What should services in the community provide for adults with intellectual disabilities and mental health problems?

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Degree: MD (Res) by Publication

Title of Thesis: What should services in the community provide for adults with intellectual disabilities and mental health problems?

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Title of MD (Res) by Publication:

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Abstract

Background People with intellectual disabilities (ID) and coexisting mental health problems are among the most vulnerable and disadvantaged in society. Services for them vary widely and there is a great need for their evaluation. A preliminary study using clinician interviews had sought to clarify what the essential features of Assertive Community Treatment might be for people with ID. It found a lack of understanding and agreement about this specific service model. A literature review of community services' research found no consensus even on what should be provided routinely. Aims The primary aim was to investigate opinions of clinicians, service users and carers regarding community service provision for people with ID and mental health problems. The secondary aim was to then test one of the service components widely considered to be essential in an exploratory study. Method Three sequential studies of opinions regarding services were carried out: (i) a comparison of focus groups of service users, carers and clinicians, (ii) a Delphi survey of clinicians and (iii) in-depth expert clinician interviews. One service component was then selected for further exploration. Results A wealth of opinions was elicited regarding community services and a number of key themes were identified. One service component discussed repeatedly was the provision of crisis information for service users. A feasibility study then demonstrated that it was possible to produce crisis information in an accessible form which people with ID valued and wanted to carry. Conclusions The findings should help generate research hypotheses and to provide a foundation for future evaluation studies of services and their components. The findings of the crisis information study will inform the planning of a larger, randomized controlled pilot study of accessible, portable crisis information. The limitations of this research and its possible future directions are discussed.
1. Background

1.1 Terminology

The term *intellectual disabilities* (ID) will be used in this MD (Res) as it is becoming the preferred term for researchers in UK academic publications. The term corresponds to both *mental retardation* (World Health Organization, 1992) and *learning disabilities*, the latter being still the most widely used term clinically in the UK. Intellectual disabilities are usually defined as (i) significant impairment of intellectual functioning with an intelligence level at least two standard deviations below the mean on a standardized test together with (ii) significant impairment of social functioning and (iii) onset within the developmental period.

1.2 Introduction

In the UK, care for people with intellectual disabilities (ID) is now overwhelmingly provided in the community. It is recognized that people with ID are more likely to have additional mental health problems than people of typical intelligence (Cooper et al. 2007a). For example, they are estimated to be around three times more likely to develop schizophrenia (Turner *et al.* 1989; Cooper *et al.* 2007b). Severe mental health problems in people with ID cause enormous human suffering as well as large financial costs for health services (Bouras & Holt, 2004). *Valuing People* (Department of Health, 2000) recognised the role mental health problems play in the social exclusion of people with ID. Effective community services for this group
would be a valuable step in improving their social integration and quality of life and easing carer burden.

There have been a wide range of service models in the community for people with ID and mental health problems (Bailey & Cooper, 1997). The community services in the UK have varied widely in constitution and purpose and research into their effectiveness has been neglected (Bouras & Holt, 2004; Chaplin, 2011). A few studies have suggested that community-based specialist services may be effective (e.g. Coelho et al. 1993; van Minnen et al. 1997; Meisler et al. 2000; Hall et al. 2006; Hackermann et al. 2006). Many of these studies were summarized in a literature review by the author at the beginning of this MD (Res) (Hemmings, 2008).

Research into community services has continued to be localised, looking at various types of service models in specific locations within countries such as the UK, North America, Holland and Australia. There have been few multi-site studies and as services vary so much it is not been easy to compare the findings (Hemmings, 2010). Many of the studies have been retrospective with their increased potential for bias. Some explored how existing services were being used rather than the actual needs of the service users. Many of these earlier studies were conducted using idiosyncratic diagnostic criteria and outcome measures and so have not been able to make use of the improvements seen in rating instruments and assessments for people with ID over recent years (Hemmings et al. 2013a). Meanwhile generic mental health services’ research has frequently excluded adults with ID (Lennox et al. 2005).
Service users with ID and coexisting mental health problems have not generally been given access to the same mental health service developments as those in the non-intellectual disabled population. This is arguably a form of discrimination and it has been argued that a human rights approach should be applied to the need for mental health service development for people with ID (Evans et al. 2012). There has been some debate regarding how specialist services providing care for people with ID and mental health problems should evolve. One question has been whether there is a need for more intensive services for some people who may be at increased risk of distressing and costly inpatient admissions? Following the introduction of intensive service model innovations such as assertive outreach, home treatment and crisis resolution for those with severe mental health problems in the general population, research interest began to grow in more intensive community services for those with ID and coexisting mental health problems (Hassiotis et al. 2003).

1.3 Assertive Community Treatment

In the general population there was support for a specific service model known as Assertive Community Treatment (Stein & Test, 1980). This model was originally developed in the USA and based on intensive case management in the community of people with severe mental illnesses at increased risk of hospitalization and disengagement. The characteristics of ACT included smaller individual caseloads for staff, flexible working with extended hours and community visits and help with daily living, with the multidisciplinary team being the source of skills as far as possible rather than providing brokerage with other agencies. The model was associated in early studies in the USA with a range of beneficial outcomes including reduced in-
patient care and loss to follow-up and improved social functioning (Stein & Test, 1980, Marshall & Lockwood, 1998).

However UK research studies did not find the model of Assertive Community Treatment to be as strikingly effective compared to standard services as the initial USA studies had been (Tyrer, 2000a; Kent & Burns, 2005, Killaspy et al. 2006). It has been argued that one reason why this model appeared so successful initially was that, compared to the UK, community mental health services in the USA had been very underdeveloped up to its introduction (Tyrer, 2000a). Even though the extent of the benefits of Assertive Community Treatment in the UK has been controversial (Killaspy et al. 2006) the use of 'assertive outreach' teams using several features of the original model has been UK Government policy (Department of Health, 2001).

1.4 Assertive Community Treatment in Intellectual Disabilities

There was accordingly debate whether 'assertive outreach' for people who have both ID and mental health problems would be an effective service delivery model. For example, Cowley et al. (2005) suggested that improvements of community care might decrease the need for some inpatient admissions and called for evaluations of assertive outreach-type community services in people with ID. This call was supported by the earlier finding of the UK-700 study that people with borderline levels of intellectual functioning spent less time in hospital if they received intensive community care compared with standard community care (Tyrer et al. 1999). It was suggested that those with lower IQ might have been helped more because they have
greater problems expressing their needs and they tend to require a more assertive approach on the part of the clinicians (Hassiotis et al. 1999; Tyrer, 2000b).

A few Assertive Community Treatment-type services for people with ID have been set up in the UK, but they have varied widely in their configurations (Hassiotis et al. 2003). For example, some services favoured a “team within a team” model whereby a few professionals tried to adopt a more intensive or assertive approach whilst being part of a wider community ID team. Other services followed a separate team model. To confuse matters more, some of these Assertive Community Treatment-type services were aimed at people with ID and coexisting challenging behaviours rather than coexisting severe mental illness.

Both Martin et al. (2005) and Oliver et al. (2005) reported exploratory studies of what they claimed were forms of Assertive Community Treatment for people with ID. Both studies found no major differences in outcomes for service users between the group receiving more intensive services and those receiving a standard service. Problems in developing and evaluating Assertive Community Treatment-type models for people with ID have included fidelity to the original Assertive Community Treatment model and a lack of distinction between the experimental and control services (Chaplin, 2006). In addition, they were typically serving persons with a wider range of mental health problems than those for whom Assertive Community Treatment was originally intended (Chaplin, 2006).

The first (preliminary) study (see Appendix III: i) of this MD (Res) used interviews of specialist ID clinicians involved in four UK services that claimed to be providing
Assertive Community Treatment-type care in order to elicit staff opinions on the model (Hemmings et al. 2008). It found much inconsistency regarding both the understanding of the original model and how the participants thought an Assertive Community Treatment model of care should be applied to people with ID (see Part 4.2). For example, some respondents saw service users as needing the support of an Assertive Community Treatment in ID service as a standalone service endeavouring to have a range of functions including supporting housing and employment needs and being fairly independent from other services, whereas others saw such services as being less ambitious and smaller scale services that would support the generic (or ‘mainstream’) mental health services.

These findings showed that it was not possible to research adequately whether service users with ID and mental health problems might benefit from Assertive Community Treatment when there were ongoing problems with the definition and implementation of this model as well as a lack of specialist professionals that had close knowledge and experience of it. It was not possible to know whether adults with ID and mental health problems might benefit from any other newer service models either when there existed no consensus about what such models should consist of for this service user group or indeed agreement even of what standard or routine services for them should provide.

1.5 What should community services provide?

The preliminary MD (Res) study (see Appendix III: i) of opinions of Assertive Community Treatment for people with ID and mental health problems thus revealed
the need for research in community services to avoid making untested assumptions regarding services. This conclusion supported a previous call which had been made for qualitative research to identify which specific components of services are considered helpful for people with ID and mental health problems (Chaplin, 2006). It is potentially more fruitful to explore the effectiveness of specialist community-based services for people with ID and mental health problems without using the terminology of specific service delivery models about which there remains a great deal of inconsistency and controversy.

It is important that research looking specifically at community services for those with ID and mental health problems is informed by the insights gained from community mental health research in the general population (Catty et al. 2002). For example, Burns et al. (2006) have argued there is a need to research the individual components of different models rather than to just make comparisons of different service configurations. Research focusing on service users with ID who have more severe mental health problems would best complement research on community mental health services in the general population (Chaplin, 2006).

In the first place therefore it was necessary to gain evidence of what key stakeholders thought services in the community ought to be providing. A consensus of opinion regarding the essential components of community services for people with ID and mental health problems needed to be established using rigorous methodologies. This research had to be informed by the three key groups of participants in service provisions: service users, carers and staff. Systematic methods of assessing agreement on which individual service components are essential were required. In
the first instance qualitative methodologies were used in which participants would not be asked to give their opinions of specific service models. In this way standardised versions of what services should comprise could potentially be agreed upon to be used as a starting point in future evaluative service research and to guide the development of any new services. The essential community service components, once identified and agreed, could be examined further in feasibility and/or pilot studies in preparation for much larger, randomized controlled studies. Research was also necessary to find if there any particular subgroups of service users with ID and mental health problems who would be most likely to benefit from more intensive (or more ‘assertive’) community services.

Any new service models must always be able to be clearly defined and implemented with consistency and thus be amenable to systematic evaluation to ensure effectiveness and value for money. The ultimate aim of this field of research should be to undertake studies of the effectiveness of different services. However as yet there is no agreed standard service for people with ID and mental health problems that can be used to test against any innovative services. Therefore an essential foundation for evaluating the effectiveness of services was an investigation of what those services should include and provide. There is a great need ultimately for evaluation studies of existing and new services for people with ID and mental health problems but it is crucial that this future research has the proper basis to ensure its validity.
1.6 The Medical Research Council’s Framework for Complex Interventions.

Studying the composition of effective community services is immensely difficult because this must consider so many, widely different, factors. Service delivery itself can be considered as multiple complex interventions, which have been described as those interventions that contain several interacting components (Craig et al. 2008). To add to this complexity a component can further be defined as “a person, intervention, method of working or style of service organisation that makes an important contribution to improve outcome for patients when incorporated into a service” (Marshall et al. 2004).

Just over a decade ago the Medical Research Council devised a framework comprising five phases for the design and evaluation of complex health interventions (Campbell et al. 2000). This framework has been widely influential (Craig et al. 2008). This framework identified five stages along a continuum of increasing evidence, with theory informing the development of a testable model (Phase I), which can be evaluated in an exploratory trial (Phase II) that helps to establish the effect size for the intervention followed by a definitive randomised controlled trial (Phase III), after which the intervention is disseminated using a long-term implementation strategy (Phase IV).

This recommended guidance for researching a complex intervention such as community services for people with ID and severe mental health problems was therefore used to investigate these services in a carefully phased approach, starting with modelling and feasibility that should enable later progression to exploratory
studies and ultimately if possible to definitive evaluations using randomized controlled trials.
2 Aims of MD (Res)

This MD (Res) programme followed the original research framework published by the Medical Research Council in 2000 in order to systematically explore what community services should provide for this specific service user group. The primary aim was to provide the foundation on which the evidence base for routine and more intensive community services for people with ID and mental health problems could be developed. It was designed on the basis that these community services were still at the modelling stage (Phase I) of the Medical Research Council’s research framework. This phase of the framework has been described by Green (2006) as a phase of “deconstructing and modelling the treatment or intervention to be studied into researchable questions” Qualitative investigation and service user, carer and clinician consultation may be of the greatest value at this stage of the overall research (Green, 2006).

Therefore qualitative studies were necessary in the first instance to model the essential service components. The research strategy aimed to actively involve service users (and their carers) by eliciting and incorporating their own views on services providing their mental health care in the community. There has been growing recognition that service users themselves and their carers should play a major role in the planning and evaluation of services. Hence there has been increasing emphasis on finding out service users and carers' views on community services that provide mental health care (Rose, 2001). The research programme was also designed to include expert clinicians’ views of services.
The MD (Res) main research programme consisted of four sequential studies which followed the completion of the study of professionals’ opinions on Assertive Community Treatment for people with ID and mental health problems (Hemmings et al. 2008). All the studies were linked and drew on the findings of those done previously. The main research programme included three studies of opinions using different but complementary methodologies. These included focus groups, a Delphi consultation survey and in-depth individual semi-structured interviews. One of the essential service components elicited from this preceding research was then selected for further exploration in the final research study. The service component selected, the provision of crisis information, was in itself a complex subject to research. The secondary aim of the MD (Res) programme was to undertake a feasibility study of this particular service component in order to prepare the foundation for a controlled pilot study and then potentially further on a much larger, definitive evaluative study.

In this research programme the term psychosis was used as a proxy for severe mental health problems/illness. This prompt was used as it was important to ensure that participants in the studies exploring opinions were considering and describing people with more severe mental health problems when stating what they thought community services should provide. Specialist services for people with ID in the UK are not usually mental health focused. It was important therefore not to inadvertently elicit opinion about services for other categories of service users with ID, in particular those with challenging behaviours without any likely associated mental illness.
2.1 Summary of Aims

- To investigate what the essential components of routine services in the community should be for people with intellectual disabilities and severe mental health problems.

- To investigate whether some people with intellectual disabilities and severe mental health problems might need more intensive community services. If this was considered to be the case, then a further objective would be to investigate the characteristics of those service users.

- To investigate what the essential components of more intensive community services should be for people with intellectual disabilities and severe mental health problems.

- To investigate expert opinions regarding how some of the key community service components could be implemented and delivered.

- To carry out a feasibility study of a particular service component for people with intellectual disabilities and severe mental health problems that had been identified as essential from the preceding studies.

* See also Appendix I, for a flowchart of the overall MD (Res) Programme.
3. Methodology

In Part 3 of this thesis qualitative methods in general will be discussed (pages 15-26) and then their specific use in the studies comprising the MD (Res) will be described (page 27-33).

3.1 The Principles of Qualitative Methodology

3.1.1 What is qualitative research?

Qualitative research is not easily defined and has been described in many different ways (Pope et al. 2000). It has often been defined simply as research which is not quantitative and which does not share its epistemological basis. However this simple definition of distinction from quantitative research is inadequate, not least because the distinction between what is quantitative and qualitative is not always clear-cut (Silverman, 2011a). Sometimes the term qualitative has been used to refer to the data collected whereas other times it has been used more to describe the actual methods used to collect and/or analyse the data. Qualitative research has also been differentiated from quantitative research by the types of research questions it seeks to answer, which are generally the more complex “how?” and why?” type of research questions rather than the more simple ‘how much?’ and ‘how many’ and “who, what and when?” type of research questions (Bowling, 1997).
For detractors of qualitative research, the very fact that it has had so many descriptions has been one major reason for their criticisms. There has often been resistance or even hostility towards qualitative research in health care research (Bowling, 1997). Qualitative research has often been criticized as subjective, non-rigorous and non-generalizable (Silverman, 2011a). These criticisms have often led in return to counter retorts that quantitative research is frequently reductionist and simplistic and lacking in validity and based on an unobtainable myth of pure objectivity for researchers (Silverman, 2011a). Qualitative research explicitly acknowledges the inevitability of subjectivity in research and so in fact often criticizes the notion of pure objectivity and value-free research (Bryman, 2012).

It seems though now that fewer researchers maintain such conflicting and confrontational views and qualitative research is now usually considered complementary to quantitative research (Pope & Mays, 2006). Qualitative research is thought particularly helpful when little is known about a topic, such as in health services research (Crombie, 1996). Qualitative research is important for providing in-depth understanding of a process or experience such as with the perspectives of participants in health services (Bowling, 1997).

In one example of the use of qualitative methods in mental health services, views about Crisis Resolution Teams (CRT) that were held by patients in North London have been researched using interviews (Nolan, 2005). Most of the twenty patients interviewed had positive views about being treated for their severe mental illness at home rather than in hospital but several expressed reservations about Crisis Resolution Team care. These included complaints about seeing too many different
clinicians, contacts with clinicians being too brief, too much emphasis on compliance with medication, lack of continuity of care and communication between Crisis Resolution Team and other mental health teams. This type of service user feedback from a qualitative research study can be vital to monitoring practice and service delivery and promoting engagement with services such as Crisis Resolution Teams.

Qualitative research is also seen as useful in feasibility studies, for example, in exploring the acceptability of interventions to both service users and clinicians (Silverman, 2011a). Qualitative methods can also be used to explore whether clinicians have the motivations and skills to carry out interventions. They are particularly good for considering a range of opinions including commissioners, clinicians, service users and carers (Ritchie, 2003).

In one example of the use of qualitative research in people with ID, the views of service users about inpatient mental health services (Parkes et al. 2007) were explored. In the first phase of that study semi-structured interviews were conducted with twelve people with ID who had been admitted to inpatient generic mental health wards in the preceding three years. In the second phase of that study nineteen people with ID were interviewed about their experiences of a new inpatient service with specialist staff input which had been set up for them. Valuable insights that could be used for improving the patient experience were gained regarding their expressed anxieties about life on the wards, the admission process, medical and other treatments, nursing care, ward rounds and making decisions.
3.1.2 The nature of qualitative research

Qualitative research is interpretative and occurs in naturalistic settings; it seeks to identify events in their natural environments or contexts (Greenhalgh, 2010). It is reflective and exploratory. It is often said to be concerned with meaning and in the development of understanding, rather than with the determining of cause and effect relationships. It is concerned with the generation of hypotheses and theories rather than the testing of them. It is often smaller scale than quantitative research owing to the complexity of the data collected. The stages of qualitative research are often less clear cut than in quantitative research (Brett Davies, 2007). It is considered more flexible than quantitative research with its stages or components more likely to overlap (Bryman, & Burgess, 1994). Qualitative researchers are usually critical of the notion that there is one single objective reality in the social world (Bryman, 2012). Qualitative research takes the view that there are multiple realities to be explored and that it is not possible to completely separate the observed world from the observer. It acknowledges and considers the influence of the researcher on the data collected. It often states that data is “produced” rather than just simply collected (Grbich, 2013).

Qualitative research is often linked to inductive reasoning as a philosophical basis for knowledge although it can also use deductive reasoning (Silverman, 2011a). The classic example often given of an inductive approach that can be used in qualitative research is grounded theory (Glaser & Strauss, 1967) which focuses on developing theory from data. At the heart of grounded theory is the ‘constant comparative method’ of constantly checking themes back and forth against the data and with the
other themes that have emerged. It has been argued by qualitative researchers that
deductive and inductive reasoning are actually on a continuum so that pure inductive
reasoning is impossible (Silverman, 2011a). From this perspective one can never be
truly value free or not have any pre-existing knowledge or assumptions before
undertaking research (Lewis, 2003).

3.1.3 Qualitative methods

The most common qualitative methods are those using participant-observation, focus
groups, interviews and examination of documents such as texts. Surveys can be
either qualitative, or quantitative in their simplest form, or be combinations of the
two approaches. The most common of all qualitative methods used in research are
interviews and these may range on a spectrum from semi-structured through to
unstructured interviews (Trainor, 2013).

3.1.3.1 The use of structures in qualitative methods

The amount and type of structure employed in qualitative methods such as semi-
interviews and focus groups is crucial as predetermining structures carries a risk of
potential bias in the data collected and the analyses that arises from the researcher
bringing preconceptions to the study. This risk can be guarded against by being
transparent about the reasons for the varying degrees of structures used in qualitative
research. The risk must be balanced against the many benefits of using some
structure in qualitative studies. The extent to which the structure and coverage of
data collection can be planned in advance will vary depending on the purposes of the
study (Silverman, 2011a).
Arthur & Nazroo (2003) have set out principles to help determine what amount of structure is likely to be optimal for qualitative data collection considering the objectives being sought. For example, data collection is likely to need to be more structured in an evaluative or investigative study looking at the operation of a service or a policy. If the study needs to provide descriptive evidence of people’s experiences or opinions of a service, a fair amount of detailed information is likely to be needed as predetermined structures to aid data collection. Studies with a particular emphasis on comparison between individual and groups of participants will usually also require relatively more structure, in order to cover the same issues with the different comparison groups. Similarly data collection may need to be more structured if more than one researcher is collecting the data to promote consistency between them. In general too, focus group data collection is less likely to be structured than in-depth interviewing because a key strength of focus groups is that data emerges through interactions between the participants (Arthur & Nazroo, 2003).

3.1.4 Qualitative analyses

It is important to note that in the research literature and text books, distinction has not always been clearly made between qualitative methods of data collection and qualitative analyses of data (Grbich, 2013). Where qualitative analytic methods in research studies have been described distinctly the two most common described forms have been content analysis and thematic analysis (Silverman, 2011b). Both of these approaches focus on the description and interpretation of qualitative data and share many similarities. Definitions for content analysis vary (Green & Thorogood,
Thematic analysis is probably the type of qualitative analysis which is most frequently cited in qualitative research papers (Silverman, 2011b). Descriptions of thematic analysis have, once again, actually varied quite broadly between researchers (Rapley, 2011). Owing to the use or interpretation of thematic analysis in often quite different ways, Braun & Clarke (2006) endeavoured to advance thematic analysis as a much more clear and defined method. They described thematic analysis as a process in which qualitative data is searched for patterns to provide an illuminating description of the phenomenon. They described six different phases within thematic analysis: Phase 1: familiarizing yourself with your data; Phase 2: generating initial codes; Phase 3: searching for themes; Phase 4: reviewing themes; Phase 5: defining and naming themes; Phase 6: producing the report.

A number of other qualitative analytic approaches have been described but very often the descriptions and the terminologies regarding them are used interchangeably which often makes distinctions between them difficult to draw. For example, grounded theory (Glaser & Strauss, 1967) has often been described either as its own analytical approach or as a concept linked to inductive thinking used in other approaches. Grounded theory emphasizes the need in an inductive approach to constantly compare and adjust theory against the data. Sometimes the differences between approaches to the analysis of qualitative data are not actually large in practice but the differing terms reflect them being derived from different philosophical traditions. For example, the analytic approach known as interpretative
phenomenological analysis (Smith & Osborn, 2008) is concerned with the psychological meaning of experiences of people and has often been used in health psychology research. Interpretative phenomenological analysis tends to place emphasis on the context of the data and thus other information outside of but allied to texts such as the emotional experiences as people speak. However as it involves creating and clustering themes and then creating super-ordinate themes it is clearly much linked and similar to thematic analysis (Howitt, 2013).

The framework approach (Ritchie & Spencer, 1994) of qualitative data analysis also has many similarities to thematic analysis, particularly the earliest phases when the themes are identified. The framework approach will be considered later in the discussion of the findings in this thesis (see Part 5.2.2, page 60).

3.1.5 Ensuring Rigour and Credibility

Qualitative research needs to be methodologically robust to ensure rigour and for its findings to be credible. Qualitative research aims to be strong on validity and has criticized quantitative research for often not being valid. However reliability is considered to be an essential prerequisite for validity and qualitative research has itself been criticized for not being reliable (Bryman, 2012). Some qualitative researchers do not believe however that the concepts of reliability and validity are relevant to them as qualitative research has a different philosophical basis from quantitative research (Silverman, 2011a). The ability of findings to represent the ‘truth’ may not be so appropriate if it is considered that there are multiple truths, for example, varying opinions about services. So instead, validity in qualitative research
is often held to be the extent to which an account seems to fairly represent the data (Guest et al. 2012).

