‘Despite the high levels of ill health and multiple conditions it is rare that there is a targeted NHS response to the needs of homeless people, particularly in primary care. As a result homeless people have a much higher use of emergency services than the general population and higher use of acute hospital services.’

A 2010 Department of Health report found that homeless people attended A&E five times more often than the local average and inpatient costs were eight times higher than the comparison population. Early intervention for people with mental health problems (particularly by the age of 14) has also been proven to have significant benefits for the individual and later costs associated to a person’s mental ill health if support is not commissioned early enough, for example lost working days, poor physical health or potential substance misuse.

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4 Dr Patrick Roycroft, Dr Barry Ingham, Dr Ewa Downie, Dr Patrick Keown, Tracy Kerry, Lesley Dowell. Michael Humes, Valentina Short, David Crawford & Jan Dobson. NHS Northumberland, Tyne and Wear Foundation Trust submission to the APPG
5 St Mungo’s
6 Office of the Chief Analyst, Healthcare for Single Homeless People, Department of Health, 2010
• **Coproduction**: Another barrier to overcome in terms of service delivery is that too few services are designed or delivered in partnership with the individual. Enforcing services on people does not encourage participation or understanding by the individual as to why their support is delivered in a certain way. Providers need to engage patients as the agents of change, particularly those with complex needs or long term conditions. It needs to be acknowledged, however, that people with complex needs often do not have the inclination to engage, therefore ‘any potential sources where interventions can be broached, for example police stations and A&E, should be invested in’.

• **A range of services**: The other barrier to integration is sometimes the lack of service options in a locality, for example lack of step down provision for people leaving secure mental health services. Without appropriate services in place care pathways cannot be integrated without large gaps existing or people being forced to access services out of area.

2. **Workforce**

There are a number of issues relating to the health and social care workforce that create significant barriers to integration. For people with co-existing mental health and substance misuse issues, for example, ‘guidance, management structures, operational policies, philosophies, commissioning arrangements, government targets and training and education remain obstinately separate.’

Each of the following need to be addressed if care and support services are to be integrated around the individual:

• **Attitude**: Whether we talk about integration around providers or around patients, ‘integrated care is attitudinal’. It depends for its effects on adopting an approach that recognises the contexts of care that call for integration. This can be considered from the perspective of the patient, the clinical pathway and the governance of care. For example: integrated care from the patient’s perspective could include prescriptions being approached as part of an integrated care plan rather than as serial disconnected interventions, and realising the coordinating potential of the patient in managing their care and the capacity of carers to help integration. In terms of Governance this can integrate and manage risk simply, manage care boundaries and can either integrate relationships or exasperate conflict.

• **Responsibility**: As the Revolving Doors Agency and others often highlight, there is currently no one person or agency locally or nationally responsible for people with complex needs, as defined above. Due to their multiple needs they often do not meet eligibility criteria and therefore fall through the gaps in service provision. They are also often excluded from overarching frameworks that ensure continuity of care such as Safeguarding of Vulnerable Adults. This means that ‘victimisation, neglect and premature death often go unchallenged. A lack of local responsibility and accountability reduces incentives to provide effective and coordinated support.’

A lack of responsibility particularly affects people with mental health conditions as they move in and out of custody. This could be exacerbated with the splitting of commissioning between the NHS Commissioning Board and the Clinical Commissioning Groups for prison health care and secure mental health.

Responsibility for conditions may be unequivocally a professional one (the consultant’s name is on the chart at the end of the hospital bed) and with this authority and status, as well as the function of the speciality in the care providing relationships. Therefore the role

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7 Andrew Brock Devon and Cornwall Police and NHS NTW submissions to the APPG
8 Stephanie Powell, Hereford PCT submission to the APPG
9 Graham Munn, Joint Commissioning team, Hertfordshire County Council submission to the APPG
10 Professor Andrew Gray submission to the APPG
11 Revolving Doors Agency Future Forum submission to the APPG on Complex Needs and Dual Diagnosis
of the GP should, and was once, a role as a coordinator of care; one that integrates care and support across agencies\textsuperscript{12}.

- **Partnership working:** Where different services trust each other and have well-established ways of working together integration can flourish. This is, however, predicated on good quality relationships between individual workers within local systems and often initiated by a forward thinking leader who drives these relationships. The potential to lose the momentum gained over the past few years, both in relationships forged and personnel skill and expertise, increases with the fragmentation of services and lack of national guidance. This could become an unintentional, and unwanted, consequence of the proposals to localise services without putting the structures in place to ensure national priorities are translated to local delivery.

- **Training, education and workforce development:** Skilling the workforce is crucial. Competencies in dealing with dual diagnosis need to be developed. Standards need to be set for what a competent workforce looks like and the training programme required to achieve this\textsuperscript{13}. This links to the fact that many people with complex needs do not proactively engage with services and therefore staff need to recognise this, understand why and take an assertive approach to engagement.