Similarly although the generalizability of findings is usually considered to be an essential objective in quantitative research many qualitative researchers reject the idea that their findings must be generalizable. Qualitative researchers vary in their attitude to the potential generalizability of their findings with some saying the concept of generalizability is not relevant to qualitative research whilst others suggesting that it can be (Silverman, 2011a). Some argue that the main purpose of qualitative research is more to stimulate thought in the readers about their own environments rather than to claim that the research findings are generalizable (Bryman, 2012). However some qualitative researchers have been keener than others to try to answer some of the criticisms of qualitative research (Green & Thorogood, 2009). In health care settings it is not generally acceptable to ignore the question of how the findings of small scale studies might be usefully applied in wider settings. So in response to critics of qualitative research various quality criteria have been developed to promote rigour (and thus the credibility) of the findings from qualitative research (e.g. Pope et al. 2000).

There are different ways in which the rigour and thus the credibility of qualitative research can be improved. Triangulation refers to the use of different data collection methods and/or sources for the data. To demonstrate consistency of the findings, multiple raters can be involved in collecting data. To help demonstrate the extent to which all views are being represented and are not being ‘cherry-picked’ the researchers should include any ‘negative’ or deviant cases from those supporting the
interpretations. Including *participant quotations* may be one way in which validity can be demonstrated in a transparent way. By reading participant quotations the reader can get straight to some of the data and see for themselves if the interpretations made by the researcher reflect their own. However whilst there should always be adequate use of the original data, including the use of quotations where applicable, unanalysed data should not be just presented simply, such as including long quotes verbatim (Silverman, 2011a). Simple *frequency counts*, for example of words or phrases, can be used to demonstrate evidence for themes that the researchers have interpreted as having emerged from the data. *Respondent validation* can also increase rigour by feeding back findings of the research to the participants. In some cases this may be simply asking respondents to check their transcribed interviews. In other cases respondents may be asked to comments on the interpretations made of the data (Green & Thorogood, 2009).

Readers of qualitative research should be satisfied that the researchers did not simply have pre-existing interpretations that they had set out to ‘prove’. This is a quite different matter from researchers introducing structures to the data collection as described above, which is very often necessary and beneficial. As qualitative analysis involves interpretation, the experience, knowledge, opinions and assumptions of the researcher are all likely to influence the process. Rather than deny this subjectivity it should be acknowledged openly at all stages of the research process including ideally at publication to allow readers to consider for themselves how this might have affected the interpretations (Bryman, 2012). This will make the researcher ‘visible’ in the research and in its findings. The reader can then consider for themselves the possible influence of any pre-existing opinions held by the researcher on the
interpretations that have been offered to them. One other way to guard against suspicions of bias is to show that full consideration has been given to all other interpretations of the data (Silverman, 2011a). The concept of saturation is used for ensuring that an adequate quantity and quality of data are collected to support the study. The point of saturation of the data is commonly described as when the collection of new data does not shed any further light on the issue under investigation (Walker, 2012).

Using the above methods and principles rigour and credibility can thus be enhanced in qualitative research. However a major problem for qualitative researchers remains that demonstrating a full audit trail of their research and a full consideration of all the above ways to increase rigour is not often practical given the usual word limits imposed by journals (Bryman, 2012).

3.2 Choice of research approaches in people with Intellectual Disabilities

The choice of which particular research method to be used is determined primarily by the purpose of the study. However research studies also have to be practical and achievable. Qualitative research is limited in people with ID owing to their increased difficulties with comprehension and expression. Focus groups have been used with people with ID and may actually be a suitable approach with suitable modifications of information and other allowances, for example, giving participants longer to consider questions. Interviews may need to involve less detail and less complex concepts than with people without ID. They tend to need to be more structured whilst being less complicated in order to make them less onerous. Surveys which may
include quantitative elements will in general tend to be more difficult to carry out owing to the difficulties in recruitment of people with ID, as a greater proportion of them will not have capacity to consent. In this MD (Res) research programme, two of the main studies involved service user participants: the focus groups study and the crisis information study.
3.3 Qualitative studies in this MD (Res) thesis: Why were the particular research approaches chosen?

This research programme set out to gather information from service users, carers and professional staff concerning their views about mental health care and the ways in which this might be improved. It employed a focus groups’ (qualitative) study, two (qualitative) semi-structured interview studies (ACT-ID and individual ‘expert’ opinion), a Delphi survey (a combination of simple quantitative (frequency counts) and qualitative methodologies) and a feasibility study of implementing crisis information for people with ID, which was also a combination of a semi-structured interview (qualitative) and simple frequency counts (basic quantitative) based on structured interview questions. The interview studies varied in structure from the relatively most structured (staff opinions of ACT for ID) where a great deal was already established as key ingredients for non-ID populations, through to the relatively least structured (expert opinion on four key areas of service provision).

3.3.1 The ACT-ID study (see Appendix III: i)

In this research programme the preliminary study based on individual interviews had explored views of Assertive Community Treatment in people with ID. In this ACT-ID study the methodology of a quite structured interview was chosen because it ensured that all of the (professional) respondents answered the same questions. In practice the interview schedule did allow considerable flexibility for the participants to elaborate so might with hindsight have been better described in the publication as
a semi-structured interview. The data was analysed using a thematic approach in order to draw out the themes of the participants’ responses.

3.3.2 The Focus Groups’ study: (see Appendix III: ii)

In this first main study of the MD (Res) research programme the aim was to elicit and compare opinions regarding community services for people with ID and mental health problems from three major stakeholder groups. The methodology of focus groups was chosen to compare views across three main groups of participants. Focus groups were a good method to select to use as pre-existing views about services in the community were likely to be quite undeveloped, particularly among service users and carers. Focus groups are considered particularly useful in generating opinions when participants may not have thought about the topics much, if at all, beforehand. Focus groups are recognized as useful in helping people clarify their own views (Kitzinger, 1995). They can produce a dynamic exchange of views. They are useful to generate ideas, especially when people are less familiar with the ideas within topics and so their thoughts may not be so developed.

A major reason for using focus groups in this study was that this method has several advantages for exploratory research using participants with ID (Fraser & Fraser, 2001). They can increase the number of opinions elicited as group discussions may be less intimidating than individual interviews. The participants can support each other (Muir & Gibbs, 2006). Groups can encourage participation from people who are reluctant to give feedback individually, especially if negative. Focus groups do not need a person to be able to read or write. Focus groups have received growing
interest in research with people with ID (Kaehne & O’Connell, 2010). Focus groups are ideal for adults with ID and their carers to feel that their stories have been heard (Lennox et al. 2005) and in so doing facilitate their expression.

However the three focus groups (by their very nature) had small numbers of participants and also were drawn from one area of the UK. What was needed after the focus groups’ study was to achieve a consensus of what routine services (and more intensive services if necessary) in the community should provide.

3.3.3 The Delphi Survey study (see Appendix III: iv)

It was decided therefore to use a survey to elicit the opinions of a large group of multidisciplinary professionals throughout the UK who were all experienced in providing services in the community for people with ID. The methodology of the Delphi technique was chosen for this study because this is a widely recognized rigorous and systematic way of establishing a consensus of expert opinion (Linstone & Turoff, 1975). The Delphi method is a group technique used to obtain the consensus opinion of a group of experts and was first used as an aid in decision-making in the military (Landeta, 2006). It is an iterative process that allows anonymity to participants, controlled feedback and quantitative analysis of responses. The Delphi survey method can be used to gather a range of opinions from a large number of participants and the findings can then be supplemented by in-depth interviews (Landeta, 2006).
The Delphi survey method provides valuable benefits over a traditional group feedback based on direct interaction. There is more extensive consideration for the participants thanks to its repetitive nature, and there is a reduction of some undesirable effects that can be found with focus groups’ such as inhibition and dominant personalities (Landeta, 2006). The Delphi method is particularly useful in areas of research such as in health service delivery where there is uncertainty, controversy or limited evidence (Campbell et al. 1999). It has been successfully used previously in generic mental health services research (e.g. Fiander & Burns, 2000). A potential weakness of the Delphi survey method is that it can be constrained by what experts already know about a topic. In this method there is no opportunity for participants to facilitate the development of their ideas, although the Delphi survey method does expose the participants to each other’s suggestions and ideas and therefore other influences en route to the gaining of the consensus agreement.

Before then proceeding to feasibility and/or pilot studies it was important to enrich the evidence elicited by the Delphi study. This was approached by using in-depth interviews of clinicians with expertise in the field of services in the community for people with ID and mental health problems.

3.3.4 The Experts Interviews study (see Appendix III: v)

From the service components considered essential in the focus groups and Delphi survey studies some key areas of service provision were selected to explore in more depth in the next study using individual in-depth semi-structured interviews of expert clinicians. The methodology for the interviews study with experts was thus chosen
because semi-structured interviews of individuals could elicit more depth to the opinions that had been elicited in the focus groups and Delphi survey studies. Semi-structured interviews can "provide a supportive, flexible and comfortable process through which to elicit narrative description of experience and allow participants to reflect on and express opinion" (Longman et al. 2011). Four areas of service provision were chosen to explore in depth and this provided another level of structure, along with the pre-determined interview questions and prompts, for the individual in-depth interviews’ study.

The data was analysed using a thematic approach in order to draw out the themes of the participants’ responses. This analytical approach was chosen as the most suitable and pragmatic. There was not any necessity to use any more complicated approach such as interpretative phenomenological analysis (Smith & Osborn, 2008), which is concerned with the psychological meaning of experiences of people. Interpretative phenomenological analysis tends to place emphasis on the context of the data such as the emotional experiences as people speak. In any case, as already described, interpretative phenomenological analysis involves creating and clustering themes and then creating super-ordinate themes so it is very similar to thematic analysis (Howitt, 2013).

3.3.4.1 Why were structures chosen in this study and how did they link to the data?

The four areas chosen to be explored were (i) the review and monitoring of service users, (ii) their access to social, leisure and occupational activities, (iii) the support,
advice and training around mental health for a person’s family or carers and ‘out of hours’ and crisis responses. The four key areas of service provision to be explored were selected after careful consideration of both the research literature and the research data collected in the preceding studies. The key topics chosen had been mentioned frequently by participants in the ACT-ID, focus groups’ and Delphi survey studies. Together with the pre-existing research literature, which had also frequently mentioned these areas of service provision as being of interest or importance, this was why these four areas were chosen to examine opinions in more depth.

Four specific topics were chosen as this number of topics seemed to give the best chance of participants sufficiently elaborating their opinions in depth about key areas of service provision without having to be interviewed for excessive lengths of time. It would have been counterproductive to try to elicit in-depth opinions in the interviews about too many aspects of services and too many service components. This impression was supported by a pilot interview which helped to finalise the amount of questions and prompts used in the main study.

It is certainly true that other areas of service provision had also been found to be of interest and importance both from the research literature and from the preceding studies in this research programme. It would have also been worthwhile to explore these if time and other resources had been greater. However in research one has to be focused whilst also being pragmatic about what is achievable. For example, it was pragmatic to choose four topics of service provision selectively being mindful of the need to keep interview length to an acceptable duration for the participants. This
does not mean that these four key areas were the only areas of service provision that could have been investigated. In fact one of the very strengths of the preceding studies was that they had generated a whole range of service components that could be used in future research.

3.3.5 The Crisis Information (feasibility) study (see Appendix III: vi)

After the first phase of this research programme one of the service components elicited was chosen to be the focus of a study to test its feasibility as an intervention. It was decided to explore the provision of crisis information as an intervention in a feasibility study. The crisis information feasibility study sought to develop a simple intervention comprising portable information about a service user and his/her wishes that might be helpful in a crisis and to record qualitatively the feedback of the service user participants (and their carers) about this approach. This study employed face-to-face individual interviews with service users with ID to elicit their use of the crisis information and their opinions about it before and after doing so.

The methodology for this study was chosen because the information provided needed to be quite straightforward for the service users with ID to understand. The face-to-face interviews with the participants combined the methodology of a short survey, using structured questions to record simple frequencies, together with more open questions. These open questions allowed participants with ID and their relatives or carers to expand (if they were able or willing to) on their opinions about the crisis information before and after using it.
3.3.5.1 Why was this intervention chosen as the most appropriate to test in a trial?

One service component (in various forms) had been considered essential by participants in all the focus groups, especially by carers. This was the need to provide information to help the service user in a crisis. In the Delphi study the service components of crisis plans, out-of-hours support and provide a comprehensive list of contacts should service user relapse were all considered essential by consensus opinion of clinicians. The need for crisis information and the problems of service users accessing crisis services was also mentioned by several participants in the individual interviews' study. Thus of all the service components that could have been chosen for a feasibility study there seemed to be the widest interest across the range of participants regarding the provision of crisis information for people with ID. This was the major reason why the provision of crisis information was chosen from all of many possibilities for the feasibility study.

In addition, the choice of this service component for feasibility testing was supported by examining published research in this area from the non-ID population. There has been research into ‘crisis cards’ and portable joint crisis plans for people with severe mental health problems in the general population (Sutherby et al. 1999). These crisis cards/joint crisis plans are designed to be carried around and to contain useful information to assist the service user, the carers and the clinicians who assess them. Joint crisis plans have been associated with a reduction in the use of the Mental Health Act and the length of inpatient admissions (Henderson et al. 2004). However for people with ID the use of accessible, portable, mental health crisis information such as this has not been previously reported. The research literature in the non-ID
population on the use of mental health crisis information also therefore provided a strong rationale for the testing of modified crisis information for people with ID as an intervention in a feasibility study.

The foregoing descriptions of the methodologies used in the five research studies have shown how the methodologies were chosen in each to best address the different research questions at each stage. It can be seen in this way that each study in this MD (Res) research programme led on to the next one and was informed by the previous data.
4 The MD (Res) Publications: (Commentary)


The aim was to identify the essential features of Assertive Community Treatment in Intellectual Disabilities so that this model could be later successfully evaluated. Semi-structured individual interviews were carried out with 21 professionals from four UK services that were providing Assertive Community Treatment-type care for people with ID and mental health problems. The interviews comprised 26 questions, each as prompts for further discussion, which had been derived from items in the Dartmouth Assertive Community Treatment Scale (DACTS), a measure designed to test the model's fidelity (Winter & Caslyn, 2000).

Participants were prompted to provide their views on whether each item applied to current practice, whether each should be an essential part of Assertive Community Treatment as applied to people with ID and what alternatives to each there might be. The methodology of a fairly structured interview ensured that all respondents answered the same questions. The responses were analysed to see whether participants agreed or disagreed with, or were neutral, about each item. Thematic analysis (Braun & Clarke, 2006) was then conducted to discover the underlying themes.
Participants agreed that some features of Assertive Community Treatment in people with ID should be broadly the same as in the general population. However other components of the original model invoked mixed or polarised views. Participants agreed that having a practicing team leader, a shared caseload, a vocational specialist on staff and meeting regularly as a team and maintaining continuity of staff should all be features of the model in people with ID. Participants felt that a team should deliver services in the community and involve service users’ support networks. It was agreed that there should be explicit admission criteria and that hospital admissions and discharge planning should involve the team operating this model but whether the team should be responsible for them produced a mixed response.

Participants did not agree on whether the team should have full responsibility for treatment services, particularly with regards to housing support, employment and rehabilitative services. Participants did not agree on whether having a 'no-dropout' policy, a high total amount of service time or having a high number of service contacts were realistic or necessary. Whilst participants did not feel it was appropriate for service users and carers to be involved as team members providing direct services, they did think that user and carer involvement in service development, support roles and providing feedback was essential.

Thematic analysis revealed overarching themes regarding (i) the target service users, (ii) the role and provision and (iii) the realistic implementation, of the model. Some of the participants felt that psychiatrists’ input should target a small, prioritised group of those service users with particularly complex needs. The participants frequently articulated that they were unclear whether or not the role of an Assertive Community
Treatment service should be to only provide intensive support for service users with complex needs, or also to provide more general support and supervision of less complex cases. Their responses also indicated their dilemma between promoting the use of mainstream services with an Assertive Community Treatment in ID team acting in support or providing the lead or main role in a service user’s care. Some respondents saw service users as needing the support of an Assertive Community Treatment in ID service in accessing mainstream services with the specialist service's staff role as consulting to, liaising with and supporting those mainstream services; others felt such a service should endeavour to provide all services seeking additional support or input only if necessary.

A constant theme expressed was that services should be based upon assessed need, and that services should not be provided which duplicate those already available. Maintaining continuity of staff, full service staffing and a service of sufficient absolute size to consistently provide the necessary coverage and diversity of staff roles were all seen as highly unlikely to be achieved for a hypothetical Assertive Community Treatment in ID service. The ideas of having a “no drop-out” policy and of only taking on service users at a relatively low frequency rate were also seen as unrealistic given likely resources. The provision of 24-hour service coverage was seen as unnecessary as similar coverage was already being provided by mainstream services.

This study highlighted the difficulties with identifying an agreed definition of Assertive Community Treatment for people with ID. It showed that research into services in the community for people with intellectual disabilities could not assume
shared knowledge or understanding of specific service models. Instead a programme of research would be needed to first deconstruct and model services in the community in order to generate valid researchable questions. This formed the main body of the MD (Res) research programme (see Appendix II).
4.2 Hemmings, C.P. (2008) Community services for people with intellectual
disabilities and mental health problems. *Current Opinion in Psychiatry*, 21, 459-462
(see Appendix 7:ii for publication).

This literature review focused on studies in community services, emphasizing those
that had been published in the preceding three years. These were identified from a
Medline, Embase and PsychInfo search using the key terms of community services,
mental health, disabilities, disability and mental retardation. The review confirmed
that there had been relatively little published and that the studies reported were
difficult to compare as there was so little consistency between the services
investigated. There needed to be shared understanding of what services should
provide in order to help progress the evidence base beyond these isolated reports.

A review of very recent research in the UK (other than this MD (Res) programme)
did not find any major findings to add more to the evidence base regarding the
provision of community services for people with ID and mental health problems
(Hemmings et al. 2013a).

It was decided therefore as the first step in the research programme to undertake a
study of opinions about services involving the three main stakeholders groups of
service users, carers and professionals.

The three main (directly involved) groups in community-based services for people with ID and severe mental health problems are the service users, carers (paid care staff and relatives) and professional staff. The methodology of focus groups was chosen in order to elicit and compare the various opinions on community services of participants drawn from these three groups and to generate ideas for future research.

Participants invited to the service user focus group were members of a service user group for adults with ID and mental health problems in South London. They were a well-established group that have met regularly over several years to discuss issues. They were used to participating in research. The facilitator aided communication and helped to create a relaxed atmosphere and encouraged people to speak (Muir & Gibbs, 2006). The author (a clinician in South London) did not attend the service users’ focus group on the advice of the group facilitator to reduce risk of service users not speaking about their views and experiences of services. The carers (paid care staff and relatives) for the carers’ focus group were invited through local services in south London. A range of multidisciplinary staff, from South London services for people with ID and mental health problems, were asked to participate in the professionals’ focus group.
Psychosis was used as a proxy term for severe mental illness to ensure participants did not talk about other service needs, particularly for those with ID and challenging behaviours without diagnosable mental health problems. The participants were asked to consider three questions: (i) What should community services provide routinely for adults with ID and psychosis? (ii) Do some people with ID and psychosis need a more intensive specialist community service and if so, what are their characteristics? (iii) What should these more intensive community-based services provide?

There was unanimous agreement between the three focus groups that there existed a subgroup of service users that sometimes needed a more intensive service. There were no great conflicts or contradictions between the three groups as to what they saw as essential components of services. However there were also clear differences in their priorities. Service users emphasized their need for practical help and advice and for staff dealing with them to be trained in ID and to get to know service users. They were keen for opportunities to discuss their mental health and to make friends. They also expressed the wish to have ‘more say’ in their care.

Carers also emphasized the need for a personalized service and prompt treatment. They also emphasized the need for a range of professional staff and the importance of good communication and help with behavioural problems. They thought more information should be made available to them, particularly what to do and where to go in a crisis. Professionals also emphasized the need for all concerned to have a good understanding of both ID and mental health problems. They emphasized the interfaces between specialist and generic services and the difficulties with them. They were concerned with early diagnosis and interventions and access to
mainstream services, particularly in a crisis. They were wary of developing new stand-alone services for people with ID and severe mental health problems/psychosis. Rather than having a separate specialist, more intensive, service the professionals were more concerned that existing services should be able to respond flexibly to offer more intensive input when necessary.

This focus groups’ study generated many opinions regarding services. However these focus groups by their very nature had small numbers of participants and were drawn from one area of the UK. What was needed next was to achieve a consensus of what routine services (and more intensive services if necessary) should provide. It was decided to elicit the opinions of a large group of multidisciplinary professionals throughout the UK experienced in providing services in the community for people with ID. It was important for the next step in the research programme to generate a consensus of experts about what these services should provide.
This was a survey of a large group of professional experts to elicit their consensus view on community services for people with ID and psychosis. Again psychosis was used as a proxy term in this study for severe mental health problems/illness. The methodology of the Delphi survey was chosen because this is a widely recognized rigorous and systematic way of establishing a consensus of expert opinion (Linstone & Turoff, 1975).

The 52 participants for the Delphi survey were selected from a non-probability, purposive sample and recruited using a snowballing technique. They were drawn from a range of professional backgrounds and service locations throughout the UK. Participants were chosen on the basis of their knowledge and experience; they were not intended to be representative of any group. The Delphi consultation was a three round exercise using either postal or online questionnaire depending on the participant’s preference. In Round one, participants were invited to list what they thought to be the essential service components and the characteristics of service users needing more intensive services. The data from this first open-round was synthesized with that from the focus groups to construct the final list of items which were presented to the participants in rounds two and three. The participants were asked to rate their opinions on 139 items including components of routine and more intensive services as well as the characteristics of service users needing a more intensive
service. In Round three participants were able to see their own previous scores in
Round two against the group median scores given for each item in round two.
Participants were asked to reconsider their ratings in light of the overall group
ratings.

This Delphi consultation survey was successful in that it increased agreement among
participants between rounds and achieved consensus for a number of service
components and service user characteristics considered to be Essential. Consensus
was defined as greater than 80% agreement rating (Green et al. 1999). Consensus
was achieved on 23 service components and nine service user characteristics.
Participants agreed that a more intensive service was sometimes needed. The
characteristics of those with ID sometimes in need of more intensive mental health
services were arguably similar to those without ID with the exceptions of the items
additional challenging behaviour and experiencing or at risk of placement
breakdown.

Eighteen service components were considered as essential for routine services. These
included such items as regular review of service user and care plans, monitoring of
mental state, monitoring of medication, access to social, leisure or occupational
activities, crisis plans and out of hours support and support/advice/training around
mental health for the person’s family, carers and support services. Five service
components were considered as essential for more intensive services, including can
react to a crisis that day and provide a comprehensive list of contacts should the
service user relapse. However several of the routine service components were
arguably those that would often be considered a core part of more intensive services also, such as the provision of *out of hours’ supports* and *crisis plans*.

It would be valuable to explore the effective implementation and delivery of many or all of the 23 service components considered essential for community services. However before proceeding to feasibility and/or pilot studies it was important to enrich the evidence elicited by the Delphi and the preceding focus groups’ studies. There had been a space at the end of the Delphi survey for participants to leave feedback and several had used this to clarify or expand on their responses. This demonstrated that many would be likely to welcome an opportunity to elaborate on their responses and thus on their opinions regarding service components. From the service components considered essential in the focus groups’ and Delphi studies some key areas of service provision were selected to explore in more depth in the next study using individual interviews of expert clinicians.
This was a study of expert opinion looking in more depth at how some key components of community services for people with ID and severe mental health problems (again using psychosis as a proxy) should best be implemented and delivered. Four areas of service provision were chosen to be explored and these were: (i) the review and monitoring of service users, (ii) their access to social, leisure and occupational activities, (iii) the support, advice and training around mental health for a person’s family or carers and ‘out of hours’ and crisis responses.

The methodology of carrying out semi-structured interviews of individuals was chosen for this study because semi-structured interviews could elicit more depth to the opinions elicited in the Delphi and focus groups’ studies.

Fourteen multidisciplinary professionals in all from specialist ID services throughout the UK were interviewed about their opinions regarding service provision in the key areas chosen. The majority of the participants were particularly ‘expert’ in that they had published research, correspondence or opinions on services in the community for people with ID and mental health problems. This group was supplemented by other specialist ID professionals who were invited after having left feedback for clarification of their Delphi survey responses. The interview data was coding using the NVivo 7 software package (Bazeley, 2007) and then analysed using thematic analysis (Braun & Clarke, 2006). Before analysis respondents were asked to check
the accuracy of the transcriptions and to make any changes they wished. They were not asked to comment on the later interpretations of the data.

Overall there was much consistency in the participants’ responses. Analysis of the opinions expressed produced ten wider themes of importance for services, all supported by the data from at least half of the interviews. The themes for services that emerged were: their Configuration/Structure, their Clarity of Purpose/Care Pathways, their Joint Working, their Training, their Flexibility, their Resources, their Evidence-Base, being Holistic/Multidisciplinary, being Needs-led/Personalized and providing Accessible Information. There was not overwhelming support for developing super-specialist services within ID services such as assertive outreach or providing daytime activities. Participants often commented that there would not be the critical mass of staff or service users to make these economically viable even if they thought these might be the most ideal.

The need for services to have clear purpose and care pathways was mentioned frequently. Interviewees often commented that joint working with mainstream mental health services needed to be improved for the best care of the service user. Interviewees frequently talked about the need for those working with people with ID and mental health problems to have sufficient training and experience. Related to this they often commented that specialist ID services need to provide training to mainstream mental health staff, care staff and other services.

Interviewees frequently cited the need for adequate resources for services, often contrasting what they would think ideal with that of financial realities that they
acknowledged. The interviewees spontaneously recognized themselves that no new great increases in funding for ID services were likely to be forthcoming and appeared to make their responses accordingly. The experts were concerned that often mainstream services do not meet the needs of people with ID and were therefore keen to develop new improved ways of working with these mainstream mental health services without necessarily developing stand-alone ‘super-specialized’ type ID services. Other themes that emerged were the need for services to be holistic/multidisciplinary and needs-led/personalized and to provide accessible information.

The findings of this study together with the preceding studies had now generated many ideas for further research. One service component identified, an intervention considered to be clearly important in the focus groups’, the Delphi and in-depth interviews’ studies, could now be chosen to be explored further in a feasibility study (Phase II of Medical Research Council Framework for Complex Interventions; Campbell et al. 2000).

After the main part of this MD (Res) research programme one of the service components elicited was chosen to be the focus of a study to test its feasibility as an intervention. As previously discussed (see 3.3.5.1) a recurring theme from the previous studies had been a widely perceived need for better crisis services and responses for people with ID. It was thus decided to explore the provision of crisis information as an intervention in a feasibility study. This study sought to record qualitatively the feedback of the service user participants (and their carers) about modified and accessible crisis information. It is unlikely that the brief crisis cards or joint crisis plans used in generic mental health services would be meaningful in an unmodified form to people with ID. Furthermore, as this intervention had never previously been tried in the ID population, it was essential to undertake a feasibility study to explore whether crisis information could be modified to make it accessible and meaningful for people with ID and to explore when and how such a system would be useful in practice.

The numbers of mental health admissions and use of the Mental Health Act for people with ID in the UK are relatively low, although once in hospital they may require longer admissions than those with more typical IQ (Hemmings et al. 2009c). These outcomes were therefore not suitable measures for this feasibility study. Instead the aim was to investigate more basic questions of a) Could crisis information be modified to make it accessible for people with ID and mental health
problems? b) Would it be carried, used and valued by them? c) Could having it increase the knowledge of service users about who to contact when they are in a crisis? The objective was to gain evidence to decide whether a further, larger-scale controlled study of mental health crisis information for people with ID would be warranted.

Personalized information of potential benefit to be used in a mental health crisis was recorded on folded A4 paper that could be carried in a wallet. Twenty participants volunteered to participate out of a total of 61 approached to take part. The participants were told that certain basic information would be on their crisis information such as their name and address and telephone numbers for a key person to be contacted in the event of a crisis. They were also asked if they wanted other additional information included such as their mental health history, physical health, medications and contact numbers of professionals involved in their care. They were also asked if they wanted other information included about themselves, their wishes and dislikes and how best to communicate with them.

The crisis information was constructed and displayed in an accessible form that was both understandable and acceptable to the participants, as evidenced by both their responses in their interviews and their carrying of the crisis information wallets. The crisis information was personalized and for the most part, the service users were able to decide independently what they themselves wanted to include. The crisis information provided knowledge for understanding the person, for building rapport and for potentially avoiding insensitive subjects that could aggravate a situation.
The feasibility study sought to record the feedback of the service user participants (and their carers) about the modified crisis information in face-to-face interviews. This study used a combination of closed and open questions to allow participants with ID (and their relatives or carers) to expand if they were able to (or willing to) on their experiences and opinions of the crisis information before and after using it. Thus it employed a combination of a structured and semi-structured interview and produced quantitative and qualitative data.

The service users and their carers expressed much positive feedback about their crisis information. Fifteen of the twenty participants carried their crisis information daily for six months before evaluation. It was not established by this study if this crisis information would actually help people with ID in a mental health crisis, as none of the participants experienced one whilst having their crisis information wallet during the study. It cannot therefore be said whether the crisis information would have helped to improve access to services or the care the participants would have received.

However, the participants clearly liked having the crisis information and having it may well have helped with their self-esteem and confidence. Two of the participants said they liked their crisis information wallets so much that they carried their Freedom bus passes inside them. One participant carried the crisis information wallet around his neck in a special bag. Another participant linked a chain to his crisis information wallet so that it could be attached to his trousers. One participant used them when attending an Accident and Emergency department for an asthma attack and another time when presenting there with unexplained seizures. She said, “I had convulsions and the nurse in the hospital said it was good…I took it with the asthma...
and it was so handy, it has everything about me”. One participant took their crisis information wallet to show their GP and also to show their supported employment advisor. They reported that staff at these different places had received their crisis information favourably. Care staff also raised the suggestion that they might be used in other situations such as in shopping centres: “She has been in Marks and Spencer’s and Boots and staff there have had to communicate with her when she was in a panic”.

There were positive comments from all fifteen participants who carried their crisis information wallets regularly. For example, comments included: “It's very nice to have it….it's a shame it wasn't available years ago…..I've been telling my girlfriend to get one…I think everyone who has a problem should have one…."It’s good.. it might help people worse than me who need help….there are people who have problems. it would help them, not only me”…”It gives me confidence, I want to keep it forever”. Carers and relatives also gave positive comments without exception: “I think it’s an excellent idea, the more people have them the better…the wallet gives her and us peace of mind if she goes out to local shops….it’s reassuring to know she has the information on her…..it promotes independence”. One participant said, “It would be helpful to have cab numbers and the local police station”. One carer talking about its use in non-health settings such as shopping centres suggested, “An awareness of when to use it would be good.” Another carer compared the crisis information wallet with hospital passports and said, “It’s important for a physical health care view…she has a hospital passport…but this is small and portable.”
The feasibility study thus showed that it was possible to record crisis information in a way which was short enough to be portable but still of sufficient depth to potentially help a person with ID in a mental health crisis. The crisis information was not expensive or difficult or time-consuming to produce. It was straightforward enough for the participants to understand and to be carried, valued and sometimes used by them, albeit sometimes unexpectedly in non-mental health settings. The sample size in this feasibility study was small but the findings suggested that the provision of crisis information might be useful if targeted at specific groups of service users. Although the modified crisis information did not constitute a full ‘joint crisis plan” as previously tested in people without ID (Henderson et al. 2004) the crisis information was constructed collaboratively and thus could be considered ‘joint.

Given the findings of the feasibility study a larger scale, further exploratory research on the use of modified crisis information leading potentially to a large scale randomized controlled study seems warranted. It would be important to try to explore the possibilities of using modified crisis information for people with ID that involved some expression of their preferences for the care they would receive in a crisis. There is a need first though for further research to prepare the ground for this, for example to clarify how often mental health crises are occurring in this service group, how often people with ID in mental health crises are presenting to services, to which types of service they are presenting to and how often mental health inpatient admissions are required.

Although the feasibility study was limited to people with previously diagnosed ID it is important to note that some people with intellectual functioning around the high end of the range of formal mild ID are often not known to services as having ID. So
only considering people with formally diagnosed ID may underestimate who might potentially benefit from modified crisis information. Furthermore many people with borderline low intelligence may have problems accessing appropriate and timely mental health services in a crisis for similar reasons to those described for people with formally diagnosed ID. Therefore consideration should also be given in the future to the evaluation of modified crisis information for people with IQ scores just above the formal ID range.

4.6.1 The Concept of ‘Shared Care’ in this context

*Shared-care* in mental health care is generally used to describe situations where care is shared between mental health services and other services, usually primary care. Definitions of ‘shared-care’ have varied (Kelly *et al.* 2011) but the term can also be used to describe shared-care with other services, for example, specialist mental health services and other secondary medical services. In shared care the delivery of care is planned jointly and that there is enhanced information exchange over and above standard correspondence (Hardwick *et al.* 2013). One of the most important objectives of shared-care is to help ensure that the patient’s pathway through the care pathway is as smooth as possible (Lester, 2005).

Patient-held records have become common in the management of chronic medical conditions such as diabetes (Lester, 2005). Randomized-controlled trials of patient-held records for people with chronic mental illness suggested that they were valued by patients and improved communication between primary care and specialist
services. However a reluctance of professionals to use shared-care records has also been suggested (Lester, 2003). In this research programme it can be argued that the modified crisis information study demonstrated a form of shared-care, or at least one important objective of shared-care, the sharing of enhanced information. One of the primary motivations of this intervention was to share information from the service user and specialist psychiatry of ID staff with other services including primary care, other general medical staff and paramedics and police.

In the crisis information feasibility study there was expressed support among service users and carers and relatives for the sharing of information and decision-making with clinicians that has been described in people without ID (e.g. Deegan & Drake, 2006; Drake et al. 2009). In the study feedback was also indirectly reported from non-ID-specialist clinicians that suggested that they too might find it helpful. The opinions of professionals such as general practitioners, paramedics and accident and emergency staff towards this form of shared care with people with ID was not investigated in this feasibility study. It would be worthwhile to know what they thought of the modified crisis information and whether there would be any reservations on their part to this form of shared-care regarding people with ID.
5 Discussion

5.1 Summary

5.1.1 Overview of MD (Res) Research programme

There are six published papers (including one literature review) submitted for this MD (Res) by publication. The five research publications submitted are all linked, each building on the findings of the preceding study. Across the studies there was a pathway that was followed in order to reach the final conclusions (see Appendix I for overall flowchart of MD (Res) research studies).

The aim of the main part of the research programme (see Appendix II) was to elicit the components necessary for community services for people with ID and mental health problems. The research programme was conceived in response to the problems demonstrated in adequately researching the specific model of Assertive Community Treatment in people with Intellectual Disabilities. The idea and design for the first (preliminary) study on Assertive Community Treatment in Intellectual Disabilities was developed by Professor Nick Bouras. The study was completed by the author of this MD (Res) who then led the analysis and writing up. Although this preliminary work did not demonstrate a clear appetite for ACT-type services for people with ID, it did highlight themes that were thought to be important in services in the community for people with ID and mental health problems including improved
management of crises. Also mentioned were problems of communication between agencies which gave further rationale for the later crisis information study.

For the four other publications based on the following four research studies the author of this MD (Res) developed all the research ideas and study designs and led the writing up from start to publication using feedback from research and supervision meetings with co-authors. A major objective was to prepare the ground for further exploratory research leading to a randomized controlled trial of an intervention to be used by community services for people with ID and mental health problems.

5.1.2 The research findings and their implications

It was clear from the initial ACT-ID study that before the effectiveness of any new services for this service user group in the community can be evaluated agreement of what should constitute routine and more intensive services first needed to be established. This agreement was achieved in this research programme using a systematic framework of research and using rigorous methodologies including focus groups, interviews and a Delphi survey.

The research findings can be used to generate many further hypotheses and to inform further research for the evaluation and development of community services and their components, including specific interventions. One of the findings was used to develop a feasibility study for modified crisis information in people with ID. This showed that crisis information could be modified to be made accessible and meaningful and to be valued by people with ID and their carers. The findings of the
feasibility study can be used to further explore the usefulness and effectiveness of crisis information in people with ID.

A particular strength of this research programme was the involvement of service users and carers. There has been little previous investigation into what service users with ID and severe mental health problems actually want or need from community services. Involving service users and carers is increasingly recognized as crucial for developing services and setting research priorities. Carers’ perspectives have been traditionally neglected although recently research interest into them has been growing. Understanding and negotiating with carers' opinions is crucial in the care of people with ID and severe mental health problems (Inwang et al. 2013).

Owing to the small scale of services and the relative small numbers of service users, any whole service evaluation studies are likely to be underpowered or to be not feasible. Funding for new service delivery models not previously evaluated or evidence based is unlikely to be forthcoming in this field, especially in the current economic climate. Researchers in the field of ID have historically found it difficult to compete for the very large research grants needed for whole service evaluations. A more realistic way forward is to look at modelling, piloting and evaluating specific service components, such as the use of crisis information or the employment of specialist staff within a generic mental health team. It is more feasible to undertake outcome studies looking at a specific novel intervention such as the provision of modified crisis information or to evaluate long-established interventions where practice has not been based on evidence of effectiveness in this specific service user
group. Where an intervention lacks evidence then policy makers and clinicians will be much less likely to continue to use it (Oliver et al. 2002).

It is important to note that UK Government policy in recent years has promoted the use of generic (or ‘mainstream’) services wherever possible for people with ID and mental health problems (Foundation for People with Learning Disabilities, 2004). However this policy itself has not been particularly evidence based. There have been ongoing problems faced by people with dual diagnoses in accessing generic mental health services adequate for their needs (Bouras & Holt, 2000). A crucial and enduring question has been, ‘Do people with ID and severe mental health problems do better in specialist ID services or in generic mental health services (Day, 1994; Chaplin, 2009)?’ As there has been so little research on which to base services there remains no conclusive evidence to favour the use of either (Chaplin, 2004). How then do the findings of this MD (Res) research programme help inform this debate?

The findings of this MD (Res) research programme were clear in that clinicians did not see the future of their specialist services as always replicating (or as they saw, duplicating) developments in mainstream mental health services. There were frequently voiced concerns that this could cause fragmentation of and lack of 'critical mass' for already small specialist ID services. In any case many in mainstream mental health services feel that specialization within those much larger services has contributed to discontinuity of care (Tyrer, 2007). It is likely to remain unclear therefore for example whether the original Assertive Community Treatment model is suitable and effective for people with ID and coexisting severe mental health problems.
Sometimes services for people with ID and mental health problems have lagged woefully behind mental health services for the general population and just need to catch up, for example in the implementation of the Care Programme Approach (Hemmings, 2007). However in other cases mental health services have moved on and specialist ID services risk trying to implement a model or idea that has since changed or lost its raison d'etre. In the case of Assertive Community Treatment it has been argued that this model is no longer so relevant to practice where other services such as crisis resolution teams are well established (Tyrer et al. 2007). The shift of service and research interest from assertive outreach to crisis services that has been seen in generic mental health services was mirrored in this MD (Res) research programme. It began with a study regarding Assertive Community Treatment and ended with a study about a mental health crisis intervention.
5.2 Methodological Considerations

5.2.1 The limitations of the approaches taken

There are many limitations to this research. Analysis of qualitative studies inevitably employs a degree of subjectivity and therefore one must be cautious to assert or accept the generalizability of the findings. The potential problem of generalizability is increased as two of the studies (the focus groups’ and modified crisis information studies) included service users or carer participants or professionals that had involvement with clinical services in South London (where the author is a clinician).

Two of the studies involved participants with ID and so some of the limitations in those studies are common to all research involving participants with ID, which has been historically problematic (Robotham et al. 2011). Difficulties have included obtaining consent from participants with ID, finding services willing to participate, choosing relevant outcomes, agreeing on definitions and recruitment of participants (Oliver et al. 2002).

The modified crisis information feasibility study was further limited by its sample size and lack of control group. The crisis information study only included participants who understood English, which might limit how well its findings could be generalized. Those who do not speak English could be the very group in which crisis information might have the most impact. Also those recruited were more likely to be those living in staffed care homes rather than living more independently.
However those who might benefit most from carrying crisis information could be those less likely to be accompanied by staff.

5.2.2 *The Framework Approach: an improvement that could have been made.*

The *framework approach* (also known as *framework analysis*) for the analysis of qualitative data was developed in the 1980s by the UK National Centre for Social Research (Ritchie & Spencer, 1994). It was developed specifically with the aim of applied qualitative research in health or social care or policy in which the objectives are set in advance, when the timescales are more likely to be short and the questions already known (Srivastava & Thomson, 2009). The framework approach breaks down the process into a series of five interconnected stages that promotes the researcher moving back and forward across the data to facilitate the emergence of a coherent account.

The stages of the framework approach are: (a) Familiarisation (b) Thematic identification or initial coding (c) indexing (this is often termed coding in other forms of qualitative analysis (d) charting and (e) mapping and interpretation. Themes are refined and may be developed into a framework displayed as a matrix. It is a matrix-based method involving the construction of thematic categories into which data can be coded. Typically the five stages of the framework method are undertaken in a sequential fashion before analysis begins, although framework analysis can also be used more flexibly when data collection and analysis occur concurrently as in grounded theory.

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Proponents of the framework approach have emphasized that it reflects the original accounts and observations of the people studied; thus is also “grounded” and in general, inductive. They have also emphasized that it can also employ deductive thinking by starting from pre-set aims informed by a priori reasoning. Thus thematic categories can both emerge from the data or be specified before data collection. This allows questions or issues identified in advance by various stakeholders to be explicitly and systematically considered in the analysis (as well as new themes emerging from the data). Framework analysis is often used when there are pre-designed samples (e.g. professional participants). This can be important in many applied studies where there are specific issues that commissioners and other stakeholders want to be addressed. Although framework analysis can therefore regenerate theories, its primary purpose is to describe and then interpret what is happening in a particular setting (Ritchie & Spencer, 1994).

An advantage of the framework approach is argued to be the use of visual charting techniques which assist in the analysis and promote the transparency of the analysis (Green & Thorogood, 2009). Charts can be either by theme across all cases or by case across all themes. These visual displays and plots aid the analysers and the readers of the analysers’ interpretations of the dates. It was argued that this stage, the linking of various themes is the hardest for researchers to describe and thus make credible to readers of qualitative studies (Ritchie & Spencer, 1994).

The framework approach also emphasizes the need for stages of the analysis which are interconnected and clearly linked to provide the greatest transparency possible for readers to understand how the interpretations were drawn from the data (Pope &
Mays, 2006). It has been argued that an effective and transparent audit trail enhances the rigour of the research and the credibility of the findings (Ritchie & Lewis, 2003). Particularly for the novice researcher in qualitative research a framework may help guide in the stages of data analysis (Green & Thorogood, 2009).

The distinction between framework analysis and thematic analysis has often varied with different authors (Green & Thorogood, 2009). The majority of the principles and components of the framework analysis were used in studies in this MD (Res) research programme, notably in the individual interviews study, without naming the analytical approach used as such. One omission though in this research programme from the methodology of the framework approach was not drawing maps or diagrams of the themes to the data and showing these for readers of the qualitative studies. Arguably this visual representation of the data may have been beneficial for analysis and for demonstration to the reader. However in-vivo codes (with N-Vivo software) were used in the interviews’ study and this allowed thinking about the themes whilst retaining links to the original data. Remaining true to the participants’ themes is a fundamental principle in the framework approach and it can be argued that this fundamental principle was achieved in this MD (Res) research programme.

5.2.3 Recruitment in Intellectual Disabilities’ research

People with ID are notoriously difficult to recruit for research (Doshi et al. 2010). Robotham et al. (2011) suggested a number of ideas to improve recruitment and the research process including involving service user participants in active roles and using accessible participant information. Cameron & Murphy (2006) argued that
people with ID need to be given more time to consider their participation. Tierney et al. (2007) suggested that individuals are more likely to participate in research if they deem it meaningful. Cleaver et al. (2010) found recruitment of people with ID was achieved best when participants were contacted directly.

Lennox et al. (2005) described several recruitment barriers for people with ID including the little time that carers feel they have available. They also noted the frequent difficulties in locating people with mild ID who were living independently. They made recommendations for improving recruitment including longer recruitment phases and more home visits. Nicholson et al. (2012) interviewed people who had acted as intermediaries in recruitment. The authors suggested strategies to improve recruitment including researchers adopting a more personal approach, developing the research process to allow for multiple meetings with participants and considering motivators for both participants and carers.

It had been hoped to recruit more participants for the crisis information feasibility study. The original objective was to gain 40 participants but only 20 were recruited and this limited what could be evaluated. This was despite the multiple considerations made to improve and retain participation, for example, by the use of accessible participant information, contacting potential participants directly, home visits, multiple meetings, inviting the participants to nominate a carer to assist them, contacting potential participants directly and giving them plenty of time to consider whether to take part or not. By offering the participants the opportunity to take an active role in the research by choosing their own crisis information the study was made more personalized and meaningful for them. As one motivator the service user
and carer participants were also asked if they would like sent the final published papers of the studies in which they took part. The major reason for the relatively small final sample despite all of these measures was the inability of many people with ID to give consent to participate. Other reasons included a widespread inability to understand sufficient written or spoken English to take part within the potential pool of participants.

5.2.4 Medical Research Council Framework Revision

During the course of this research programme the Medical Research Council revised its Research Framework for Complex Interventions (Craig et al. 2008). The original framework characterised the process of development through to implementation of a complex intervention in terms akin to the linear phases of pharmacological research. The revision recommended much greater attention to early phase piloting and development work and a less linear model, with integration of process and outcome evaluation (Craig et al. 2008). The revision emphasized even further the need not to launch prematurely into larger scale studies including randomized controlled trials. This MD (Res) research programme did attend to such early development work suggested by the guidance.

After the research studies corresponding to Phase I of the MRC framework it was decided to move on to a feasibility study of the delivery of a particular service component, the provision of crisis information. However the service components elicited in the focus groups’, Delphi and interviews' studies can generally be considered as complex interventions in their own right. It would also therefore have
been justified to go back again in the research continuum to model some of these
service components in order to consider how best they could be delivered and
implemented.

For example, one limitation of the crisis information feasibility study is that what
constitutes a mental health 'crisis' was not clearly defined. A pragmatic definition of
crisis has been to describe situations in which there is an urgent need for professional
help or interventions arising at least in part from mental health problems (Johnson &
Thornicroft, 2008). A more narrow definition of a (mental health) crisis is that the
situations are severe enough for in-patient admission to be considered as a potentially
appropriate response (Johnson & Thornicroft, 2008). A 'crisis' is actually a relatively
complicated concept to understand for many people with ID. Crises are subjective for
all (Weiss & Lunsky, 2010) and often a crisis for someone with ID might often not
be considered a crisis in people with more typical intelligence.

Further modelling might therefore have helped define a crisis for this specific service
user group more closely before the feasibility study was undertaken but it is
important to be pragmatic in clinical research and accept that exploration to increase
further understanding can potentially be never ending. The Medical Research
Council’s Framework has been criticized for being somewhat reductionist (Hawe et
al. 2004) but there is always a balance to be held in research between some
simplification in order to gain tangible results and capturing the complexity of
clinical service delivery in the real world.
5.2.5 Randomized Controlled Trials in People with ID

The revised guidance recommended greater consideration of alternatives to randomized controlled trials in complex interventions. There have been very few randomized controlled trials involving people with ID (Hassiotis & Sturmey, 2010). Robotham et al. (2011) highlighted the under-recruitment or high dropout rates of people with ID in these studies. Lennox et al. (2005) described factors that act as barriers to using this study design including paid carers acting as 'gatekeepers' and lack of understanding of the methodology among service users and carers. Oliver-Africano et al. (2009) argued that stakeholders in specialist ID services can be hostile to randomized controlled trials. Although some service users with ID may understand some aspects of randomized controlled trials (Fisher et al. 2006) it may be that pharmacological studies are easier to be understood and supported by them and their carers compared to relatively more complex interventions. Robotham et al. (2011) elicited the perceptions of professionals, carers and service users about randomized controlled trials and found generally positive views except for concerns about capacity and resources. Understanding of the methodology though, for example about random allocation to intervention and control groups, was poor among service users and some carers.