- **Language:** Different providers using different language create significant barriers to integrated working. The NHS tends to talk a different language than local government and civil society organisations. The NHS is primarily driven by a ‘medical’ narrative and thinks in terms of disease. Local Government does not think or operate in this way, rather in terms of processes, policy, legislation and infrastructure\textsuperscript{14}. Without a common language teams will continue to see the differences between them before seeing the similarities and shared priorities.

3. **Systems**

Different organisations have a multitude of different systems, targets and outcome measures. This means that services that need to cooperate do not and cannot without significant effort on all sides. This is often the case between the NHS and social care partners where different information, billing, payment and staffing structures all impact on each party’s ability to work in partnership. These system barriers can, and are, overcome. However challenges remain and there are changes that could be made at a national and local level that could make this easier.

- **Information:** The integration of information systems, particularly between the NHS and the Any Qualified Providers entering the market, will go a long way to integrating services for people supported by multiple agencies. This will reduce the need for the individual to repeat information unnecessarily and will link providers around the needs of the individual, rather than working in parallel to each other.

- **Funding:** One issue that promotes silo thinking is diagnosis, or the categorisation of people according to symptoms. This causes problems when funding follows this categorisation. The lack of pooled funding is one of the most significant barriers to achieving integration. People’s needs are constantly changing and having separate funding streams does not cater for the flexible approach to care and support that is needed. Instead it results in the fragmented services that cost the overall public purse more.

For example, establishing a commissioning structure that pooled mental health, substance misuse, health and social care budgets dedicated to the purchasing of dual diagnoses services would be more effective than current disparate arrangements. The same principle can be applied to pooling funding from criminal justice agencies (including

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\textsuperscript{12} Professor Andrew Gray

\textsuperscript{13} Graham Munn, Joint Commissioning team, Hertfordshire County Council submission to the APPG

\textsuperscript{14} Dr Nick Maguire, Chartered Clinical Psychologist, University of Southampton
Police and Probation), health and mental health, substance misuse and housing. This would focus responsibilities, accountabilities, desired outcomes and development of interventions\(^{15}\).

With separate and often competing budgets, there remains no incentive to share resource or agree locally to coordinate services. It is often the case that investment in one area reaps benefits in others, however this may be disproportionately higher than the savings made by the funding service. One incentive, as proposed by Revolving Doors is to allow local areas to keep the savings made through coordinated action, based on work around ‘Justice Reinvestment.’

The introduction of **Payment by Results (PbR)** for people with complex needs (including current pilots in substance misuse, the criminal justice system and mental health) could look at how the role of separate partners impacts on the outcomes achieved and how they should be paid for this activity. However currently different PbR models are being developed separately by the NHS and for the Work Programme. Without a payment system that integrates funding and outcomes, the necessary incentives to encourage providers to work with people with complex needs will not exist.

**The Solutions**

Below are a range of solutions suggested by the organisations that have fed into this response. These draw from a breadth of experience across health, social care and criminal justice, demonstrating how three ‘different’ sectors are very clear and consistent in how to take this agenda forward for people with complex needs.

**Named individuals\(^{16}\):** Specific roles should be nominated in national government and in every local area to be responsible for this group of people broadly defined by their complex needs. They would be accountable for the provision of effective support for this group and evidence in support of this. They would be required to develop a strategy to address the needs of these individuals and monitor which services are providing them with support. They could then be held to account much in the same way as Clinical Commissioning Groups will be around their annual reports. This responsibility could rest with the Director of Public Health or a named person within the Health and Wellbeing Board.

**Eligibility:** People with complex needs must be included within the eligibility criteria for social care services or at least an initial Community Care Assessment to gauge how best to meet the individuals needs in partnership with health, public health, housing and other support services.

**Integration embedded in new structures:** Rhetoric around integration set out in the Health and Social Care Bill needs to be assured through the implementation of guidelines, commitments and practice. This needs to guarantee that each part of the system works together in a proactive and integrated way and that this is evidenced. The HWBBs will have a role in encouraging integrated working, but it needs to be a responsibility owned by each health, social care and public health lead who is then held accountable for any failure to work together.

**Expanding the use of Community Budgets:** The majority of the organisations that responded to the APPG support the expansion of Community Budgets as currently applied to families with complex needs and applying this model to individuals in the form of a pooled budget.