Randomized controlled trials are certainly desirable to strengthen the evidence base of services for people with ID and mental health problems but they need to be considered in a balanced way. They need to be given a proper foundation and often this will necessitate evidence from study designs further back in the research continuum as occurred in this MD (Res) research programme.
6.1 Possible design for an exploratory controlled trial of modified crisis information (including possible timescales and outcomes)

This MD (Res) included a feasibility study of crisis information in people with ID. It showed that crisis information could be modified to be made accessible and meaningful for people with ID. Recently Lunsky et al. (2008), Lunsky & Gracey (2009) and Weiss et al. (2009) all reported problems of accessing and using emergency mental health services for people with ID, from the various perspectives of service users, carers and the hospital staff. These studies reinforced the rationale for further exploration of the use of modified crisis information for people with ID. Also published during the course of this MD (Res) was a randomized controlled trial of the use of crisis cards/joint crisis plans in people without ID which did not replicate the earlier positive findings of the use of crisis cards/joint crisis plans (Thornicroft et al. 2013). However this follow-up study did find a secondary outcome of improved therapeutic relationships between staff and patients. This finding is also a reason for further exploration of the use of modified crisis information for people with ID. Carrying the crisis information could potentially improve access to care for people with ID in a mental health crisis, improve the process of the assessment of that person and improve the outcomes of the crisis.

In the feasibility study the actual use of modified crisis information in a mental health crisis could not be evaluated. This was because no mental health crises were
reported in which the crisis information was used. The lack of mental health crises in the participant cohort was probably due to the relatively small sample of twenty and the short evaluation period of six months. There are therefore some questions which need to be addressed before we can be sure that more extensive research in the use of modified crisis information in people with ID is warranted. These are:

- How frequent are the presentations of mental health crises in people with ID?

- Where do these present? How frequent are presentations of people with ID in mental health crises to a range of settings, including accident and emergency services, police, mental health and specialist learning disability services?

The key research question to be answered eventually is, would the carrying of modified crisis information help to resolve mental health crises for people with ID? However this question may only be worth exploring in a randomized controlled trial (RCT) if we know beforehand the answers to the above questions in order to guide the minimum sample size and study duration that would be needed for a definitive study.

**Study 1: Determining the frequency and characteristics of crises**

The frequency of presentations of mental health crises could be investigated using a new system for searching patients’ electronic records that has been recently implemented in the author’s own Mental Health Trust (South London and Maudsley). The *Clinical Record Information System* (CRIS) is an anonymised copy of the electronic patient record that can be searched by researchers against fixed field
or open text criteria (Stewart et al. 2009). An example illustrating the potential of the CRIS in research was the recent study by Underwood et al. (2012) on the mental health needs of adults with ID and autism spectrum disorders (ASDs). It used the CRIS to compare adults with ID and ASD receiving specialist mental health services with participants without ASD. Data were collected from 371 anonymized case records of a clinic-based population in South London. The CRIS enabled the researchers to find from the electronic records that participants with ASD were younger, more likely to be male, less likely to live independently and had more severe ID than those without ASD. Furthermore, those with ID and ASD were less likely to be diagnosed with a psychiatric disorder but had significantly lower health and social functioning than those without ASD.

Using the CRIS the author could search for all cases known to the Mental Health of Learning Disabilities’ service over a fixed period of time (such as two or three years) and count the number of hospital in-patient admissions days and contacts with Accident and Emergency or other emergency services. It would also be possible to use ‘text-mining’ approaches to search the electronic patients’ records for words like ‘emergency’ or ‘crisis’. Sections of the clinical records identified through the electronic search with the CRIS could then be examined in more detail to extract a number of demographic and clinical characteristics of patients and information about the crisis itself including time of day, pathways into care and service response. Although this would yield data from just one, albeit large geographical catchment area it would help give the estimates of the wider prevalence of crisis presentations. This would therefore help us to decide whether further trials of the crisis information wallets are warranted and if so, inform the design of a pilot RCT.
Study 2: A Pilot RCT of modified crisis information

Armed with the essential information on the likely frequency of mental health crises over a defined period of time the next step would be a RCT of modified crisis information. However, given what is already known about the difficulties of recruitment to clinical trials in an ID population, this study would best be set up as a further pilot that tests the acceptability of randomization and provides more accurate estimates of likely effect size needed to plan a definitive RCT. Even at this pilot stage, it is still very likely that several geographical sites would be needed in order to have enough participants in the intervention and control group to carry out simple quantitative as well as qualitative analyses.

**Design:**

The design would be a pragmatic two arm RCT of the use of modified crisis information in patients with comorbid ID and additional mental disorders. The two groups would comprise a group of service users who have been helped to construct, carry and use the crisis information contained in personal wallets and a ‘treatment as usual’ waiting list comparison group.

**Intervention**

The intervention condition would be the modified crisis information carried in wallets as described in this thesis. It is likely that the modified crisis information would need to be carried by the participants in this pilot RCT for a much longer period than six months, (perhaps two or three years) to give more time for mental health crises to occur in order for the use of the modified crisis information to be evaluated.
For the control condition patients would not be given the modified crisis information and essentially receive ‘treatment as usual’ for the duration of the study. They would be offered the crisis information wallets at the conclusion of the study if the findings suggested there was benefit. This control condition of being on a ‘waiting list’ to be offered the modified crisis information at the conclusion of the trial would be chosen as there is no appropriate alternative to the novel intervention of modified crisis information in this service user group.

**Randomization**

Randomization to the two conditions would be carried out independently of the research team by the Institute of Psychiatry Mental Health and Neuroscience Clinical Trials Unit. Randomisation would be at the level of the individual but stratified by centre (assuming that more than one centre is needed).

**Study Population**

The core target population of participants for a pilot RCT would remain people with ID and co-morbid mental disorders, to include those with mental illnesses such as psychotic or severe affective illnesses and/or personality disorders. However consideration would be also given to the inclusion of people with mild ID and autistic spectrum disorder with risk behaviours but without additional diagnosed mental illness or personality disorder, if they have a history of presenting in crisis. People with autism and ID often do present in crisis and require inpatient admissions. Using the CRIS this group of service users could be included as it would give the diagnostic profiles of the people accessing emergency services.
Outcomes:

(a) Eligibility, recruitment, and acceptability of the system.

Eligibility would be assessed in terms of the proportion of patients who meet inclusion criteria for the study. Recruitment rates and acceptability would be assessed in terms of the number of those approached who do not wish to take part. We would also keep track of all participants across the study, carefully recording drop-outs and assessing whether or not the crisis information wallet is carried and used. We would also carefully monitor the acceptability of the assessment methods.

(b) Primary outcome

As previously discussed there is much anecdotal evidence as well evidence from earlier studies in this MD (Res) to suggest that people with ID (and their relatives and carers) often do not know how to access mental health care at all (or at least in a timely manner) in a crisis. Furthermore, when they do access emergency care there can often be important problems in the assessment and management process which are essentially caused by the increased difficulties of communication for people with ID. They are relatively less able to articulate their distress and more likely to be misunderstood or misinterpreted by others. These problems of communication may lead to a range of undesirable consequences including potentially increased distress and agitation and misdiagnosis and thus also to more inpatient admissions especially if the assessment process itself does not allay or reduce distress and agitation or paradoxically increases these or the staff do not accurately understand or diagnose the presentation.
For these reasons, efficacy would be determined primarily by a measure of the primary (quantitative) outcome, which would be the difference in hospital inpatient admission days observed in the intervention group when carrying the modified crisis information. This would be a quantitative outcome.

(c) Secondary outcomes

There would also be a range of secondary (quantitative and qualitative) outcomes relating to what may change in these mental health crises because of the carrying of the crisis information wallets:

1) A secondary (quantitative) outcome would be the change in proportion of service users and carers who, following the introduction of their modified crisis information, would now be able to know how and where to access mental health services. This outcome would be simply defined on the basis of their opinion whether or not they had this knowledge. We would hypothesize that having this knowledge would be important to help reduce distress in service users in crisis (and their carers and relatives) and may also help these service users to gain more appropriate and timelier input from services to help manage their mental health crises (and thus also reduce risk of inpatient admissions).

2) Given the findings of the Thornicroft et al. (2013) study described above, an additional secondary (quantitative) outcome would be the change between the two groups in the clinician-ratings of the therapeutic relationships between keyworkers and patients. The hypothesis would be that carrying the collaboratively constructed modified crisis information would improve the therapeutic alliance between the
keyworkers and the patients, as the patients feel their wishes and preferences have been more listened to and taken on board by the clinicians. The keyworkers would be interviewed using the (clinician rated) therapeutic relationship Working Alliance Inventory (WAIT) adapted for use in community settings (Neale & Rosenheck, 1995). The patient-rated equivalent (WAIC) rating scale has not been used for people with ID and appears unsuitable for people with ID so would not be used in this pilot RCT.

3. Another secondary (qualitative) outcome would be the potential increase in satisfaction of the service users (and their carers) with the clinical encounters they experience when in mental health crises when carrying the crisis information. A semi-structured interview would be devised to elicit their opinions of the care they received in encounters in which crisis information was used or not used.

4. In the feasibility study there was no direct gathering of opinions of the usefulness of crisis information from the range of people that might assist people with ID in a crisis. For example, one somewhat unexpected finding of the feasibility study was that the mental health crisis information seemed to be useful in other circumstances, such as at a GP practice or for ‘non-mental health’ presentations elsewhere. Another secondary (qualitative) outcome in this pilot RCT would thus be the potential increase in satisfaction of staff with clinical encounters with people with ID in crises when they were carrying the crisis information in a range of settings such as primary care and social services as well as accident and emergency and psychiatric liaison. A semi-structured interview would be devised to elicit their opinions of the clinical
encounters and compared between clinical encounters in which crisis information was used or not used.

Sample size calculation:
As noted earlier, it is not yet possible to calculate a sample size for the pilot RCT but the intention would be to use the information gathered in the preliminary CRIS study to estimate the number of crises and likely outcomes between the two groups.

Analysis:
Results of interest would be the recruitment, successful randomization, the fidelity of the intervention (crisis information wallet) and the compliance with the research protocol including intervention adherence and the completion of the research assessments. Descriptive statistics would be used to summarize these results. We would also carry out efficacy comparisons (primary and secondary outcomes as described above) of the crisis information wallets versus treatment as usual. These outcomes would be analysed on an intention-to-treat basis, with data from all participants entered into the analysis including from any who drop out. Regression modelling would be used to compare the outcomes between the intervention and control groups at each of two post intervention implementation time points.

Qualitative analyses of the service user experience of using the crisis information wallets would also be carried out. We would explore the various blocks and enablers of the use of the crisis information and as far as possible, ascertain the contextual factors associated with its use. This qualitative analysis in the study would follow the framework approach and use NVivo software to organise and code the data.
6.2 Other areas for future research

Rather than further attempts then to evaluate newer service models such as Assertive Community Treatment for people with ID it will instead be more feasible and arguably more useful to research the clinical outcomes of existing generic mental health and specialist ID services, and/or hybrid service models such as generic mental health services supplemented by specialist ID input. A lesson learned from generic mental health research is that a much wider range of outcomes than days in hospital should be investigated such as quality of life, service user satisfaction, carer burden and cost evaluations of service delivery (Oliver et al. 2002; Chaplin, 2004).

Some outcomes of services important to people with ID have been identified using service user and carer focus groups and interviews (Miller et al. 2008) and these could be further explored and elaborated in future research studies.

Examples of areas of service provision which are particularly important to research would be the most effective ways in the community of monitoring mental state and medication adherence and promoting the continuing engagement with service users with ID prone to disengagement. Important questions to address include, what are the interventions or components of service delivery that alter the rates of inpatient admissions? What factors might be currently promoting or obstructing the access of people with ID to newer service models of mental health services and the effectiveness of these services for this specific service user group?

We need further research also into the training of staff in generic mental health and specialist ID services and also for carers (Jess et al. 2008). We also need further
research such as that by Crowley et al. (20012) into psycho-education for service users, carers and families; this was a service component shown in this MD (Res) to be considered essential by all stakeholders.

The participants in this MD (Res) research programme came from specialist community services for people with ID. It would be important to elicit the views from staff in generic mental health and primary care services, which currently provide much of the health care for people with ID and severe mental health problems. This should include qualitative work to understand better the perceptions and experiences in generic services of service users, carers and clinicians. As described above it would be valuable to explore the views of others involved too such as social care professionals, and emergency services’ personnel such as police and paramedics about their professional encounters with people with ID and mental health problems. This might also in turn clarify what training might be helpful for them.

As services continue to vary so widely it would be helpful to establish details of the structure and functions of current UK services. The evidence from this MD (Res) research programme could be used to compare the expert consensus view of what services should be providing with the provision of current community services. This might promote more consistency in what these services currently provide. It is important to acknowledge though that this MD (Res) research programme was entirely UK focused. It would be important for future research and service developments to consider the delivery of services elsewhere in the world, even
though in this field most other countries have less developed specialist ID services than in the UK (Torr et al. 2008; Jess et al. 2008).
6.3 The author’s reflections on the MD (Res) research programme.

At the beginning of this MD (Res) research programme my opinion was that it was highly problematic that mental health services for people with ID in the UK remained relatively undeveloped and highly variable in configuration and purpose. This situation of great heterogeneity of community services is likely to continue when comparative research into the effectiveness of different service models has been virtually non-existent. As previously stated, UK Government policy has been to encourage the use of generic (or ‘mainstream’) services wherever possible for people with ID and mental health problems (Department of Health, 2000), whilst recognising that specialist services are sometimes necessary. My own view has been (and remains) that specialist mental services for people with ID should have been developed and trialled and evaluated in some of the ways that newer models of service delivery within generic mental health services have been. I was keen at the outset to see if these relatively more recent models of mental health service delivery such as assertive outreach/Assertive Community Treatment, home treatment and crisis resolution teams could be utilized for people with coexisting ID.

The research findings in this MD (Res) programme suggested however that there is not widespread support for developing new standalone specialist ID services. Specialist ID clinicians saw the future for specialist ID services in developing new and closer ways of co-working with staff in generic mental health services. This viewpoint seemed borne from recognition that adequate resources would not be likely to be allocated for this service user group in order to develop new service models that would have specialist staff in numbers of critical mass to ensure
effectiveness. In turn these research findings have influenced my own views as without widespread support new types of standalone specialist services for people with ID and mental health problems are unlikely to be supported, established and sustained.

My own view is now that specialist ID services need to focus on developing closer working relationships and practice with generic mental health services including with newer service models such as home treatment and crisis resolution teams. It is important that staff in specialist ID services do not just complain about people with ID being misunderstood or neglected by generic mental health services but instead take an active role in changing and developing services. Joint or co-working or ‘hybrid’ service provision needs should not be based on goodwill only but needs to be evaluated and evidence-based through research.

Dissemination of the MD (Res) research findings and the original critical thinking within it is now planned. This will include a review publication drawing substantially from the findings of the MD (Res) research programme which will consider the future of mental health services for people with ID, together with academic presentations and journal correspondence. It is hoped that the findings and the research ideas generated from this research programme will thus be considered widely and that many of the research ideas can be progressed by others.

In many ways mental health services for people with ID have continued to lag behind those for the general population. There are multiple reasons for this but they include the extra difficulties of undertaking research in people with ID particularly when
studying health services and complex interventions. The provision (and funding) of services is still heavily influenced by the still widespread dualistic thinking that seems to prevent many from understanding that people can have *coexisting* ID and severe mental health problems. Ongoing research, including as described above, is vital to clarify further what services should provide for this doubly disadvantaged group, how these services should be implemented and how they should now evolve.
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Is Assertive Community Treatment a suitable model for people with ID?

ACT-ID Interviews Study

Literature review

What should services in the community provide for people with ID and MH problems?

Focus Groups’ Study

What should services in the community provide for people with ID and MH problems?

Delphi Survey Study
Essential routine and intensive components for services in the community

What should services in the community provide for people with ID and MH problems?: How should service components in four key areas be delivered?

Expert Opinion (Interviews) Study
Essential routine and intensive components for services in the community

Feasibility study exploring one of the service components: Can crisis information be modified to make it accessible and useful for people with ID and mental health problems?

Crisis Information Study

Future research: e.g. preparation for an exploratory controlled pilot study of crisis information.
Appendix II: Detailed Flowchart of Service Components’ Studies

Focus groups of service users, carers & professionals

Qualitative Delphi round

Analysis of responses

Literature review

Pilot Delphi questionnaire

Lists of potential components for routine and intensive services

Two quantitative Delphi rounds

Short lists of components considered by consensus to be essential for services

In-depth exploration of key essential service components

Selected individuals invited to interviews

In-depth interviews with 14 expert professionals in specialist services for people with ID and mental health problems

Additional experts invited

Essential routine and intensive components for services in the community for adults with intellectual disabilities and mental health problems

For use in future pilot evaluation studies e.g. Provision of Crisis Information
Appendix III: MD (Res) Publications:

   ACT for People with Intellectual Disabilities and Mental Health Problems. 
   *Psychiatric Services* 59, 936-937.

   Community services for people with intellectual disabilities and mental health problems.  
   *Current Opinion in Psychiatry*, 21, 459-462.

   What should community services provide for adults with psychosis and learning disabilities? : A comparison of the views of service users, carers and professionals. 
   *Advances in Mental Health and Learning Disabilities* 3, 22-27.

   Services in the community for adults with psychosis and intellectual disabilities: A Delphi consultation of professionals' views. 

   Expert opinions on community services for people with intellectual disabilities and mental health problems. 
   *Advances in Mental Health and Intellectual Disabilities* 7, 169-174.

   Mental Health Crisis Information for people with intellectual disabilities. 
   *Advances in Mental Health and Intellectual Disabilities* 7, 135-142.
Letters from readers are welcome. They will be published at the editor’s discretion as space permits and will be subject to editing. They should not exceed 500 words with no more than three authors and five references and should include the writer’s telephone number and e-mail address. Letters related to material published in Psychiatric Services, which will be sent to the authors for possible reply, should be sent to Howard H. Goldman, M.D., Ph.D., Editor, Psychiatric Services, American Psychiatric Association, 1000 Wilson Blvd., Suite 1825, Arlington, VA 22209-3901; fax, 703-907-1095; e-mail, psjournal@psych.org. Letters reporting the results of research should be submitted online for peer review (mc.manuscriptcentral.com/appi-ps).

A Question of Disclosure

To the Editor: The May 2008 issue focusing on the results of Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) was excellent. However, I wish to take exception to the article by Dr. Duckworth and Mr. Fitzpatrick (1), who are medical director and executive director, respectively, of the National Alliance on Mental Illness (NAMI). The authors express doubts about placing any restrictions on the availability of second-generation antipsychotics, claiming that restrictions “will hurt clinical care” and that cost savings will be “illusory.” Their article strongly supports the position of the pharmaceutical industry.

In the same issue the article by Rosenheck and colleagues (2) notes that second-generation antipsychotics cost $10 billion more per year than first-generation agents. I agree that all individuals with schizophrenia should be given a trial of second-generation drugs, but unless these drugs are superior for that individual, first-generation agents should be routinely used. If the newer agents are no more effective for, say, half of all patients—I am guessing here—that would be savings of $5 billion a year.

Whether we like it or not, the funding of mental health services is a zero-sum game. Five billion dollars will buy a lot of case managers, social workers, clubhouses, supported employment, and supported housing. The views expressed by Dr. Duckworth and Mr. Fitzpatrick thus do not represent my views as a member of NAMI nor, I suspect, the views of many other NAMI members.

The other issue raised by Duckworth and Fitzpatrick’s article is the claim at the end of the article that the authors have “no competing interests” in writing about the issue of second-generation antipsychotics. The guidelines for articles submitted to Psychiatric Services state that “conflicts of interest may be direct . . . or indirect . . . Reporting must include all arrangements that may present an appearance of bias” and should cover “the 12-month period preceding acceptance of the manuscript.” The authors in this case are both employees of NAMI, which receives more than half its budget from pharmaceutical companies. According to the Eli Lilly Web site (3), that company gave NAMI chapters 62 separate grants in 2007; in the first quarter of 2008 Lilly gave $520,000 to the national office of NAMI. These sums do not include gifts from other companies that market second-generation antipsychotics.

Thus it would seem appropriate for the authors to have acknowledged this potential conflict of interest so that readers could make their own assessment about whether the opinions expressed were the result of bias.

E. Fuller Torrey, M.D.

Dr. Torrey, a longtime NAMI member, lives in Bethesda, Maryland.

References


In Reply: Dr. Torrey raises an interesting point. In fact, the journal’s standard disclosure forms submitted by both authors contained the following statement: “NAMI receives financial support in part from pharmaceutical and healthcare companies, but does not endorse or promote any specific treatment, medication, service, or product.” We decided not to add this information as a disclosure statement in the published article because the support in question is provided to the organization and not directly to the authors.

The decision reflects the journal’s policy. Neither the editor nor the staff has the resources to make determinations about the levels of budgetary support provided by commercial interests to the variety of public, academic, and private organizations where authors work. If an author’s research efforts or manuscript production are not directly supported by a commercial enterprise, then the journal does not require disclosure.

However, as Dr. Torrey points out in his letter, organizations such as NAMI that work to ensure effective care for people with mental illness have historically received large sums from pharmaceutical companies. The journal’s staff and I hope that the decision not to list industry support for NAMI did not prevent our readers from assessing the validity of the authors’ statements.

Howard H. Goldman, M.D., Ph.D.

In Reply: The history of care for people with serious mental illness in the United States has been one of broken promises. Dr. Torrey has done more to expose this shameful history than anyone else. In so doing, he has be-
come a true hero to NAMI members throughout the country. Thus it is surprising that Dr. Torrey would suggest that monies saved by prescribing first-generation rather than second-generation antipsychotic medications would be reinvested into more community mental health services. If this were so, then the dollars saved in recent years through downsizing and closing state hospitals should have translated into more community services. Sadly, this has not happened. Rather, states have taken these dollars and reinvested them in roads, prisons—anything but services for people with serious mental illness.

Dr. Torrey points out that NAMI receives contributions from the pharmaceutical industry. However, this does not mean that NAMI’s advocacy agenda is driven by these contributions. NAMI has advocated consistently over many years to protect access to a wide range of treatment and services for people with serious mental illnesses, including antipsychotic medications. This position has solid grounding in science. Antipsychotic medications are not interchangeable. A medication that works for one person may not work for another. Thus, for people with schizophrenia and related disorders, a wide range of medications must be available so that clinicians can make informed choices in partnership with their patients about what works best.

Public education advocates would not argue among themselves about whether to prioritize funding for teachers or textbooks. Advocates for people with serious mental illness should similarly not argue over whether funding for medications or case management should be prioritized. Both are desperately needed.

Kenneth Duckworth, M.D.
Michael J. Fitzpatrick, M.S.W.

ACT for People With Intellectual Disabilities and Mental Health Problems

To the Editor: There is no consensus on whether assertive community treatment (ACT) for people with intellectual disabilities who also have mental health problems should be identical to ACT for people with mental illnesses.

Two studies have evaluated ACT for people with intellectual disabilities and coexisting mental health problems (1,2). However, they used versions that were significantly different from each other and from the original ACT model (3). To evaluate the suitability of this model for this population, characteristics of ACT that are necessary for people with intellectual disabilities need to be identified. We therefore report the results of a study that explored the opinions of specialist health staff.

The participants were 21 staff from four sites in the United Kingdom that deliver ACT-type services to people with intellectual disabilities. Participants included psychiatrists, psychologists, intellectual disability nurses, support workers, and occupational therapists. In-depth structured interviews were carried out in 2006 by two experienced clinicians. Participants were asked to express their opinion about each of 26 statements about ACT derived from the Dartmouth Assertive Treatment Scale (4). After complete description of the study, written informed consent was obtained from all participants. Ethical approval was obtained from Guy’s Research Ethics Committee. In general, participants’ opinions were similar, although some disagreement was noted. Participants believed that ACT for people with intellectual disabilities should include most of the structural and human resource features of the original model, including a shared caseload, regular team meetings, a practicing team leader, continuity of staff, and a vocational specialist on staff. They also thought that there should be more than one psychiatrist and more than two nurses per 100 service users. In regard to organizational boundaries, they believed that there should be explicit admission criteria, but having a low intake rate, 24-hour coverage, and a rule about not closing any cases were seen as unnecessary, unrealistic, or inappropriate for this population. Participants indicated that hospital admissions and discharge planning should involve personnel from the ACT service, but it was not agreed whether these personnel should take responsibility for such planning.

There was disagreement about whether the ACT service should have full responsibility for treatment services, particularly housing support, employment, and rehabilitation. Participants agreed that the nature of the ACT service should be similar to that of the original model, including community delivery of services, involvement of service users’ support networks, and a stage-wise treatment model for those who misuse substances. There was disagreement on whether a no-dropout policy or high levels of service time and contacts were realistic or necessary. Participants did not support direct service provision by service users and family caregivers but agreed that their involvement in service development, support roles, and provision of feedback was essential. [Three tables that provide more details about participants’ responses are available as an online supplement to this letter at ps.psychiatryonline.org.]

The main limitation of this study was that participants did not share the same level of understanding about the original ACT model. In addition, they were typically serving persons with a wider range of mental health problems than those for whom ACT was originally intended. A focus on patients with more severe mental health problems—for example, by restricting future research on ACT among persons with intellectual disabilities to those who also have psychotic disorders—would better complement research on ACT among persons with mental illnesses.

We thus hope that the findings reported here are useful for generating further discussion about ACT for persons with intellectual disabilities. It remains difficult to adequately determine whether service users with intellectual disabilities and mental...
health problems might benefit from ACT because of ongoing problems with the definition and implementation of the model for this service user group as well the lack of specialist professionals working with people with intellectual disabilities and mental health problems who have close knowledge and experience of ACT. Hence studies such as this one will be similarly limited. In our opinion, therefore, it may be more fruitful at present to explore the effectiveness of broader models of specialist community-based services for people with intellectual disabilities and coexisting mental health problems.

**Colin Hemmings, M.B.B.S., M.R.C.Psych.**

**Lisa Underwood, B.Sc.**

**Nick Bouras, Ph.D., F.R.C.Psych.**

Dr. Hemmings, Ms. Underwood, and Professor Bouras are affiliated with the Estia Centre, Institute of Psychiatry, King’s College London.

**Acknowledgments and disclosures**

The authors acknowledge the contributions of Stephen Higgins, M.Sc., Geraldine Holt, F.R.C.Psych., Dimitrios Paschos, M.R.C. Psych., Elias Tsakanikos, Ph.D., and Steve Wright, M.Sc.

The authors report no competing in interests.

**References**


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Table 1. Summary of responses on the structure and human resources of ACT for people with intellectual disabilities

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<th>Component</th>
<th>ACT statement</th>
<th>Summary of responses</th>
<th>Conclusion</th>
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<tr>
<td>A. Small caseload</td>
<td>Service user to staff ratio of 10:1</td>
<td>Responses were very mixed, equally positive and negative. A ratio of 10:1 was seen as realistic by some but unrealistic by others. Many participants felt that caseload should be lower whilst others thought it should be higher. Suggestions ranged between 5 and 25:1.</td>
<td>No agreement</td>
</tr>
<tr>
<td>B. Shared caseload</td>
<td>Provider group functions as a team rather than individual practitioners.</td>
<td>Most participants said that working as a team with a shared caseload would be beneficial. The few negative responses suggested that this way of working was unsuitable for people with intellectual disabilities who may prefer to deal with one individual, that it was unrealistic and would not work in practice. There was concern that specialists would be providing a generic function.</td>
<td>Should be a feature of ACT</td>
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<tr>
<td>C. Team meeting</td>
<td>Team meets regularly to plan, review services for each client.</td>
<td>All participants expressed positive views on holding regular team meetings. This was seen as an important and realistic way of working although some participants explained that it could be difficult to maintain in practice.</td>
<td>Should be a feature of ACT</td>
</tr>
<tr>
<td>D. Practicing team leader</td>
<td>Supervisor of front-line clinicians provides direct service</td>
<td>This was seen as a useful and important way of working. Some participants had reservations about team leaders having sufficient time to fulfill both roles but all felt they should be involved to some extent.</td>
<td>Should be a feature of ACT</td>
</tr>
<tr>
<td>E. Continuity of staff</td>
<td>The service maintains same staffing over time</td>
<td>Responses were mainly positive. Participants thought that continuity was important and helpful. However, this was seen as an ideal that would be difficult in practice. Issues around recruitment, high staff turnover and training rotations were mentioned. Some participants felt that an element of change could be beneficial.</td>
<td>Should be a feature of ACT</td>
</tr>
<tr>
<td>F. Staff capacity</td>
<td>The service operates at full staffing</td>
<td>Participants had mixed views about whether this was possible, though many felt it was a good ideal. Operating at full staff capacity by using temporary staff to cover short term absences or gaps in appointments was mentioned as being at odds with maintaining continuity.</td>
<td>No agreement</td>
</tr>
<tr>
<td>G. Psychiatrist on staff</td>
<td>At least one full-time psychiatrist per 100 service users assigned to the team</td>
<td>There was an assumption that there would be a psychiatrist on staff. Participants focused on whether one per 100 service users was enough. This was seen by most as too high a caseload. Some participants felt that this might be feasible if the psychiatrist had a more consultative role but not if they were a full team member.</td>
<td>The team should include more psychiatrists than 1 per 100 service users</td>
</tr>
<tr>
<td>H. Nurse on staff</td>
<td><strong>Two or more full-time nurses per 100 service users</strong></td>
<td>All participants said there should be more than two nurses per 100 service users. This was seen as necessary to achieving a small caseload. Suggestions ranged from 3 or 4 nurses per 100 service users up to 10 per 100.</td>
<td>The team should include more nurses than 2 per 100 service users</td>
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<tr>
<td>I. Vocational specialist on staff</td>
<td><strong>Two or more with one year’s training or experience in vocational rehabilitation/support</strong></td>
<td>This received a mainly positive response. Participants felt it that having a vocational specialist of staff would be important and that helping service users into work was beneficial. Some thought this should be provided by the team’s occupational therapist. Many participants acknowledged the difficulties faced by people with intellectual disabilities in accessing vocational support from other services and finding employment in general.</td>
<td>Should be a feature</td>
</tr>
<tr>
<td>J. Service size</td>
<td><strong>Sufficient absolute size to provide consistently the necessary staff diversity and coverage</strong></td>
<td>Participants felt that staff diversity and adequate coverage was important. Many expressed doubts on whether it was possible to have sufficient absolute size to achieve this. Difficulties within the UK NHS and with resources were cited as the main problems. The need for flexibility and a balanced skill mix were also mentioned.</td>
<td>No agreement</td>
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### Table 2. Summary of responses on the organizational boundaries of ACT for people with intellectual disabilities

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<th>Component</th>
<th>ACT statement</th>
<th>Summary of responses</th>
<th>Conclusion</th>
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<tr>
<td>A. Explicit admission criteria</td>
<td>Clearly identified mission to serve a particular population; measurable, operationally defined criteria to screen out inappropriate referrals</td>
<td>Most participants thought it would be important to have explicit admission criteria but acknowledged that this would be difficult to apply. Some felt that this should be assessed case by case, that it was important to be flexible and that it would be good to operate an inclusive service. Participants suggested there would be pressure from other services for an ACT team to take service users who didn’t fit the criteria. They also mentioned problems regarding diagnosis and complex needs in this population.</td>
<td>Should be a feature of ACT</td>
</tr>
<tr>
<td>B. Intake rate</td>
<td>Takes service users in at a low rate to maintain a stable service environment</td>
<td>This received a large number of negative responses. Participants felt it was unrealistic and difficult in practice. One participant said that it could lead to staff becoming bored and a culture of dependency. Those who felt that intake should be low acknowledged that there might be a high number of people who need or want access to the service and that refusing to accept them would be difficult.</td>
<td>Should not be a feature of ACT</td>
</tr>
<tr>
<td>C. Full responsibility for treatment services</td>
<td>As well as case management/psychiatric services programme directly provides counselling/psychotherapy, housing support, employment and rehabilitative services</td>
<td>Many participants had both positive and negative views on accepting full responsibility for all these services. Some thought that mental health services should be provided but were unsure about housing, employment and rehabilitation. They felt this was either outside the role of an ACT team, that it went against the principles of Valuing People UK White Aper on intellectual disabilities services), or that other services were better placed to provide specialist support. But, some participants did feel that this would be effective and could be done. They felt it would be smoother for service users even if it was hard to implement.</td>
<td>No agreement</td>
</tr>
<tr>
<td>D. Responsibility for crisis services</td>
<td>Twenty-four hour coverage of psychiatric services</td>
<td>Many participants felt this was neither necessary nor realistic. Those who gave a positive response also said that boundaries would be needed, that it might not be feasible and that there may be resistance from staff. Participants felt that 24-hour coverage could be subject to inappropriate use and that services in place for the general population were appropriate for people with intellectual disabilities.</td>
<td>Should not be a feature of ACT</td>
</tr>
<tr>
<td>E. Responsibility for hospital admissions</td>
<td>Programme is involved in hospital admissions</td>
<td>Involvement in hospital admissions was viewed positively. It was seen as necessary to providing continuity and important when service users were admitted to mainstream wards. However, some participants were less sure that the team should remain responsible for service users. Roles as an education or support service were suggested. A few thought this was outside the team’s remit and that it would be</td>
<td>Team should be involved in hospital admission.</td>
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difficult in practice.

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<tr>
<th>F. Responsibility for hospital discharge planning</th>
<th>Programme is involved in planning hospital discharges</th>
<th>Team should be involved in hospital discharge planning</th>
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<tr>
<td>All participants felt the team should be involved in discharge planning, provided the service user still fulfilled the admission criteria. A distinction was made between involvement or providing support and whether the team should be responsible for this.</td>
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<tr>
<th>G. No time limit on services.</th>
<th>Programme closes no cases, remains point of contact for all service users as needed</th>
<th>Cases should be closed if appropriate. There should be no set time limit on service users’ involvement with team</th>
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<td>Participants saw a distinction between having no set time limit and closing no cases. Not closing cases provoked a large number of negative responses. Participants felt this went against the principles of valuing people and that the team should be working to get people into mainstream services and that service users had to take some responsibility. Some said it was sometimes necessary to close cases if service users weren’t engaging or were ready to move to another service. In some cases closure could be beneficial to service users. However, there was a view that there should be no set time limit on service users’ involvement with the team and that even after a case had been closed the service could still be available for re-referral, advice or a point of contact.</td>
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### Table 3. Summary of responses on the nature of ACT for people with intellectual disabilities

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<th>Component</th>
<th>ACT Statement</th>
<th>Summary of responses</th>
<th>Conclusion</th>
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<tr>
<td>A. In vivo services</td>
<td>Service monitors status, develops community living skills in community rather than the Service system</td>
<td>Most participants responded positively, they said that in vivo services would be more user friendly and that it was better to see service users in a naturalistic environment. Some participants felt there was still a place for inpatient setting for more complex cases and some outpatient services. There were reservations over the amount of time that community visits take up and the resources implications of this.</td>
<td>Should be a feature of ACT</td>
</tr>
<tr>
<td>B. No-dropout policy</td>
<td>Service engages and retains clients at a mutually satisfactory level</td>
<td>There were mixed views on having a no-dropout policy. Some participants agreed that it was necessary; they felt that services should be proactive in their engagement with services users but acknowledged that there were some limits as to how much service users could be pursued. Others felt that service users had to take responsibility for their engagement and that their motivation was necessary.</td>
<td>No agreement.</td>
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<td>C. Assertive engagement measures</td>
<td>Uses outreach involvement, plus legal mechanisms (e.g., representative payees, probation/parole, OP commitment) as indicated</td>
<td>Participants felt it was important that these measures were available but that they should only used when necessary. There was concern that the rights of service users should be considered and that more restrictive, coercive measures should only be used as a last resort.</td>
<td>Should be a feature if necessary</td>
</tr>
<tr>
<td>D. Intensity of services</td>
<td>High total amount of service time, as needed</td>
<td>High intensity of services was seen as positive in theory but many participants felt there would be resources limitations and that some limits would have to be in place. A need for flexibility was mentioned with intensity varying according to the need of each service users at particular times. Participants felt there would be difficulties balancing the amount of input needed with the resource needs of the team and that prioritizing needs might be required.</td>
<td>No agreement</td>
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<tr>
<td>E. Frequency of contact</td>
<td>High number of service contacts, as needed</td>
<td>Some felt that high frequency of contact was important if required so long as the type of contact varied and included brief visits or telephone calls. Others felt this was unrealistic and not necessary.</td>
<td>No agreement</td>
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<tr>
<td>F. Work with support system</td>
<td>With or without the service user present, programme provides support/skills for client’s support network families,</td>
<td>Involving service users’ support system was viewed very positively. Participants said it was essential. Many felt this needed to be done in a formal and systematic way. There was some concern about service user confidentiality.</td>
<td>Should be a feature of ACT</td>
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<td>ACT in Intellectual Disabilities</td>
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<tr>
<td><strong>Group modalities used as treatment strategy for clients with substance abuse disorders</strong></td>
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<td>Views on whether the team should provide substance abuse services were mixed. Though most people felt it was important that these were available, many felt that mainstream mental health or substance abuse services might be better placed to provide them. Those who felt this was part of the team’s role said they would need more training and would want to seek specialist help from mainstream services. Those who discussed group modalities had differing views on whether it was suitable for people with intellectual disabilities.</td>
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<td>No agreement</td>
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<tr>
<td><strong>Uses stage-wise treatment model that is non-confrontational, follows behavioural principles, considers interactions of mental illness/substance abuse and has gradual expectations of abstinence</strong></td>
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<td>Participants thought this model sounded reasonable and that if it had an evidence base within generic mental health then it should be used by intellectual disabilities services. There was concern that there wouldn’t be any evidence on this approach for people with intellectual disabilities and that it should be adapted to suite their abilities and needs. Many participants expressed concern at the lack of knowledge among existing services and others felt that substance abuse issues weren’t common enough to require inclusion.</td>
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<td>Should be a feature of ACT</td>
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<tr>
<td><strong>Service users and carers are involved as team members providing direct services</strong></td>
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<td>Many participants thought that services users had a role in providing advocacy, support, role modeling or points of contact for other service uses. But involving service users as team members was viewed less positively, particularly with respect to providing direct services. Whilst some felt this would be a good idea and would be useful, many participants felt it would be inappropriate and would result in ethical and confidentiality problems. Obtaining feedback from service users and involving them in the development of services was seen as important.</td>
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<td>ACT should encourage service user involvement</td>
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Community services for people with intellectual disabilities and mental health problems
Colin P. Hemmings

Introduction
This review will focus on recent studies of community services for people with intellectual disabilities and coexisting mental health problems. As there have been so few such studies reported this review will consider those published within the last 3 years. These were identified from a Medline, Embase and PsychInfo literature search using the key terms of community services, mental health, disabilities, disability and mental retardation. The term intellectual disabilities will be used here. This corresponds to both mental retardation and learning disabilities, the latter being a widely used term in the UK.

Community services
In many developed countries there have been rapid moves away from institutionalized care towards community care for people with intellectual disabilities. They are more likely to be diagnosed with co-existing mental disorders than the general population [1]. A significant proportion of people with intellectual disabilities in the community therefore have coexisting mental health problems causing much morbidity, carer burden and health and social care service costs. Recently published case studies illustrate the ongoing problems faced by people with these dual diagnoses in accessing generic mental health services [2,3]. Despite this situation there remains a serious lack of evidence on the effectiveness of services in the community for them. There have continued to be only a few isolated reports in the literature, the most recent of which are described here.

Purpose of review
This review will examine the most recently published studies of community services for people with intellectual disabilities and mental health problems.

Recent findings
There is a continuing lack of evidence regarding these community-based services. Few studies have been published at all whilst even fewer still have reported outcomes in any detail. Recent studies have attempted to evaluate assertive community treatment for this service user group; however, they have been unsuccessful owing to inconsistency about what an assertive community treatment service should be for people with intellectual disabilities.

Summary
An evidence base is urgently needed for these community-based services. Research should utilize the opinions of service users and their carers as well as professionals and focus on those people with intellectual disabilities and more severe mental health problems. It may be more fruitful to examine the components of community-based services rather than use the terminology of specific models such as assertive community treatment. The service components considered to be essential need first to be identified using a systematic methodology and then evaluated using a broad range of outcomes.

Keywords
community services, intellectual disabilities, mental health
the range of outcomes in both community and inpatient groups. Risk and unmet needs appeared to be the most important determinants of admission rather than diagnosis. The community group were shown to have a reduction in their problems associated with mood changes and relationships. The service user ratings for the community group showed significant decrease in unmet needs and significant increase in met needs. Staff ratings, however, did not show such changes. Those in the community group often experienced a slight deterioration in outcomes between the 9-week and 6-month follow-up points. Compared with those admitted to the inpatient unit those within the community arm of the study were more likely to have input from a community mental health nurse. The authors suggested this could have been related to primary inequalities in service provision or differing degrees of insight that affected take-up of services.

Cowley et al. [5] looked at predictive factors for psychiatric inpatient admissions within a cohort of 752 adults with intellectual disabilities living in community settings in south London, UK. This study showed that a diagnosis of schizophrenia spectrum disorders (as well as the presence of physical aggression) in its large sample was associated with admission.

Maitland et al. [6] analysed the pathways to care of a cohort of 791 adults with intellectual disabilities referred for a specialist mental health in intellectual disabilities service in south London. They found that the referrals from generic mental health services were more likely to have schizophrenia spectrum disorder, personality disorder and mild intellectual disabilities and were more likely to be referred inpatients and to have an Asian ethnic origin than referrals from primary healthcare.

Spiller et al. [7] conducted an analysis of the factors associated with consumption of the same service in south London. They constructed a service consumption index based on the number of outpatient clinics attended, contacts with community psychiatric nurses, home visits by a psychiatrist and the number of admissions. This consumption index was used to divide the sample of 115 service users into heavy and light service users. Those with schizophrenia spectrum disorders and with higher number of affective/neurotic symptoms were more likely to be heavy service users. Age, living situation and the degree of intellectual disabilities were not found to be significant predictors of severe consumption. A small proportion of service users were found to consume almost half of the service resources.

Bhaumik et al. [8] published their audit of the effectiveness and quality of care in the community of people with intellectual disabilities by specialist psychiatrists in Leicestershire. Using a specially designed questionnaire and audit standards set by local consensus they investigated the opinions of 49 patients/carers about the psychiatric service. The patients/carers reported a high level of satisfaction with the service they had received.

Lindsay et al. [9] followed up 247 referrals to a community forensic intellectual disabilities service over a 12-year period. These included male sex offenders, males with other offending behaviours and 21 female offenders. They looked at a number of their characteristics including the prevalence of mental illness in the three groups. Although they only included schizophrenia and mood disorders to determine the overall prevalence of mental illness, they still found high rates in both male groups (31.4% for sex offenders, 32.1% for other offenders). The prevalence of mental illness in the female offenders with intellectual disabilities was even higher still, at 66.6%. The rate of reoffending in the female group was low which led the authors to hypothesize that treatment of their mental health problems could possibly have helped reduce recidivism.

Hackerman et al. [10] have described a community outpatient programme for people with intellectual disabilities and mental health problems in the USA. The authors reported a number of positive outcomes including linking to primary healthcare services, reduced inpatient admissions, imprisonment and homelessness and increased employment rates and carer satisfaction.

### Assertive community treatment

Whilst there continues only to have been a very few studies published regarding community services for people with intellectual disabilities and mental health problems, research into community mental health service delivery in the general population has continued at pace. This has led to many developments in community mental healthcare. For example, there has been support for the implementation of a specific model known as Assertive Community Treatment (ACT) [11] for those difficult to engage and prone to relapse and frequent inpatient admissions. Although the benefits of ACT in the United Kingdom remain controversial [12] the use of ‘assertive outreach’ teams is now Department of Health policy [13]. An ‘assertive outreach’ approach is widely assumed to employ many features of the original ACT model. According there has been interest in whether or not ACT as applied to people who have both intellectual disabilities and mental health problems could be an effective service delivery model. This interest was strengthened by the UK-700 study that found that people with borderline intellectual functioning spent less time in hospital if they received intensive, rather than standard, community care [14].
A few ACT-type services for people with intellectual disabilities and mental health problems have been set up in the UK. Prakash et al. [15] described one such service. Hassiotis et al. [16] reviewed these services and found that several service configurations have operated. There has been no consensus therefore about what constitutes ACT for people with intellectual disabilities. There has been no agreement as to whether ACT for people with intellectual disabilities should share the characteristics of ACT as operationalized in the Dartmouth Assertive Treatment Scale (DACTS) [17] and as described in the UK by Department of Health guidelines [13].

Two recent studies attempted to evaluate forms of ACT for people with intellectual disabilities in the UK using randomized controlled trials. In the TACTILD study Oliver et al. [18] compared their ACT-type model with ‘standard community treatment’ of participants with mild or moderate intellectual disabilities and serious mental health or behavioural problems. They assessed global functioning as their primary outcome measure with carer burden and quality of life as secondary measures. Assessments were made at baseline and again 12 weeks later. Participants included those with ‘challenging behaviour’ as well as severe mental health problems. They also included those with IQ between 70 and 75 as well as less than 70 but excluded those with severe intellectual disabilities and those who needed immediate intensive treatment. The ‘assertive community treatment’ group was defined as those who received more than one visit per week from one or more professionals and the ‘standard’ group as those that received no more than one visit per week from a professional. Hence ‘assertiveness’ was measured only in terms of frequency of contact. Despite a 25-month recruitment period they were only able to include a total of 30 participants owing to ethical concerns [19]. The authors found no significant differences between the groups on any outcome measure. The service received by 33% of participants in the ‘standard’ treatment group, however, met the study’s definition of ACT. The authors concluded that there is a blurring between standard and assertive approaches in practice.

In the ACT-ID study Martin et al. [20] compared their ACT-type model with ‘standard community treatment’ in a sample of 20 participants with mild or moderate intellectual disabilities and a coexisting mental illness (schizophrenia spectrum or affective disorder). People with ‘challenging behaviours’ but no diagnosable mental illness were excluded in this study. Those with severe intellectual disabilities were also excluded, as were those who needed immediate intensive treatment. Participants were assessed at baseline and again at 6 months after beginning treatment. The ACT-type model used in this study was again defined only in terms of contact with professionals. ACT was defined as contact with two staff members as often as required. Contact with one staff member no more than once weekly was defined as ‘standard community treatment’. This study also showed no major differences between the assertive and standard groups using a range of outcome measures. Both standard and assertive groups showed decreased unmet needs and carer burden and increased functioning and quality of life. There were, however, no statistical differences between the two treatment groups.

Both sets of authors cautioned that their results did not indicate that ACT in people with intellectual disabilities is clearly ineffective. Instead the studies highlighted the difficulties in both the research methodology and in the implementation of ACT in intellectual disabilities services. Problems in developing and evaluating ACT-type models for people with intellectual disabilities have included the fidelity of the models to the original ACT model, a lack of distinction between them and the control services, and other methodological or ethical issues. The definitions of ACT used in the TACTILD and ACT-ID studies were significantly different from the original ACT model and also different from studies of mainstream community mental health services in the UK, which have tended to focus on caseload size alone [21]. The treatment received from control services in the TACTILD and ACT-ID studies were similar to the intervention (assertive) services and this may therefore have accounted for the lack of difference in outcomes. Methodological and ethical problems encountered by both of these studies included their difficulties in finding existing services that were willing to participate, recruiting samples of sufficient size, obtaining consent from participants with intellectual disabilities, and choosing relevant outcomes to measure [20].

**Future research**

It can be argued that people with intellectual disabilities with coexisting mental health problems have not had the same access to the developments in mainstream community mental health service delivery that have occurred in recent times. For this service user group, the lack of research into the effectiveness of the community services they receive together with the inexcusable failure of many community intellectual disabilities services in the UK to implement the recognized national care standard of the Care Programme Approach [22,23] can be considered important forms of disempowerment. Any new community service models, however, must be able to be implemented with consistency and be amenable to systematic evaluation to ensure effectiveness and value for money. It is impossible to research adequately whether service users with intellectual disabilities and mental health problems might benefit from ACT when there are ongoing problems with the definition and
implementation of this model. It remains unclear therefore whether the original ACT model is suitable for people with intellectual disabilities and mental health problems. It may be more fruitful to explore the effectiveness of specialist community-based services for people with intellectual disabilities and mental health problems without using the terminology of specific service delivery models about which there remains a great deal of inconsistency and controversy.