**Responsibility for people in custody:** It is essential that local and national commissioning is closely linked and that Clinical Commissioning Groups maintain responsibility for people from their localities while they are in custody to ensure step-down and discharge

\(^{15}\) Graham Munn, Joint Commissioning team, Hertfordshire County Council submission to the APPG  
\(^{16}\) Revolving Doors Agency and Hereford PCT submissions to the APPG
arrangements are in place to move people through services quickly. The risk otherwise is that people whose needs are most complex, and costly, will continue to experience inconsistent care, gaps in provision and delayed discharges when they are at their most vulnerable.\(^{17}\)

**Wraparound services:** The wraparound approach brings together the full range of services a person requires to offer them the best possible support to maintain or regain their independence. This means integrating with schools, housing providers, employment, welfare services, the police and many others to ensure their collective efforts are pooled to create the biggest impact.\(^{18}\)

**Certification of engagement:** To ensure that services are commissioned based on an understanding of individual and community need, there should be a certification process for Health and Wellbeing Boards (in relation to the formation of the JSNA) and the Clinical Commissioning Groups (CCGs) to evidence that they have indeed engaged, understood and responded to these needs through the provision of services. This could come in the form of a kite mark which would be lost if sufficient evidence was not available as part of the CCG annual reports.\(^{19}\)

**Strengthening the role of Health and Wellbeing Boards:** Strengthening the powers, scope and support for HWWBs would enable them to fulfil more of their potential to act as ‘glue’ between a range of services in their localities.\(^{20}\)

**Integrating systems:** Health and Wellbeing Boards should be tasked under its responsibility to encourage integration, to look at the systems different organisations use and where the pressure points are. There could then be a workstream of the HWBBs to look at getting rid of these barriers so the system as a whole can reap the inevitable efficiency savings that would follow. This would likely focus on determining standards and pathways for integrated care.\(^{21}\)

**A multi-skilled workforce:** A training programme to achieve a competent workforce to recognise, understand and support people with complex needs and dual diagnosis. This is particularly relevant for frontline staff in A&E, the police and prison staff.

**Analysing needs in terms of behaviour:** Funding follows needs however currently, based on diagnosis, this does not adequately cater for people with multiple complex needs or a dual diagnosis. Analysis of needs based on behaviours which are problematic, however, could support people to be treated for the emotional, cognitive and historic factors that underpin them. A service that takes account of behaviours and does not blame people for those behaviours, and is not limited to categories creates a ‘good’ service.\(^{22}\)

**A shared language:** We need to establish a common language, or at least formulate the differences and the effects of those differences, on the creation of integrated services and partnerships across health, social care and public health. Without a shared language the Health and Wellbeing Boards, where each stakeholder will come together, may struggle to formulate a coordinated approach to care and support.

**The Criminal Justice System as a partner:** There are various reasons why the different levels of the criminal justice system should be linked into the wider health and social care system to ensure that the gaps that exist are minimised, and the advantages that partnership working with the police, courts and prisons can achieve are utilised. Police Custody, for example, is an ideal example where the person is a captive audience and in a vulnerable position due to having their liberty taken from them.\(^{23}\)

\(^{17}\) Revolving Doors, Centre for Mental Health and Turning Point
\(^{18}\) Centre for Mental Health and Andrew Brock, Devon and Cornwall Police
\(^{19}\) Turning Point
\(^{20}\) Centre for Mental Health
\(^{21}\) Professor Andrew Gray
\(^{22}\) University of Southampton
\(^{23}\) Devon and Cornwall Police
Case study: An evidence based framework for bio-psycho-social needs

Northumberland, Tyne and Wear NHS Foundation Trust (NTW) have developed a framework to help professionals involved in working with dual diagnosis to assess and understand people’s needs and can be used to bring bio-psycho-social factors together for multi-disciplinary teams.

Key features:

- Formulation should always be assembled collaboratively with the service user wherever possible; it should be dynamic and will change over time as the service user’s needs change and as they make progress.

- Using such a formulation, together with a Recovery focused outcome tool such as the Recovery Star, will guide the intervention for the multi-disciplinary team and the named nurse when care-planning. It can help a team decide when to access specialist/external input.

- Psychologists, Psychiatrists, Nurses and Occupational Therapists are developing and researching a framework within NTW and are finding it helps in:

  1. achieving a consistent team approach to intervention
  2. helping them, service user and carers to work together
  3. gathering key information in one place
  4. generating new ways of thinking
  5. dealing with core issues (not just crisis management)
  6. understanding attachment styles in relation to the service as a whole
  7. supporting each other with service user who are perceived as complex and challenging
  8. drawing on and valuing the expertise of all team members
  9. challenging and unfounded ‘myths’ or beliefs about service users
  10. reducing negative staff perceptions of service users
  11. processing staff counter-transference reactions
  12. helping staff to manage risk
  13. minimising disagreement and blame within the team
  14. increasing team understanding, empathy and reflectiveness
  15. raising staff morale
  16. communicating meta-messages to staff about hope for positive change.

Contact
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24 Dr Patrick Roycroft et al, NHS Northumberland, Tyne and Wear Foundation Trust