The ACT studies in people with intellectual disabilities have revealed the need for future research to start from further back in the research design continuum. Campbell et al. [24] have described a framework for design and evaluation of complex interventions to improve health. Services for adults with intellectual disabilities and mental health problems are still at the modelling stage of this framework. Therefore qualitative studies are necessary in the first instance [25]. These could establish what are considered to be the essential components of services. These essential components could then be examined further in pilot studies in preparation for much larger, randomized controlled studies. This further research should be informed by the findings of generic community mental health services research. For example, it must investigate a wide range of outcomes such as quality of life, service user and carer satisfaction, rather than just hospital admissions. A focus on service users with intellectual disabilities and more severe mental health problems would also better complement the existing research on community mental health services in the general population [26]. This research should also utilize the opinions and experiences of service users and their carers as well as professionals.

Conclusion

People with both intellectual disabilities and mental health problems are among the most vulnerable and socially excluded in society. Yet there has been far too little attention to the evaluation of community services they currently receive and to the identification of the specific service components they might need. Research is needed to determine what community services should be like for this service user group. It will be necessary to employ systematic methods of assessing agreement on which individual service components are essential for the provision of an effective and satisfactory service. This research should focus on those with intellectual disabilities who have more severe mental health problems and involve a range of stakeholders as well as outcomes. Such research should also help to define which groups of service users with intellectual disabilities and mental health problems are most likely to benefit from more intensive or assertive services.

References

What should community services provide for adults with psychosis and learning disabilities? A comparison of the views of service users, carers and professionals

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Abstract
Three separate focus groups were conducted to compare the views of service users, carers and specialist health professionals on community services for adults with psychosis and learning disabilities. Participants were asked which staff, treatments or interventions and methods of working or style of service organisation make a significant contribution to helping people with psychosis and learning disabilities. Although there were few direct contradictions or conflicts between the three groups, the priorities of service users, carers and professionals often differed. Development of community services for adults with psychosis and learning disabilities should incorporate the views of service users and their carers as well as clinicians.

Key words
community services; learning disabilities; psychosis

Introduction
In countries such as the UK nearly all care for people with learning disabilities is provided in community settings. A significant proportion of people with learning disabilities have additional psychotic illnesses (Cooper et al, 2007), causing much morbidity, carer burden, and health and social care service costs. However, there is a severe lack of research on services for adults with learning disabilities and psychosis in the community (Hemmings, 2008). It is increasingly recognised that service users themselves and their carers should play a major role in the development of services, so there has been increasing emphasis on establishing service users’ and carers’ views on community services (Rose, 2001).

Focus groups can be an effective method of conducting exploratory research among adults with learning disabilities (Fraser & Fraser, 2001). They have also been used to explore the experiences of carers of people with learning disabilities in accessing primary health care (Thornton, 1999). Focus groups have elicited the views of service users without learning disabilities on generic mental health services (Powell et al, 1996; Higet et al, 2004; O’Toole et al, 2004; Mason et al, 2004). Most research investigating the views of service users with both learning disabilities and mental health problems has focused on inpatient care (Parkes & Hassiotis, 2007; Young & Chesson, 2006; Samuels et al, 2007; Longo & Scior, 2004). Their views of generic mental health services have also been explored (Gates & Waight, 2007). Little else has previously been reported on service users’ or carers’ or clinicians’ views on community services that provide care for people with learning disabilities and mental health problems. The aim of this study was to compare the views of service users, carers and specialist health professionals on the help needed by adults with psychosis and learning disabilities from community services.
Method

Ethical approval was obtained from the Joint South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee (ref: 07/Q0706/19). Three focus groups (service users, carers and professionals), each of one hour, were held in South London between September and October 2007. All participants had experience of using services, caring for a service user or working for community services in South London that provide care for people with learning disabilities and mental health problems including psychosis. Service users were recruited from a group of people with learning disabilities who meet to discuss mental health issues; all had capacity to consent to take part. Carers and professionals were recruited through community services. Written informed consent was obtained from all participants.

The group facilitators (authors CH and LU) asked the participants in the carers and professionals’ focus groups the following three research questions.

- What help in the community do people with learning disabilities and psychosis need?
- Do some of these people need more intensive help and if so, what are their characteristics?
- What more intensive help over and above routine care in the community do these particular service users need?

The three main types of help, or service components, discussed were staff, treatments or interventions, and methods of working or style of service organisation that make a significant contribution to helping people with psychosis and learning disabilities (Marshall et al., 2004). For the service users the same questions were asked, except that the term mental health problems was used instead of psychosis. This was necessary because it was not possible to convene a service user focus group only of people with experience of psychosis. The researchers felt that it was inappropriate to ask people with learning disabilities to focus on psychosis when they might not fully understand what is meant by the term or it was outside their own experience. Service users were also provided with hand-outs that included pictorial aids. Each focus group was audio-recorded and transcribed.

The transcriptions were divided into text units by sentences or the different utterances of each participant. Two researchers then coded each of them separately according to whether they thought it constituted a potential routine service component, a potential characteristic of people needing more intensive services, a potential intensive service component or none of these. Similar components and characteristics were grouped together using categories with face validity.

Results

The service user focus group consisted of six (three female, three male) participants. Their mean age was 44.2 (range: 42–47). Three were black/black British and three were white/white British. All had experience of using specialist mental health services for people with learning disabilities. The carers’ focus group consisted of five (two female, three male) participants with a mean age of 50 years (range: 46–56). Three were black or black British, one white British and one Irish. They included a family carer, an adult placement carer, a community support team manager and two paid carers. All had experience of caring for someone with psychosis and learning disabilities. The professionals’ focus group consisted of five (two female, three male) participants. Their mean age was 38.2 years (range: 32–48). There were two psychiatrists, one nurse, one occupational therapist and one psychologist. All had experience of working with people who have psychosis and learning disabilities. The mean length of their experience of working for community-based services that provide care for people with psychosis and learning disabilities was 8.6 years (range: 3–15).

Routine service components

Staff

Service users mentioned various staff as having been helpful to them: ‘Community nurse’, ‘Social worker’, ‘Key worker’. They felt that staff should get to know service users and should receive training on learning disabilities and mental health.

- ‘They need a bit of training to build them up… to give people advice.’

The carers emphasised the need for a range of staff.

- ‘Professional to address behavioural issues.’

- ‘You know when we go to the CPA… and meet social workers… you have maybe the psychologist and speech and language therapy… the OT… it’s a kind of multidisciplinary setting, you know a consultant psychiatrist…’

- ‘The social worker is a very key person.’

Paid care staff were keen to refute any idea that they too were not ‘professionals’ and felt that this distinction between them and health staff was inaccurate and unhelpful. They stressed how important it was for staff such as social workers and housing workers to know the service user.

- ‘I don’t think the social workers know the actual person… and I think that is a big problem.’

The professionals distinguished between core staff and other staff also necessary.

Advances in Mental Health and Learning Disabilities  Volume 3 Issue 3 September 2009 © Pier Professional Ltd
‘I think in terms of core professionals that would be… psychiatry and CPNs… psychology and OT… and social workers as well.’

‘Support workers help service users access services.’

‘You might also have some untrained staff… more sort of dealing with people’s social needs.’

‘It’s essential you have access to them… whether they’re necessarily in the same team… is slightly different.’

They thought it was crucial that all staff should have an understanding of both psychosis and learning disabilities.

‘You’ve got to have someone who can diagnose psychosis in people with learning disabilities, a psychiatrist…’

‘Staff with an understanding of both psychosis and learning disabilities, everybody who was coming to contact with client, and has influence over that client in assessment, or treatment, should be able to understand both of these diagnoses.’

Treatment or interventions
The service users were keen for more opportunities to talk about their mental health, make friends and talk about problems. They preferred that, when receiving counselling, there should be more frequent sessions over a longer period and that they would have more say about when they stopped.

‘Someone speaking to them about relaxation sort of thing and helping them relax sort of thing… like going to classes and talking about the anxiety.’

They wanted advice.

‘Might need advice about things… like going to classes and things like that… Or getting a job, little things like that help.’

They wanted practical help with looking for work, applying for jobs, paying bills and budgeting, looking after themselves, going on holiday, housework, shopping and travel, making appointments, visiting services, and going to classes and events.

‘You might need a bit of help… Like making appointments.’

‘I think people who can’t read forms, someone should read leaflets out to them.’

Housing was important; they wanted help with finding a place to live, getting repairs done and with what to do when experiencing housing problems.

Carers emphasised the need for prompt treatment.

‘The problem sometimes is the wait to get treatment… you might have to wait months and months.’

They also thought there should be a source of information available for carers detailing what help and interventions are available to help the people they care for.

‘If we can have a kind of dossier… like a yellow pages… where these interventions are being mapped out.’

Professionals mentioned a range of specific interventions.

‘Medication including clozapine.’

‘There are different components of CBT some of which can come through on different levels.’

‘Family interventions... the family or carer support to understand the illness the drugs... the side effects, how to spot relapse, how to support someone if they’re hearing voices.’

Methods of working or style of service organisation
Service users wanted:

‘More say about things’.

Carers emphasised the need for communication.

‘I just think the key to all of this is actually just professionals working together.’

‘The distinction between mental health and learning disability… often look at that as two separate things... and only look at one.’

The professionals emphasised the need for diagnosis and early interventions.

‘We should also have staff that are accessible for people who are getting it earlier… the age groups that need an early diagnosis.’

There was also support for a needs-led service.

‘Should start with the clients and find out what… their needs are.’

What should community services provide for adults with psychosis and learning disabilities?
There were no calls for any radical changes to current ways of working or large-scale changes from what is available to those without learning disabilities.

‘The service should mirror the service for somebody without a learning disability as well but the difference being maybe the different knowledge that people have or the length of time that people need to engage effectively.’

**Characteristics of service users needing more intensive services**

There was unanimous agreement across the focus groups that there is a sub-group of adults with psychosis and learning disabilities who sometimes need more intensive services. Service users mentioned people who self-harm, who are experiencing housing problems or who have suffered bereavement as those needing more intensive support.

‘If like you lost someone.’

‘If you’ve got worries in your house.’

‘The one who tried to harm themselves.’

The carers emphasised that this subgroup would not be static.

‘There could be just a thing happening in their life that is making them more stressed.’

‘Could be changes in the environment, bereavement.’

‘Particular time, change of staff.’

‘Moving out of one location to another.’

Professionals also emphasised that this subgroup might not be fixed.

‘I think there are people who move in and out of that group.’

They emphasised risk and comorbidity, including general medical, substance misuse and other mental disorders.

‘Some who are more treatment-resistant and who are acutely ill and presenting a form of high risk.’

‘Non-compliers or non-engagers.’

‘A relapse or crisis.’

‘First diagnosis.’

‘Just coming out of inpatient treatment.’

‘Their social circumstance, how much support they’re getting… the place they are living… whether they’ve got a job or occupation.’

**Intensive service components**

Service users did not discuss any differences between routine or more intensive services. The professionals mentioned that there should be access to an approved social worker. Otherwise there was no difference in the staff or in treatment or interventions from routine services thought necessary by the three focus groups.

The carers emphasised the need for response by services, but on an individual basis. They considered it important for service users to be able to access things when they were needed, and that frequency of contact should be flexible, depending on the individual. They considered it necessary for service staff to make a relationship with the service user before times of crisis in which they might need more intensive services. There was support for use of a specialist inpatient unit rather than generic mental health units.

‘One of our service users who lives in the community was getting a lot of grief from other people in the unit who didn’t have learning disabilities and knew how to manoeuvre, and they’re quite vulnerable.’

The carers felt that the role of services should include educating other health staff such as general doctors and others in the general public such as college staff or staff in banks about the difficulties of people with learning disabilities. They also were of the opinion that Accident and Emergency Departments were not the best places for people with learning disabilities and psychosis in crisis. They preferred a more specialist emergency mental health clinic.

‘If they’re told to go after hours to A and E and often they are seeing someone who hasn’t got any experience of seeing someone either with psychosis or with learning disabilities.’

‘It’s quite a distressing place to go to.’

They agreed that it was important that extra support in the community, especially if funded by social services, should happen quickly.

‘We may then of course need extra hours because we don’t have time with other clients so you can’t put the hours in… you know go through the social work to referrals to a panel you’re talking maybe five, six weeks, you need it now.’
They were not necessarily sure that people in crisis needed to be seen every day, and cautioned that it might sometimes be counterproductive.

‘You’ve got to be careful … because too many people, too many meetings can add to the crisis.’

The professionals were concerned that distinctions and relationships between specialist services and generic services remain unclear. Their opinion was that people with learning disabilities and psychosis should be able to access more intensive generic services such as home treatment and assertive outreach and that they should not necessarily be provided by specialist learning disabilities services.

‘Access to… somewhere you could have daily monitoring of a medication.’

‘Access to a 24 hour service that may be provided by adult mental health.’

‘I think it’s about helping them access the generic services especially the housing… and substance misuse and employment.’

There was little support for the idea of super-specialist services that might, for example, see only people with psychosis and learning disabilities, or a separate intensive specialist service, because it could split further already scarce resources. Rather than having a distinction between a ‘routine’ and an ‘intensive’ service, they felt that services should be able to respond flexibly.

‘Having… routine team and… intensive team could be less useful than saying there are all the people that could help them.’

‘I can’t think of anything more that we would have in the intensive team that we haven’t for the routine… only they might want staff who’ve lower caseloads… you might need a greater flexibility of staff… who can respond.’

Discussion

This is the first reported study to compare the views of professionals, carers and service users about services in the community for adults with learning disabilities and psychosis. There was little conflict between the views expressed in the three focus groups. For example, there was unanimous agreement across the focus groups that some people with learning disabilities and psychosis (or mental health problems, as discussed in the service user group) needed more intensive services. However, there were considerable differences in what was discussed and emphasised. Service users emphasised the need for advice and practical help. Their expressed desire for self-determination is consistent with other reports (Dudley et al, 1997).

The carers stated a need for a wide range of staff, often to deal with behavioural problems. They might have been thinking more widely of service users with behavioural problems without a diagnosis of psychosis. Alternatively, they might have been concerned about the day-to-day challenges of caring for adults with psychosis and learning disabilities. They emphasised the need for communication between all involved, and for service personnel to know the service user well as a person.

Professionals were concerned with the current relationships between generic and specialist services, which appeared to make it difficult for them to suggest components of hypothetical routine or intensive community services. They were concerned that service users should be able to access more intensive services for the non-learning disabilities population, such as home treatment or assertive outreach. They were wary of the development of any services narrowly focused on people with psychosis and learning disabilities, or that separated intensive from routine community services.

The study has some limitations. It is not possible to generalise beyond what was said by the participants. They were all drawn from South London and have contact with community-based services in that area, so they may have somewhat biased experiences and views. The service users’ group cannot be said to represent the ‘average’ user of services for people with mental health problems and learning disabilities.

A further limitation is that the service users did not discuss psychosis specifically, as did the carers and professionals, but discussed mental health problems in general. Participants in the carers group were also known to one of the researchers through their local clinical work, but this did not seem to inhibit the participants, who were very keen to discuss their experiences and views even if they were negative.

Conclusions

This study comparing focus groups of service users, carers and professionals shows that each of these stakeholder groups can bring important perspectives to service development. Although there were few direct contradictions between them, there were different perspectives on what was most important. These views can be used to inform future research, including a wider consultation of opinions on the specific components of community services should be for this service user group. It is essential that service users and carers, as well as clinicians, contribute to the planning, delivery and evaluation of services in the community for adults with psychosis and learning disabilities.
What should community services provide for adults with psychosis and learning disabilities?

What do we know already on this topic?
- There has been increasing emphasis on establishing service users’ and carers’ views on the services that they use.
- Most research investigating the views of service users with both learning disabilities and mental health problems has focused on inpatient care; there has been a lack of research on the services for adults with learning disabilities in the community.
- Focus groups can be an effective method of conducting exploratory research among adults with learning disabilities.

What more does this study contribute?
- Focus groups can be an effective way of eliciting views about mental health services from service users with learning disabilities and their carers and professionals.
- This appears to be the first report to compare directly the views of service users, carers and professionals on mental health services for people with learning disabilities.
- The views of the three groups were not in conflict or opposition, but they differed in their emphases and priorities.
- All three perspectives are necessary for the planning, delivery and evaluation of good services in the community for adults with mental health problems and learning disabilities.

Acknowledgements
The authors would like to thank Steve Hardy for developing the participant information sheet and consent form for the service user focus group. Steve Hardy and Pete Woodward are also thanked for their input during the service user focus group.

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Services in the community for adults with psychosis and intellectual disabilities: a Delphi consultation of professionals’ views

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Abstract

Background There remains a severe lack of evidence on the effectiveness of community services for adults with psychosis and intellectual disabilities (ID). There has been little consensus even of what services should provide for this service user group.

Method A consultation of multidisciplinary professionals was carried out by using a three-round Delphi exercise. Participants were recruited nationally. They rated their views on the importance of 139 items for the care of adults with psychosis and ID. These included 85 routine service components, 23 service user characteristics for those needing a more intensive service and 31 more intensive service components.

Results Forty-nine out of 52 participants completed all three rounds of the Delphi consultation. Consensus of opinion (≥80% agreement as essential) was obtained on 18 of the routine service components, nine of the service user characteristics and five of the more intensive service components. The routine service components considered essential can be broadly considered under a need for a focused approach on the service user and their illness (e.g. monitoring of mental state) and the added need to work within the wider context of the service user with psychosis and ID (e.g. access to social, leisure or occupational activities). Five of the more intensive service components were considered to be essential (e.g. can react to a crisis that day). However, the routine service components considered essential already contained many components such as out-of-hours support and crisis plans also relevant to more intensive services.

Conclusion These findings can be used to develop further the evidence base for services in the community for this user group and to assist in the preparation of much needed service evaluation studies.

Keywords Delphi, intellectual disabilities, psychosis, services

Introduction

In many developed countries including the UK the vast majority of people with intellectual disabilities (ID) now live in small community settings. Many have additional mental health problems (Deb et al. 2001). A significant proportion of these have severe and enduring psychotic illnesses such as...
schizophrenia spectrum and bipolar affective disorders causing much morbidity, carer burden and health and social care service costs. Recent studies have confirmed the increased prevalence and incidence of psychotic illnesses in people with ID (Cooper et al. 2007; Smiley et al. 2007). Despite this there remains a severe lack of evidence into the effectiveness of community services for adults with psychosis and ID (Hemmings 2008). There has been little consensus even of what services should provide for this service user group in the community. Research into specific models of care for adults with psychosis and ID in the community has been hampered by problems of model fidelity and implementation (Hemmings et al. 2008). Meanwhile generic community mental health research has shown a need to research the specific components of services rather than service configurations or service model names (Burns et al. 2006). There is a great need for evaluation studies of current and any innovative services for people with ID and psychosis, but it is crucial that this future research is informed to increase its validity. Before the effectiveness of service components can be evaluated, agreement of what should constitute routine and more intensive services needs to be established in the first place. This should be done with expert opinion obtained by using a rigorous and systematic methodology. It will also be essential to gain and incorporate the views of service users and their carers before meaningful evaluation studies can be conducted.

Consensus panel methods such as the Delphi technique provide a quantitative approach to issues such as in health service delivery where there is uncertainty, controversy or limited evidence (Campbell et al. 1999). The Delphi technique is a method used to gain consensus on the opinions of experts (Adler & Ziglio 1996). It is a group facilitation technique that uses a series of structured questionnaires. It is an iterative process that allows anonymity to participants, controlled feedback and quantitative analysis of responses. The Delphi technique has been previously used to elicit views on services in mental health care for the general (non-ID) population (Fiander & Burns 1998; Burns et al. 2000; Marshall et al. 2004; Mohan et al. 2004). Similar research into services in the community for those dually diagnosed with both ID and psychosis has not been reported. There is no guarantee that research findings into services for those without ID can be applied with validity to those with ID who may often have additional or even more complex needs.

The aim of this study was to achieve consensus on the views of specialist professionals on what help adults with psychosis and ID need from community services. The three research questions were:

- What should be the components of routine community services for adults with psychosis and ID?
- Do some adults with psychosis and ID need more intensive community services? If so, what are their characteristics?
- What should be the components of more intensive community services for adults with psychosis and ID?

Method

Design

A Delphi consultation was carried out between August 2007 and January 2008 by using a series of questionnaires. A qualitative, open-question round was followed by two quantitative, rating-scale rounds. The study received ethical approval from the Joint South London and Maudsley and the Institute of Psychiatry NHS Research Ethics Committee (ref: 07/Q0706/19).

Recruitment

A range of multidisciplinary professionals based nationwide within the UK were recruited. The inclusion criterion was that participants had experience of working for community-based services that provide care for people with psychosis and ID. A purposive sampling method was used. Recruitment emails and letters about the study were sent out to relevant multidisciplinary individuals, organisations and services throughout the UK. Recruitment to the study began in June 2007.

The Delphi questionnaires

Two versions of each questionnaire were prepared. An online survey tool (http://www.surveymonkey.com) was used to design the ques-
tionnaires, send out emails, collect responses and collate data. For participants who preferred not to use the online questionnaires, MS Word document versions were used instead. Participants could receive the Word questionnaires by email or post. The online and Word versions were identically worded as were the emails containing the links to the online questionnaires and the letters accompanying the paper questionnaires.

Round one questionnaire

Participants were provided with the study’s definition of a component: ‘a person, treatment or intervention, method of working or style of service organisation that makes a significant contribution to helping people with psychosis and intellectual disabilities’ (adapted from Marshall et al. 2004). This was followed by the three research questions of the study (see Introduction). For each question, participants were asked to list at least 10 suggestions.

Analysis of Round one

The suggested components or characteristics for each question were arranged in three lists. Any items that were exact duplicates were removed, and the remaining suggestions were analysed thematically. They were first assigned to a broad category (e.g. staff) and then further assigned to narrower categories (e.g. type of staff, staff training and staff characteristics). Duplicate or similar suggestions were grouped together within each narrow category. Two researchers (first two authors) discussed whether each narrow category was appropriately labelled and agreed which category each suggestion belonged to. The researchers then looked at whether each narrow category represented a component/characteristic that should go forward into the next Delphi round. Categories were considered inappropriate for further inclusion if they were too vague or could be generally considered as ‘good practice’ points. The researchers then looked at each group of similar suggestions within the narrow categories. They discussed what component/characteristic was represented and selected one suggestion that best represented that group of similar suggestions. In some cases elements of a number of suggestions were combined. In other cases some words were removed so that it was clear that participants were rating the component itself rather than whether it should be for example, ‘good’, ‘adequate’ or ‘effective’. Other suggestions outside of the scope of community-based services were removed. A draft questionnaire was then constructed by using the remaining components and characteristics.

Round two questionnaire

The draft of the Round two questionnaire was pilot-tested by five multidisciplinary professionals who had not taken part in Round one. Following feedback from the pilot participants and further development, the number of items in the second round questionnaire was reduced. Pilot participants’ responses were not used in any further analyses.

In Round two, participants were asked to indicate how important they thought each of the items for each of the three research questions was when community-based services provide care for people with psychosis and ID. The routine and intensive service components and service user characteristics were presented, in alphabetical order, alongside a rating scale from 1 to 4 (Essential, Important, Less important and Unimportant). Participants were asked to mark the response for each item that was nearest to their own view. The median ratings for each item were calculated to represent the group average responses. These group averages were then used to compile the Round three questionnaires in which participants received feedback on the results from Round two.

Round three questionnaire

Participants were presented with the same items as in Round two with the same rating scale. This time however participants received feedback on their own and the group average response ratings in the previous round. For each item, participants were asked to compare their Round two rating with the group average rating and in light of this information reconsider their response and indicate their own rating for Round three. They were informed that they were equally free to give the same rating as they had done in the previous round or give a different rating.
Analysis of Rounds two and three

MS Excel was used to calculate the number of responses for each item, the number and percentage of participants whose response was equal to the group average response for each item (agreement), the number of items with consensus agreement and the mean level of agreement. The level of agreement for consensus was defined as ≥80% agreement (Green et al. 1999). The variance between participants’ responses and between items and the extent to which level of agreement and variance changed between Rounds two and three were analysed.

Missing data in Round three

Where there were missing data, participants’ Round two responses to those items were brought forward (if a participant also had not responded to an item in Round two the data remained missing). A sensitivity analysis was carried out to check whether replacing missing data had any effect on the results.

Results

Participants

Twenty-three (47%) female and 26 (53%) male participants completed all three rounds. Their mean age was 41.5 years old (SD = 8.6, range = 25–63). Ten (20%) participants described themselves as Asian or Asian British, three (6%) as Black or Black British, 35 (71%) as White or White British and one person preferred not to give their ethnicity. There were 12 nurses (25%), one occupational therapist (2%), one operational manager (2%), 29 psychiatrists (59%), five psychologists (10%) and one social worker (2%). Their average length of experience of working for services that provide care to people with psychosis and ID was 9.6 years (SD = 7.7, range = 4 months–30 years). Twenty-three participants were based in London and the others in the south-east, south-west, west Midlands, north of England, Wales and in Scotland.

Round one

Fifty-two participants completed the first round questionnaire. The mean number of suggestions given by participants to each of the three research questions was 10.6 (SD = 4.8, range = 0–26). Fifty-one participants (98%) were of the opinion that some adults with psychosis and ID sometimes need a more intensive community-based service. Once exact duplicates and comments not relevant to the questions had been removed there were 623 suggestions for routine components, 218 suggestions for service user characteristics and 415 suggestions for intensive service components. These were narrowed down after thematic analysis and piloting to 85 routine components, 23 service user characteristics and 31 intensive components. A 139-item questionnaire was thus used for Rounds two and three.

Round two

Fifty participants completed Round two. The average level of agreement (percentage of participants whose rating was the same as the group average rating) for the 139 items was 56.6% (SD = 12.2, range = 34–91.7%). There was consensus of opinion (≥80% agreement with the group average) on nine (23.7%) of the 139 items.

Round three

Forty-nine participants completed the third round (a response rate of 94% between Rounds one and three). Of the 139 items, 60 had a group average rating of Essential and 74 had a group average rating of Important. Only five items had a group average rating of Less important, and no component or characteristic had a group average rating of Unimportant. The mode rating was the same as the median rating for all 139 items. The average level of agreement for the 139 items was 72.0% (SD = 11.6, range = 46.9–95.9%). The level of agreement increased across all 139 items in Round three compared with Round two, by an average of 15.4% (SD = 6.72, range = 2.2–31.6%). There was consensus of opinion (≥80% agreement with the group average) on 33 (23.7%) of the 139 components/characteristics. Of those, 32 (23.0% of the total) had a group average rating of Essential and one had a group average rating of Important. All 49 participants rated these items. There was consensus of opinion on 18 (21.2%) of the 85 routine service components, nine (39.1%) of the 23 service user characteristics and six (five rated Essential and one rated as Important; 19.4%) of the 31 intensive service components.
Missing data

A sensitivity analysis carried out to assess the impact of carrying forward data from the previous round showed that there was no effect from this on any of the group average ratings, levels of importance or the number of items reaching consensus.

Table 1 shows the routine service components considered Essential by consensus.

Table 2 shows the service user characteristics considered Essential by consensus.

Table 3 shows the more intensive service components considered Essential by consensus.

Discussion

This is the first reported study investigating the views of a large group of professionals about ser-

Table 1 Routine service components considered Essential by consensus

<table>
<thead>
<tr>
<th>Agreement with group average (%)</th>
<th>Routine service components</th>
<th>Group average</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 95.9</td>
<td>Monitoring of mental state</td>
<td>Essential</td>
</tr>
<tr>
<td>2 93.9</td>
<td>Monitoring of medication</td>
<td>Essential</td>
</tr>
<tr>
<td>3 91.8</td>
<td>Access to social, leisure or occupational activities</td>
<td>Essential</td>
</tr>
<tr>
<td>4 91.8</td>
<td>Named care coordination (by service or worker providing the priority need)</td>
<td>Essential</td>
</tr>
<tr>
<td>5 91.8</td>
<td>Risk assessment and risk management</td>
<td>Essential</td>
</tr>
<tr>
<td>6 91.8</td>
<td>Service provided is based on assessment of person’s needs</td>
<td>Essential</td>
</tr>
<tr>
<td>7 91.8</td>
<td>Staff training</td>
<td>Essential</td>
</tr>
<tr>
<td>8 89.8</td>
<td>Antipsychotic medication</td>
<td>Essential</td>
</tr>
<tr>
<td>9 89.8</td>
<td>Learning disability psychiatrist</td>
<td>Essential</td>
</tr>
<tr>
<td>10 87.8</td>
<td>Appropriate housing with adequate support</td>
<td>Essential</td>
</tr>
<tr>
<td>11 87.8</td>
<td>Crisis plans</td>
<td>Essential</td>
</tr>
<tr>
<td>12 85.7</td>
<td>Out-of-hours support</td>
<td>Essential</td>
</tr>
<tr>
<td>13 85.7</td>
<td>Work with inpatient staff to enable coordinated care and discharge</td>
<td>Essential</td>
</tr>
<tr>
<td>14 83.7</td>
<td>Operational policy including referral procedure and eligibility criteria</td>
<td>Essential</td>
</tr>
<tr>
<td>15 83.7</td>
<td>Regular review of service users and care plans</td>
<td>Essential</td>
</tr>
<tr>
<td>16 83.7</td>
<td>Social worker or care manager</td>
<td>Essential</td>
</tr>
<tr>
<td>17 83.7</td>
<td>Support/advice/training around mental health for the person’s family, carers and support services</td>
<td>Essential</td>
</tr>
<tr>
<td>18 81.6</td>
<td>Care programme approach</td>
<td>Essential</td>
</tr>
</tbody>
</table>

Table 2 Service user characteristics considered Essential by consensus

<table>
<thead>
<tr>
<th>Agreement with group average (%)</th>
<th>Service user characteristics</th>
<th>Group average</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 95.9</td>
<td>Risk to themselves/risk to or from others</td>
<td>Essential</td>
</tr>
<tr>
<td>2 93.8</td>
<td>Acute phase of illness</td>
<td>Essential</td>
</tr>
<tr>
<td>3 91.8</td>
<td>Frequent relapse</td>
<td>Essential</td>
</tr>
<tr>
<td>4 89.8</td>
<td>Difficult to engage</td>
<td>Essential</td>
</tr>
<tr>
<td>5 87.8</td>
<td>Poor compliance (or concordance)</td>
<td>Essential</td>
</tr>
<tr>
<td>6 87.8</td>
<td>Additional challenging behaviour</td>
<td>Essential</td>
</tr>
<tr>
<td>7 87.8</td>
<td>Experiencing or at risk of placement breakdown</td>
<td>Essential</td>
</tr>
<tr>
<td>8 81.6</td>
<td>High level of distress and/or difficulties coping</td>
<td>Essential</td>
</tr>
<tr>
<td>9 81.6</td>
<td>Offending behaviour</td>
<td>Essential</td>
</tr>
</tbody>
</table>

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vices in the community for adults with ID and psychosis. This also appears to be the first time specifically that a Delphi consultation has been used to obtain consensus opinion about services for people with ID and mental health problems. This study benefited from using a well-established method, the Delphi technique, for obtaining consensus. Participants were multidisciplinary and recruited nationally. The sample size was large, and the response and retention rates across the three Delphi rounds were excellent. Overall there was much consistency across the participants’ responses. The components or characteristics were derived from their own original suggestions and mostly reflected their own wording. No items had a group average response of Unimportant. Only five items had a group average of Unimportant (e.g. physiotherapist, day hospital, minimum of daily contact), but the level of agreement for these items did not reach consensus (there was 57–76% agreement).

The overwhelming majority of items were rated as either Important or Essential by the participants reflecting a general level of agreement between them. The Delphi consultation was successful in that it increased agreement among participants between rounds and achieved consensus for a number of service components and service user characteristics considered to be Essential.

Routine components considered Essential by consensus can be broadly considered under a need for a focused approach on the service user and their illness (e.g. monitoring of mental state, monitoring of medication, antipsychotic medication, named care coordination, risk assessment and risk management, regular review of service users and care plan, care programme approach) and the added need to work within the wider context of the service user with psychosis and ID (e.g. access to social, leisure or occupational activities, appropriate housing with adequate support, support/advice/training around mental health for the person’s family, carers and support services). The service user characteristics considered Essential when deciding whether someone should receive more intensive services can arguably be considered to be similar to what might be expected for those with psychosis but without ID with the possible exception of the items ‘additional challenging behaviour’ and ‘experiencing or at risk of placement breakdown’ that possibly may not have been given such prominence or emphasis by non-ID professionals. Only five intensive service components were considered to be Essential for services (e.g. staff who can administer/monitor medication daily if required and can react to a crisis that day). However, the routine service components arguably contained many components rated by consensus as Essential such as out-of-hours support and crisis plans, which are also very relevant to more intensive services.

When using the Round one suggestions to construct the second and third round questionnaires, the researchers tried to limit their own bias by using the participants’ words as much as possible. However, there needed to be decisions made on what should be included or excluded, based on the researchers’ judgement. The large number and wide range of suggestions received in Round one meant that it was not possible for every potential service component or user characteristic to be rated. It was important that the second and third rounds were not overly long and time-consuming in order to maintain participants’ enthusiasm and willingness to take part.

### Table 3 Intensive service components considered Essential by consensus

<table>
<thead>
<tr>
<th>Agreement with group average (%)</th>
<th>Intensive components</th>
<th>Group average</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 87.7</td>
<td>Staff who can administer/monitor medication daily if required</td>
<td>Essential</td>
</tr>
<tr>
<td>2 87.7</td>
<td>Can react to a crisis that day</td>
<td>Essential</td>
</tr>
<tr>
<td>3 85.7</td>
<td>Provide a comprehensive list of contacts should service user relapse</td>
<td>Essential</td>
</tr>
<tr>
<td>4 85.7</td>
<td>Risk assessments for staff visits</td>
<td>Essential</td>
</tr>
<tr>
<td>5 81.6</td>
<td>Additional staff with necessary skills to work within the home to improve monitoring and increase the confidence of the usual carers</td>
<td>Essential</td>
</tr>
</tbody>
</table>
The authors felt that many of the suggestions given in Round one are widely regarded as ‘good practice’, and it was thus highly likely that they would achieve consensus easily. It was felt that it would be more useful to ask participants to rate items where there was not already an obvious consensus among professionals. Therefore a number of potential routine and intensive components that were not included in Rounds two and three should probably be viewed as Essential to any services that provide care for people with psychosis and ID. These include adequate staff numbers, multidisciplinary working, culturally sensitive, wide ranging support, good communication, comprehensive initial assessment, supervision for staff, liaison with other services and information gathering from people known to service user.

It is necessary to use a threshold to define consensus in Delphi consultations, but this means that perhaps the importance of those items just under the cut-off point are somewhat downplayed. For example, a psychologist was considered to be Essential by over 70% of the sample. The ratings for nurses were complicated, as so many participants had suggested specifically either learning disability nurse or community psychiatric nurse in Round one that both were included to be rated in the subsequent rounds. These two items each subsequently scored only just narrowly under the threshold for being considered Essential. However, 45 (92%) participants rated one or the other as Essential so it seems probable that if the participants had been asked to rate nurse without qualification then this item would have been considered Essential with one of the highest levels of consensus. In addition, while the items ‘care management’, ‘protocols with all relevant services/agencies to be agreed’ and ‘service user involvement in service planning and delivery’ all failed to achieve consensus, most participants considered them Essential as routine service components, and all of the rest considered them Important; no one rated them Less important or Unimportant.

It is possible that a different group of professionals would have given different ratings, for example if they had been comprised of a different regional or professional makeup even though the participant group was large, multidisciplinary and nationally recruited. There was a potential bias to some extent in that health professionals, and particularly psychiatrists comprised the majority of the sample. The items ‘learning disability psychiatrist’ and ‘care manager or social worker’ reached consensus agreement as being Essential to services. Although more than half of the participants were psychiatrists, only one was a social manager/care manager so it is of note that social care professionals were thought to be Essential by health professionals. Although invitations to participate in the study were sent to a wide range of individuals and organisations only one social manager/care manager responded and took part. Similarly, the majority of participants came from specialist community services for people with ID. No quotas were set for the recruitment of particular professions (or any other participant characteristics) but it may have been useful to have done so in order to ensure increased participation of certain groups, for example social care professionals or those involved in generic, non-ID mental health and primary care services who often currently provide much of the care for people with ID and psychosis.

It is important to recognise that the findings of the present study should be seen in the context of current UK policy guidance, for example from the Green Light Toolkit (Foundation for People with Learning Disabilities 2004) that promotes an increasing role for mainstream mental health services in delivering care to people with psychosis and ID. The advantage of focusing on individual components rather than service models or configurations is that this study has identified the staff, treatments or ways of working that are considered Essential for people with psychosis of ID regardless of which organisation, or type of service provides them.

Further research should try to elicit the opinions of service users themselves and their carers. In this study, it was felt that it was not possible to include carers, service users and professionals in the same Delphi consultation. Analysing responses from the first round and compiling one set of questionnaires that were relevant and accessible to all three groups would be difficult if not unworkable. It would however be very interesting to collate the results of three separate Delphi consultations run concurrently. It would also be of great interest to conduct a Delphi study of professionals in different countries in order to compare views of essential service
components cross-culturally. The present study also assumed a shared understanding of the diagnostic criteria for psychotic illnesses in people with ID. Another potential use of the Delphi technique therefore would be to explore whether a consensus exists about the validity of the current diagnostic criteria for psychosis in people with ID.

**Conclusion**

Components considered Essential for services in the community for adults with psychosis and ID have been identified by expert opinion. A range of these components needs to be studied further, expanded upon and explored in detail to learn more about how it is thought that they should be delivered and implemented. This will prepare the ground for the evaluation studies of community services, both existing and innovative, which are greatly needed for this service user group.

**References**


Accepted 4 December 2008
Expert opinions on community services for people with intellectual disabilities and mental health problems

Colin Hemmings and Alaa Al-Sheikh

Abstract
Purpose – There has been limited evidence on which to base services in the community for people who have intellectual disabilities and coexisting mental health problems. Recent research involving service users, carers and professionals has identified a number of key service components that community services should provide. More detail is needed to explore how best these components could be implemented and delivered. This paper aims to discuss these issues.

Design/methodology/approach – A total of 14 multidisciplinary professionals from specialist intellectual disabilities services in the UK were interviewed about their opinions on four key areas of community service provision. These included the review and monitoring of service users, their access to social, leisure and occupational activities, the support, advice and training around mental health for a person’s family or carers and “out of hours” and crisis responses. The interview data was used for coding using the NVivo 7 software package and then analyzed using thematic analysis.

Findings – Analysis of participants’ views on these key essential service components produced wider themes of importance. The ten major emergent themes for services were: their configuration/structure, their clarity of purpose/care pathways, their joint working, their training, their flexibility, their resources, their evidence-base, being holistic/multidisciplinary, being needs-led/personalised and providing accessible information.

Originality/value – These views of experts can help inform further research for the development and the evaluation of services.

Keywords Services, Community, Intellectual disabilities, Mental health, United Kingdom

Introduction

There has been a limited evidence base on which to decide how services should be provided for people with intellectual disabilities and severe mental health problems. Previously focus groups (Hemmings et al., 2009b) and a Delphi study (Hemmings et al., 2009a) was used to investigate the opinions of service users, cares and clinicians regarding a number of service components. A consensus regarding the service components considered to be essential for effective community services was achieved among the clinicians. A service “component” was defined as “a person, treatment or intervention, method of working or style of service organisation that makes a significant contribution to helping people with psychosis and intellectual disabilities” (adapted from Marshall et al., 2004). It is important to explore some of these service components in more depth to understand how best they could be implemented and delivered. Some individual professionals are particularly well qualified to give their views regarding services given their clinical experience in this highly specialized field allied with their service development and research interests. Semi-structured interviews can “provide a supportive, flexible and comfortable process through which to elicit narrative description of experience and allow participants to reflect on and express opinion” (Longman et al., 2011). The aim of this study was therefore to use semi-structured in-depth interviews to elicit expert opinion regarding some key areas of service provision of services in the community for people...
with intellectual disabilities and coexisting mental health problems. After consideration of the service components considered as essential from the previous focus group and Delphi studies it was decided to explore in depth expert opinion regarding four key areas of community service provision: review and monitoring of service users, access to social, leisure and occupational activities, support, advice and training around mental health for a person’s family or carers and out of hours and crisis response.

**Method**

**Recruitment**

Recruitment e-mails and letters about the study were sent out to relevant multidisciplinary clinicians throughout the UK. The sample to be approached was purposively selected from those who had previously published research, correspondence or opinions on services for people with intellectual disabilities and mental health problems in the community. This group was supplemented by other multidisciplinary clinicians who had completed the previous Delphi study and who had extensive experience in working with this specific service user group. 16 professionals in total were approached by a snowballing technique. Of these 14 were able to participate in the study. They included four psychiatrists, four nurses, three psychologists, two social workers and one occupational therapist. Ethics approval was granted by the local NHS Research Ethics Committee.

**Interviews**

Interviewees were requested to specifically focus on services in the community for certain types of service users with intellectual disabilities: those over 18 and with coexisting severe mental health problems. Psychosis was given as an example of severe mental health problems for the participants to consider. For each item the participants were asked to give their views on how service components should be provided and implemented, rather than what is current practice. Each participant was asked the following questions regarding the following four areas of service provision: how should this be done/provided? Which professional or support staff should do/provide this? How often should this be done/provided? Where should this happen? Do you think there is anything that would make a key difference to how well services in the community could do/provide this? A semi-structured interview schedule including these questions was designed by the authors. The interviews were designed to allow the interviewees to speak uninterrupted as much as possible but prompts were available to ensure relevant topics were covered. The interview schedule was piloted and tested with one expert who was not then included in the final study. Following the pilot three prompts for the interviewer were added or refined. The interviews were audio recorded, anonymized and transcribed. In-person interviews lasted between 27 and 67 minutes (mean 47 minutes) and were audio-recorded and transcribed for analysis. Individual summaries were sent to participants to allow them to reflect on the transcripts and clarify or elaborate. Interviews were conducted during the latter part of 2008 at the Estia Centre, London or at the interviewee’s place of work at various locations in the UK.

**Analysis**

A thematic analysis (Braun and Clarke, 2006) of the interview data was undertaken by the two authors. The first author (CH) first identified and coded themes using NVivo 7.0 software (www.qsrinternational.com), based on repeated reading of the transcripts and coding of issues of interest to the research questions. Coding involved reading each transcript and putting like elements of text into broad groupings. Coding is “the process of identifying persistent words, phrases, themes, or concepts within the data so that the underlying patterns can be identified and analyzed” (Morse and Field, 1995). The NVivo software package was used to group segments in wider, overarching themes according to their codings (Bazeley, 2007). The reliability of the themes was tested by examining differences and similarities between the coded data. The two authors then read and re-read the transcripts independently to confirm and agree the themes. Discussions between the two authors compared preliminary findings and debated interpretations of the data. Following the delineation of key themes,
all interviews were re-examined to verify the presence of each theme. The researchers independently reviewed the transcripts to identify meaningful descriptions or noteworthy statements related to the research questions. All the themes that were generated in the analysis were supported by the data from at least half of the interviews. Each theme was checked for frequency, consistency and inter-rater agreement. Trustworthiness of the analysis was further strengthened through post-analysis transcript searches (Ryan and Bernard, 2003). This found no conflicting or disconfirming evidence of the emergent themes.

Results

Analysis of the interview data identified ten emergent themes. Selective quotations are presented in the following text to illustrate the participants’ opinions and demonstrate examples of each major theme. The quote represents verbatim quotation from the participants. The major emergent themes are summarised as follows.

Interviewees frequently mentioned the configuration/structure of services in their comments. There was not overwhelming support for developing “super-specialist” services within intellectual disabilities services such as assertive outreach or providing daytime activities. Participants often commented that there would not be the numbers of staff or service users to make these economically viable even if often they did think these would be the most ideal:

You’ve not got a critical mass of people . . . to justify the assertive outreach team, but certainly I would say that you need an assertive outreach function, and a crisis contingency function, crisis planning contingency function, bolted on to the CPA review process.

I think people should access the mainstream but there should be available in-reach and enriched support, so you might have some on-call system from the LD service that can enhance the mainstream, I’m not saying a team, I don’t think it should be a standalone team”, “The way forward is the integration of general teams but we would still be recognised as specialist but working in a more generic team so there’d be combined resources and finances.

The need for services to have a clarity of purpose/care pathways was mentioned frequently:

By having a clear care pathway for service users regarding interventions from different disciplines and having one person coordinating that pathway . . . and that’s across services.

Ideally you’d have a 24 hour crisis support service staffed by people who knew about people with LD . . . you’d have a clear focussed pathway and they’d be able to deliver services promptly and effectively or make sure that parallel services were in place that were more appropriate.

The key thing would be having a very good structure and sort of protocol on what to do if there’s a crisis after hours . . . So everybody knows who to call . . . on a telephone so that carers or the person can ring up for advice and those people have this information in hand.

Interviewees often commented that joint working with mainstream mental health services needed to be improved for the best care of the service user:

I don’t think you could just do it on a teaching model, I don’t think that teaching alone brings up the experience, because you could tell someone what somebody with a learning disability is like . . . (but) having the skill base as part of the team . . . would be important, in my ideal . . .

I just think there need to be more staff that are trained in mental health and learning disabilities, I think mainly crises are responded to by either mental health staff or learning disability staff and not people who have necessarily have both sets of skills.

In an ideal world you would have a duty person that was LD trained and to respond to LD crisis problems, and whether that would be within a specialist service or whether you would have somebody in the main duty team trained in LD, I don’t know if it would matter really.

Interviewees frequently talked about the need for people working with people with intellectual disabilities and mental health problems to have adequate training and experience. Related to this they often commented that specialist intellectual disabilities services need to provide training to mainstream mental health staff, care staff and other services:
Education around mental health with carers and parents and anybody working with the client is helpful . . . it's difficult for us to rely on them to monitor people if they don't know what they're looking for, and lots of things are just put down to a person's learning disability.

One need is a skilled support, skilled support staff on a day to day basis, having that skill level of knowing and being confident in how to monitor someone, I just think that the general concept of mental health and what's going on, is often missing.

Professionals who have the knowledge and experience of mental health problems and also the knowledge and experience of supporting a person with a learning disability, you often find that the two don't come together.

The need for services to show flexibility in their delivery and response to demands was supported by a large number of statements:

Unfortunately I think a nine to five service is very restrictive, not because of what we want, it's driven by economics and I think carers and families would welcome a seven day a week service with flexible hours.

People aren't ill between nine and five, they're ill when they're ill, and night times can be really quite difficult and there's not enough support for . . . nine to five is not the way forward, you need to be creative and flexible.

People need some sort of assertive outreach out-of-hours stuff and I prefer to not call it out-of-hours but to look at extending hours . . . rarely do our service users get into crisis at three o’clock in the morning . . . So if you had teams that work different hours..that would be fine and in a more assertive kind of way.

Interviewees frequently cited the need for adequate resources for services, often contrasting what they would think ideal with that of financial realities. The interviewees spontaneously recognized themselves that no new great increases in funding for intellectual disabilities services were likely to be forthcoming and they pitched their responses accordingly:

There does need to be some access to specialist advice but of course these things are very rare, so to actually commission a specific service of expensive health professionals on a 24-7 basis for direct access to them is not feasible . . . within our resource bracket really.

A service needs to have capacity . . . to respond flexibly to people’s needs and in times of crisis to have a much more proactive and high intensity monitoring of people . . . .

It would be nice to offer an enhanced out of hours service from the learning disability services but I think the cost of and use of that wouldn't make it economically justifiable.

Respondents frequently commented that services should be evidence-based:

They’re all different models and I’m not sure anybody’s ever done adequate research to say which would be the better model for working with people with learning disabilities . . . .

Having an evidence base, having somebody actually properly evaluating a service, so you’ve got something to do some planning on rather than just making it up, so many services are based on charismatic individuals putting in loads of energy and time but aren’t necessarily going to be replicated elsewhere.

What’s needed is to scope the problem and think about and evidence it, I mean the problem is there's just no evidence base to develop services properly.

Other themes in the responses that emerged were the need for services to be holistic/multidisciplinary and needs-led/personalised and to provide accessible information:

(monitoring) should be done through the CPA process and that appears to be, if done consistently, a good way of reviewing someone’s care in a multi-disciplinary way.

An understanding of the individual’s needs, I think that’s paramount. And that would include their mental health needs.

There’s a lot of emphasis on translation into other languages but I don’t think there’s the same emphasis and or money spent on translating into say symbols or easily constructed sentences that people can access and using other materials apart from written information.
Discussion

Community services in the UK for people with intellectual disabilities and mental health problems vary widely and randomly in their constitution and purpose. There is a great need for evaluation studies of these and innovative services (Hemmings, 2008). However, it is crucial that this research will be fully informed in order to increase its validity. To our knowledge there has not been previously any similar study eliciting expert opinion via semi-structured interviews regarding services in the community for people with intellectual disabilities and coexisting mental health problems. Participants in this study were multidisciplinary and recruited nationally. Overall there was much consistency across their responses. The themes emerging from content analysis overlapped but were evidenced independently by a number of statements from multiple interviewees. The findings of the present study and suggestions for further research must be seen in the context of current UK policy guidance, for example from the Green Light Toolkit (Foundation for People with Learning Disabilities, 2004) which promotes an increasing role for mainstream mental health services in delivering care to people with intellectual disabilities and mental health problems. Experts were concerned that often mainstream services do not currently meet the needs of people with intellectual disabilities and were therefore keen to develop new improved ways of working with non-intellectual disabilities professionals without necessarily developing stand-alone “super-specialized”; type intellectual disabilities services. In part these opinions appeared to be borne of realism including acknowledgement of financial constraints.

A study of this design has a number of limitations. A semi-structured interview inevitably does impose a bias as to what areas are important for discussion although the key questions were based on the findings from previous research. The process of analysing the interview data is fundamentally a subjective one. The generalisation of the findings to the wider pool of expert opinion potentially available must be very cautious. It is possible that a different group of professionals would have given different opinions, for example if they had been comprised of a different regional or professional makeup even though the participant group was large, multidisciplinary and nationally recruited. Most were health care professionals; only two social workers/care managers took part. All of the participants worked in specialist services for people with intellectual disabilities rather than mainstream services. It may have been useful to explore the views of more social care professionals or those of staff in generic, non-intellectual disabilities mental health and primary care services as they often provide at least some of the care for this service user group. The date of the interviews was in the latter part of 2008 and views may have changed since then particularly as the economic climate has not improved.

The purpose of this study was not to give a representative sample of views but to elicit an in-depth understanding of a group of experts’ opinions. This was done in order to explore previous research evidence in a descriptive and exploratory way to help to develop the evidence base on which future quantitative service evaluations can be prepared. Important themes from this study for services are those of considering the structure/configuration of community services, the need for clarity of purpose/care pathways, the importance of joint working with mainstream services, the need to deliver training in the assessment of dual diagnosis (intellectual disabilities and coexisting mental health problems) and that services should be needs-led/personalised, use accessible communications, be flexible in their delivery and have sufficient resources to be effective. Service delivery should also be holistic and multidisciplinary and evidence-based. These findings can be used to help generate hypotheses for further services research.

What do we already know about this topic?

- Community services for people with intellectual disabilities and mental health problems vary widely across the UK.
- There is not a sufficient evidence base to understand what makes these community services most effective.
- In depth expert opinion about these community services has not been previously investigated.
What more does this study contribute?

1. The ten major themes identified by experts for services in the community were:
   - configuration/structure;
   - clarity of purpose/care pathways;
   - joint working;
   - training;
   - flexibility;
   - resources;
   - evidence-base;
   - holistic/multidisciplinary;
   - needs-led/personalised; and
   - accessible information.

2. These themes should be considered in the development of community services and research into their effectiveness.

References


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Mental health crisis information for people with intellectual disabilities

Colin Hemmings, Shaymaa Obousy and Tom Craig

Abstract

Purpose – The use of accessible, portable, mental health crisis information in people with intellectual disabilities has not been previously reported. The purpose of this paper is to explore whether crisis information could be modified to be made accessible and meaningful for people with intellectual disabilities.

Design/methodology/approach – Personalized information to help in a mental health crisis was recorded on folded A4 sized sheets that could be carried in a conveniently sized wallet.

Findings – Three quarters of the participants carried their crisis information wallets on a daily basis for six months before evaluation. They and their carers expressed positive feedback about them carrying the crisis information. No one carrying the information actually experienced a mental health crisis in the six months follow up period so their usefulness in such crises could not be evaluated. However, they were unexpectedly used in other non-mental health settings and reported to have been helpful.

Originality/value – The sample size in this was small but the findings suggested that the carrying of crisis information might be a helpful measure for some people with intellectual disabilities. A further, larger scale trial is warranted.

Keywords Mental health, Crisis, Intellectual disabilities, Information

Paper type Research paper

Introduction

Adults with intellectual disabilities are often unsure how to access urgent mental health care. This widespread impression from clinical practice has been supported by evidence from carers that their knowledge of how to access mental health crisis care is often not clear and that the experience of this urgent care for service users and carers is often unsatisfactory (Hemmings et al., 2009b). Further research, on the opinions of a large number of specialist clinical staff, highlighted the need for the provision of information should the service user relapse. A Delphi survey found that the service components of crisis plans, out-of-hours support and provide a comprehensive list of contacts should service user relapse were all considered essential by consensus opinion of clinicians (Hemmings et al., 2009a).

Mental health crises in people with intellectual disabilities are often responded to by staff (for example clinicians in generic emergency services) that do not have specific experience or training in working with this population group. Lunsky et al. (2008), Lunsky and Gracey (2009) and Weiss et al. (2009) have described problems of emergency psychiatric services for people with intellectual disabilities, from the various perspectives of service users, carers and the hospital staff. It is widely recognized that people with intellectual disabilities tend to have increased difficulties in communicating their experiences and distress. These differences are likely to be even more pronounced when they are in a crisis. Provision of key information about the service user would therefore potentially be of great benefit for the person, their carer, emergency workers, clinicians and other staff that may help them. Knowledge of basic information about services and contacts might also improve the ability...
of service users to seek urgent help. Increased awareness of how to access help in a crisis would be likely to help reduce distress for both service users and carers.

In generic mental health services there has been research into the provision of crisis information by use of mental health crisis cards and joint crisis plans (Sutherby et al., 1999; Henderson et al., 2004). Their use has been associated with a reduction in the use of the Mental Health Act and the length of inpatient admissions (Henderson et al., 2004). Crisis cards are designed to be carried around by the owner and can record a range of useful information to assist the service user, their carers and the clinicians who see them. The simplest versions have been credit-card sized including only brief information of names and contact numbers. More elaborate versions have also incorporated joint crisis plans negotiated between service users and clinicians and some also included “advance directives”. However, the use of crisis information has not been specifically evaluated in people with intellectual disabilities. None of the various forms of the crisis information and the menus to produce them have been written in an accessible format that would be more suitable and understandable for people with intellectual disabilities. It is unlikely that the crisis information used to date would be meaningful in their brief and unmodified form to service users who have intellectual disabilities. Crisis information for them should ideally be personalized and accessible to encourage their ownership and use. The United Kingdom Equality Act of 2010 states that service providers must provide accessible forms of communication for people with disabilities. It would be important to give service users with intellectual disabilities, as well as their carers and relatives if they so chose to involve them, a prominent role in the process of producing crisis information that they might want to carry and use.

There has also been a separate strand of practice development from the crisis cards/joint crisis plans of mental health research with the introduction in recent years of hospital passports for people with intellectual disabilities (Blair et al., 2010). Hospital passports are documents largely concerning the medical history of service users with intellectual disabilities. They are written in an accessible format so that the service user themselves can best understand them. They also include information on how best to communicate with that person. They have mostly been designed to assist in the care of people with intellectual disabilities when they have been electively admitted to general hospitals for investigations and operations. These hospital passports are usually quite bulky being based on full-size A4 sheets and have not been designed to be carried at all times where they could be accessible in a crisis. Also the provision of information for staff in the forms of traffic light systems and grab sheets have been introduced in some areas of the UK to assist general hospital staff when caring for people with intellectual disabilities. These are based on more portable documents than hospital passports but again these have not been focused on mental health care. Therefore, the use of accessible, portable, mental health crisis information specifically in people with intellectual disabilities has still not yet been attempted.

The aim of this study was therefore to explore the feasibility of using modified mental health crisis information for people with intellectual disabilities. The overall numbers of mental health inpatient admissions and use of the Mental Health Act of people with intellectual disabilities in the UK are relatively low, although once admitted to a hospital they may require longer admissions than those with more typical IQ (Hemnings et al., 2009c). Admission into mental health inpatient units of people with intellectual disabilities and use of the Mental Health Act are therefore not suitable outcome measures for a feasibility study. This study aimed instead to explore more basic questions of:

1. could crisis information be modified to make it accessible for service users with intellectual disabilities and mental health problems;
2. would modified crisis information be carried, used and valued by these service users; and
3. could having modified crisis information increase the knowledge of service users about who to contact when they are in a crisis?
The study sought to record qualitatively the feedback of the service user participants (and their carers) about the modified and accessible crisis information. The objective was to gain evidence to decide whether a further, larger-scale controlled trial of personalized crisis information for people with intellectual disabilities and mental health problems might be warranted.

Method

Participants

Ethical approval for the participation of the service users and carers was granted from the relevant local research ethics committee (REC reference 09/H0807/87). Service users were recruited from the Croydon psychiatry of learning disabilities outpatient clinics. The service provides psychiatric assessment and treatment to adults in Croydon, UK, with intellectual disabilities and mental health problems. It had an active caseload of approximately 320 service users at the time of this study. Approximately one-third each of the entire caseload are of white UK, black or Asian, or other ethnic origin. About one-third were in independent accommodation or living with family, the others being in supported or residential accommodation with various degrees of staff support. The lead author considered which service users in the caseload might be suitable participants. They were identified purposefully as those who might be likely to have a mental health crisis based on their history, for example, previous presentations to emergency services. They were sent a letter in accessible format telling them about the study and formally inviting them to participate. If they did not reply a further letter was sent and then a follow-up telephone call made. If they expressed an interest in taking part they were sent participant information sheets. Each person was asked if they also wished to nominate a carer or relative to assist them; those nominated were also sent a participant information sheet. A specially created menu form in accessible format (available on request from the first author), detailing the options for each person's crisis information was also sent to each participant. This menu form was created after extensive discussion with two speech therapists experienced in accessible communication with people with intellectual disabilities. The participants were telephoned again to be offered an appointment to attend for their research meeting.

Inclusion and exclusion criteria

The service user participants had mild intellectual disabilities as well as mental health problems (including psychotic disorder, severe affective disorder and/or personality disorder but not autistic spectrum disorder). They were excluded from the study if they were not considered able to understand sufficient spoken or written English to participate: this exclusion was solely to simplify the procedure for this feasibility study. Service users were also excluded from the study if they were in an actual crisis at the time of recruitment.

Procedure

Meeting 1. The participant information sheets were read through and clarified if necessary with the service users and their carer. Consent to participate in the study was then obtained. The service users’ preferences for their own personalized crisis information were then clarified from the menu form. The participants were told that certain basic information would be on their crisis information. This consisted of their name and address and contact numbers for a key person they would like to have contacted in the event of a crisis, their GP and out of hours GP service, the local community learning disabilities team, the local hospital accident and emergency department and social services including the out of hours contact number. The participants were then asked a series of questions about additional information they could include as part of their crisis information if they so chose. They could choose whether or not they wanted to have a picture of themselves on a plastic identity card to be kept with the crisis information. They were also asked if they wanted the following additional information included: their mobile telephone number, mental health history, physical health, medications, allergies and contact numbers of professionals involved in their care.
They were then asked if they wanted the following information included and if so, asked to give details: “What happens when I first become unwell...What I think would help me if I am in a crisis...What doesn’t help me if I am in a crisis...Which things or belongings are important to me...How I would like people to talk to me...What makes me sad or unhappy...What makes me happy and cheerful...What makes me irritable or angry...What makes me worried or anxious...What makes me calm or relaxed...What makes me scared or frightened...Any other important information I would like people to know”.

**Meeting 2.** Participants attended to collect their completed crisis information which was colour printed on A4 paper tri-folded down to fit in provided leather wallets, suitable in size to be kept in pockets or bags. The participants were asked if they would like any final changes to their crisis information. A brief semi-structured interview comprising a short list of questions (available from the first author) was conducted to ask whether they had had any crises in the preceding six months and if so, about the responses from staff or other individuals who had helped them. All were also asked if they knew where to get help in a crisis.

**Meeting 3.** A follow-up meeting was arranged for each participant six months after they had received their crisis information wallets. A brief interview was conducted to evaluate the use of the crisis information wallets based on a similar short list of questions to those used at Meeting 2 (available from first author) and completed by the participants with the help of their carers/relatives if necessary. Service users were asked if they had carried and used their crisis information wallet. They were also asked their impressions of their crisis information, including any problems or benefits that had emerged from producing, carrying and using it. They were also asked their opinion on the menu of items they had been offered and whether there should be any modifications to these.

**Results**

**Recruitment**

65 potential participants were identified. Four were excluded, as their mental health was too unstable at time of recruitment. This gave a purposive sample of 61 service users who were formally invited to participate. 31 (50.8 percent) did not respond. Ten (16 percent) service users declined explicitly to take part. 20 (32.8 percent of sample) service user participants agreed to participate. Nine (45 percent) participants were men and 11 (55 percent) were women. Nine were under age of 40 and 11 were aged over 40. 15 (75 percent) were of white UK or Irish ethnicity and five (25 percent) were of Black UK or African or Asian ethnicity. Four (20 percent) were in independent accommodation with outreach support whilst 16 (80 percent) were in staffed accommodation of various forms.

**Construction of the crisis information**

17 of the 20 participants (85 percent) nominated a carer or relative to assist them in the completion of their crisis information. The majority (80 percent) wanted to include a picture card and their own mobile phone number if they had one (65 percent). Nearly all wanted to include contact numbers of professionals involved in their care (95 percent), details of their mental health (95 percent), physical health (90 percent) and current medications (85 percent). The majority wanted to include the following items: “How I would like people to talk to me (95 percent), What makes me calm or relaxed (95 percent), What happens when I first become unwell (90 percent), What I think would help me if I am in a crisis (90 percent), What makes me happy and cheerful... (90 percent), Which things or belongings are important to me (90 percent), What makes me irritable or angry (85 percent), What makes me sad or unhappy (80 percent), What makes me scared or frightened (80 percent), What doesn’t help me if I am in a crisis (70 percent), What makes me worried or anxious (65 percent). The item which produced the most detailed response was How I would like people to talk to me”. The details given included: “People being kind”, “Please talk softly and calmly”, “I want people to talk to me politely, no big words, not talking too much, going on and on”, “Slow and simple, I don’t like too many questions”, “Not too many people,
two or three people and that's enough”. The participants provided several comments on what they would not like to happen in a crisis. One said, “I don’t like people talking about my mum because she is dead”.

Ten (50 percent) of the participants did not want to record any information about allergies. Eight (40 percent) did not want to record any information about what they believed would not help them in a crisis. Only two (10 percent) of the participants wanted to add any information (the name of their cat and where they took holidays) that was not prompted by the questions included on the menu form. Ten (50 percent) were able to give some idea of where they could get help in a crisis. However, this was often sketchy and dependent on care staff or relatives’ own knowledge. One participant said, “In the evenings and the weekends I wouldn’t know who to contact”. Only four participants had had a mental health crisis in the preceding six months before receiving their crisis information. All felt that not enough had been known about them by the staff who saw them. One had taken an overdose and been taken to a hospital accident and emergency department. She said, “I don’t think they understood me… the ordinary doctors fobbed me off, they didn’t listen, they didn’t know enough about me”.

Carrying and use of the crisis information

Crisis information wallets were carried regularly (most days) by 15 (75 percent) participants. Some needed reminders from care staff to do so but these did not cause any conflicts. Crisis information wallets were lost or mislaid by three (15 percent) participants. Two of the participants who did not carry the wallet on them valued having them so much that they did not ever take them out of their bedrooms, as they were concerned to keep them safe. Two of the participants said they liked their crisis information wallets so much that they carried their freedom bus passes inside them. One carried the crisis information wallet around his neck in a special bag. Another participant linked a chain to his crisis information wallet so that it could be attached to his trousers.

Feedback on the crisis information

None of the participants who regularly carried their crisis information wallets had a crisis specifically regarding their mental health during the six-month evaluation period. One participant did have a mental health crisis during the evaluation period but she had mislaid her crisis information wallet so the use of it in the crisis could not be evaluated. The crisis information wallets were however used in situations which were not mental health crises. One participant used them when attending an accident and emergency department for an asthma attack and another time when presenting there with unexplained seizures. She said, “I had convulsions and the nurse in the hospital said it was good…I took it with the asthma and it was so handy, it has everything about me”. One participant took their crisis information wallet to show their GP and also to show their supported employment advisor. They reported that staff at these different places had received their crisis information favourably. Care staff also raised the suggestion that they might be used in other situations such as in shopping centres: “She has been in Marks and Spencer’s and Boots and staff there have had to communicate with her when she was in a panic”.

There were positive comments from all 15 participants who carried their crisis information wallets regularly: “It’s very nice to have it…it’s a shame it wasn’t available years ago…I’ve been telling my girlfriend to get one…I think everyone who has a problem should have one…”. “It’s good…it might help people worse than me who need help…there are people in the world who have problems. It would help them, not only me”… “It gives me confidence, I want to keep it forever”. Carers and relatives also gave positive comments without exception: “I think it’s an excellent idea, the more people have them the better…the wallet gives her and us peace of mind if she goes out to local shops…it’s reassuring to know she has the information on her…it promotes independence”. 19 out of 20 (95 percent) participants wished to have crisis information wallet after the six month evaluation period. Five participants or their relatives or carers wished that the crisis information could be updated after the six months and this was done for them. They were also given the electronic file of their crisis information so that they and their carers/relatives could have full ownership
of it and make any future changes themselves. Service users and carers/relatives did not feel that any crucial details had been missed out. One participant said, “It would be helpful to have cab numbers and the local police station”. One carer, talking about its use in non-health settings such as shopping centres suggested, “An awareness of when to use it would be good”. Another compared the crisis information wallet with hospital passports saying, “It’s important for a physical health care view...she has a hospital passport...but this is small and portable”.

Discussion

The use of accessible, portable, mental health crisis information in people with intellectual disabilities has not been previously reported. This feasibility study has shown that it is possible to record crisis information in a way which is short enough to be portable but still of sufficient depth to be able to provide a range of key information to potentially help a person with intellectual disabilities in a mental health crisis. The crisis information was displayed in an accessible form that, as evidenced by the interview responses and the carrying of it by the participants, was both understandable and acceptable. The crisis information was personalized and for the most part, the service users in the cohort were able to decide independently what they themselves wanted to include. Others who were less able needed some assistance with their choices from their care staff or relatives. The crisis information was not expensive or difficult or time-consuming to produce once a template had been established. In clinical practice it would entail at least a meeting of approximately 30 minutes for the person to choose what would be in their crisis information and to have their picture taken if they chose to have an identity card as well. Updating the crisis information would take additional time when changes were necessary although care staff and key workers may often be able to do that.

Did the participants like having and carrying their crisis information? The evidence is that they and their carers and relatives valued having the crisis information wallets. The majority (75 percent) carried them every day. The questions on the crisis information menu form appeared to be understandable and relevant to the participants. They were able to answer all questions (some with assistance) and most were agreeable to include additional information in their crisis information. The participants were less keen to include some information. It may have been that some did not understand some questions fully. For example, they were relatively less inclined to include information about allergies because the majority did not have any and so possibly did not understand the purpose of recording this information. It can be speculated also that they were less inclined to include negative things in their crisis information. Several of the participants did not want to include information about things that frightened or scared them or made them feel unhappy or sad or anxious.

Would having a crisis information wallet actually help people with intellectual disabilities in a mental health crisis? The answer unfortunately is not known from this feasibility study, as none of the participants used it for a clear mental health crisis. The participants clearly liked having the crisis information wallets and having them may well have helped with their self-esteem and confidence. However, there were no mental health crises in which to evaluate the crisis information during this study. We cannot say therefore say whether the crisis information would have helped to improve access to services or the care the participants would have received in a crisis. Did the crisis information wallets help others apart from the service users? In this study there was no direct gathering of opinions from generic staff that would assist people with intellectual disabilities in a crisis. The only suggestive evidence is that several times the service users and carers and relatives reported that staff had been approving in comments made about the wallets. The crisis information provided knowledge for understanding the person, for building rapport and for potentially avoiding insensitive subjects that could aggravate a situation, such as asking about relatives that had died.

The aim for this study was to see if modified crisis information could be used specifically in mental health crises in people with intellectual disabilities. One somewhat unexpected
finding was that the crisis information wallets seemed to be useful in other circumstances, such as at a GP practice, an accident and emergency department and an employment advisory service. It is important to note that non-“mental health” situations such as attendance for physical health problems at hospital or being lost in a shopping centre could potentially develop into mental health crises if a person with intellectual disabilities is not dealt with in a personalized and sensitive way. The distinction between what is a mental health crisis and what is a physical health crisis or other crisis is any case often not clear-cut. This unexpected and unintended use of the crisis information wallets in non-mental health crises would make them more comparable with hospital passports, which have been used for elective admissions of people with intellectual disabilities to general hospitals. A number of carers commented favourably that the crisis information wallets were portable and would be available without any prior planning. It seems that mental health crisis information and hospital passports could exist as complementary forms of accessible and personalized health information for some people with intellectual disabilities.

One possible negative consequence of people with intellectual disabilities carrying personal crisis information is the potential risk to their confidentiality. People with intellectual disabilities are at risk of exploitation. Crisis information wallets were lost by three participants in the sample. There may also be concerns if a person with intellectual disabilities showed information about their mental health history and other key personal information to unknown strangers, although this did not happen in this study.

Limitations

The findings of this study are limited by its small sample size and lack of control group. It had been hoped to recruit more participants but people with intellectual disabilities are notoriously difficult to recruit for research (Oliver et al., 2002). The sample size limited the outcomes that could be evaluated. This study only included participants who understood English which might limit the generalizability of its findings to those who can understand other languages. Those who do not speak English might indeed be the very group in which the provision of crisis information might potentially have the most impact. Although the sample was not designed to be representative of the wider caseload those recruited were slightly more likely to be of white UK origin and were more likely to be those living in staffed care homes rather than living more independently. However, those who might benefit most from carrying crisis information could be those who are less likely to have staff with them. Some of the people who might have most to gain from having a crisis information wallet might be less likely to carry one. More than one service user living more independently who had marked persecutory-type thinking explicitly declined to take part. A further limitation is that what constitutes a mental health “crisis” was not strictly defined. A “crisis” is actually a relatively complicated concept to understand for many people with intellectual disabilities. Furthermore, what is considered a crisis for someone with intellectual disabilities would very often not be considered a crisis for other people without intellectual disabilities.

Conclusion

This feasibility study showed that crisis information can be adapted to be accessible and portable for people with intellectual disabilities. The crisis information was straightforward enough for the participants with intellectual disabilities and mental health problems to understand and to be carried, valued and used by them albeit sometimes unexpectedly in non-mental health settings. The sample size in this feasibility study was small but the findings suggested that the carrying of crisis information might be a useful measure, if selectively targeted at specific groups of service users. It would also be important to investigate the cost-effectiveness of the provision of crisis information. It would be important also to investigate the extent to which health professionals might make use of accessible crisis information. A larger-scale trial of mental health crisis information for people with intellectual disabilities thus appears warranted.
What do we already know about this topic?

- People with intellectual disabilities often do not know how to get urgent help if they have a mental health crisis.
- In general mental health services people have been given crisis information cards to carry and use in a crisis.
- Portable information about a person with intellectual disabilities and how they can get urgent mental health care would potentially be of great benefit for the person, their carers and the staff that may help them in a crisis.

What more does this study contribute?

- It was possible to construct modified crisis information in an accessible form which appeared understandable and meaningful for people with intellectual disabilities.
- Three quarters of the people with intellectual disabilities carried the crisis information on them every day.
- Nearly all the people with intellectual disabilities gave positive feedback about having the crisis information and wanted to continue to own it.

References


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