

AN INVESTIGATION INTO THE PRACTICALITIES OF INTRODUCING CLIENT HELD HEALTH RECORDS TO A MULTIDISCIPLINARY COMMUNITY TEAM FOR PEOPLE WITH A LEARNING DISABILITY

Simon Kennedy

Introduction

Central to the directives detailed within *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001) is the drive to improve efforts to communicate effectively with people with Learning Disabilities. Improved access to information impinges on the fundamental tenets of the paper i.e. enhancing the legal and civil rights and independence for the learning disabled while offering opportunities for improved choice and social inclusion. It is therefore vital that making improvements in the quality of communication with service users becomes a priority for service providers at all levels. One way of doing so, is through the use of Client Held Health Records (CHHRs). These are a means of sharing information which encourages the client to take an active role in their care. The introduction of CHHRs has been successful in a number of fields, serving as a useful adjunct to conventional note

keeping practices by providing a central source of information about a client's current management and progress (Curtice and Long, 2002; Elbourne *et al.*, 1987; Essex *et al.*, 1990; Laugharne and Stafford, 1996; Lee and Goodburn, 1993; Lovell and Elbourne, 1987; Reuler and Balazs, 1991; Stafford and Hannigan, 1997; Stafford and Laugharne, 1997; Hebron and Wooldridge¹, unpublished).

Essentially, CHHRs are documents providing an ongoing record of an individual's healthcare interventions. Details of each client contact that a health professional makes can be documented within the resource and so become accessible to the client and other professionals involved in their care between consultations.

Consequently, CHHRs can be regarded as serving three main purposes:

1. As a means of service user empowerment. CHHRs can potentially help clients better understand their health needs and the support that is available to them.

*Simon Kennedy, B.Sc.(Hons.)

Assistant Psychologist, Psychology Department, Laureate House, Wythenshawe Hospital, Southmoor Road, Wythenshawe, Manchester, M23 9LT, UK
Tel: +44 (0)161 9987070 Fax: +44 (0)161 291 6972 E-mail: simonkennedy1@hotmail.com

* For Correspondence

2. As a tool to facilitate communication between service providers and their clients.
3. As a tool to facilitate communication between service providers giving input into a client's care (and so minimise the potential for the duplication of work).

Despite the potential benefits of using CHHRs, comparatively little has been published regarding their utility for the Learning Disabled or the practicalities involved in coordinating their implementation on a large scale, yet this client group is regarded as having greater physical and mental health needs than the general population and is more likely to require input from specialist services (Borthwick-Duffy, 1994; McLaren and Bryson, 1987). Hebron and Wooldridge (unpublished) assessed the viability of establishing a CHHR system for this client group and achieved considerable success in demonstrating that the implementation of such a system is feasible. However this study, while offering justification for the use of CHHRs gives little advice to providers of Learning Disability services regarding practical issues to consider should they wish to successfully introduce CHHRs to their staff and clients.

In order to investigate such issues, Reading Community Team for People with a Learning Disability² (CTPLD) piloted CHHRs for use with a number of its clients. The project, guided by the directives within *Valuing People*, paid specific attention to the presentation, content and format of CHHRs and issues of client and staff training in their use.

Method

Participants and Procedure

Eleven Reading CTPLD clients were approached to participate in the project. Each client presented with differing physical and mental health needs and was viewed by their community nurse to be someone who could potentially benefit from using a CHHR. Seven clients agreed to take part and use their CHHR for a period of approximately 3 months.

Twenty professionals from a variety of disciplines were approached to participate in the project. Each professional had input into the care package of at least one of the service user participants. Upon the introduction of each client's CHHR an information pack and questionnaire were sent to each service provider involved. The questionnaire contained 17 items designed to gauge service providers' opinion of the service they provide in terms of communicating and collaborating with service providers and communicating with and empowering their clients.

After a period of approximately 3 months, follow-up interviews were arranged and the opportunity to feed back opinion was made available. In total, follow-up interviews were carried out with 4 clients, the remaining 3 participants were not consulted at this stage because of illness and difficulties in client engagement. Service providers were given the same questionnaire as at baseline with the opportunity to feedback opinion also being made available.

Record Book Format

The Reading CHHR format was based upon that used in the Hebron and Wooldridge study. Information within most CHHRs was presented in text form and complemented by Rebus (Woodcock and Davies, 1969) and PCS (Johnson, 1981) symbols though some used text alone. Revisions were made to the original format in an attempt to make the information within the resource transparent to the reader. These revisions to the original CHHR format were devised and agreed upon by the project's multidisciplinary steering group and included the development of a system to assist clients in remembering appointments and forthcoming important events. Digital photographs were taken of people and places relevant to each client's care. Multiple copies of these photographs, reduced in size, were kept in the record book and stuck onto a 'appointments' page when needed. This was specifically designed for those with poor literacy and those unfamiliar with the use of symbols.

Results

Reading CTPLD Clients

Follow-up interviews highlighted a number of issues regarding the use of CHHRs from a service user's perspective:-

1. The introduction of the CHHR caused concern for some clients regarding taking responsibility for ownership of the record book itself and what it would entail.
2. Information within the resource must

be pitched at a level that the client can readily understand.

3. The CHHR can successfully serve a function as an appointment diary.

Service Providers

Information collected was limited to the reports of those who came into contact with the CHHR over the 3 month period. Nonetheless, valuable information was obtained regarding the practicalities of implementing CHHRs from a service provider's perspective:-

1. Issues regarding gaining access to and the client taking responsibility for the CHHR were a concern:
"Difficulties with [client] taking responsibility for said record. [Client] agreed to keep them in the office [of sheltered accommodation in which he is resident] but they were often unavailable to me if no staff on duty at the time." *Community Nurse*.
". . . client does not always remember to bring them . . . they have been of most use during home visits. Client has used relevant parts and usually has had them to hand on home visits. Workers hope to add photographs for future use." *Family Worker*.
2. For some, the CHHR was viewed as serving primarily a health monitoring function:
"[CHHR] not used much as client tends to have seizures when not attending [day centre]." *Day Centre Support Worker*.
3. The design of the CHHR was an important factor regarding its ease of use:
"Workers discussed the size of file

with client and felt a smaller size that fits in a bag may be helpful." *Family Worker*.

Discussion

In endeavouring to maximise the clients' understanding of information in each record book the project raised a number of issues relevant to the implementation of future CHHR systems.

Design Issues

Materials

The choice of materials used in the making of CHHRs is an important consideration as each must be hard wearing to ensure durability over time. In this instance each CHHR took the form of a flexible A4 size ring binder. The fastenings in the binders were large enough to ensure that those clients with limited manual dexterity would not struggle in adding or removing pages and so that the record book could be updated with ease should the users' needs change. However, for some the size of the CHHR was off-putting as it was too large to be easily carried about their person.

Text, symbols and photographs

Text has to be in large enough print for the client to read without difficulty. Similar considerations have to be made as to the use of photographs and symbols. This creates problems in that each page has a limited amount of space to use with

the addition of extra pages to compensate making each CHHR large and bulky. Consideration also has to be made for the fact that pages may require replacement on a regular basis so the book does not become full too quickly. This poses the question of how to store old CHHR pages in a way that protects client confidentiality.

Text based CHHRs are often not ideal for many clients, though they do have considerable utility for the professionals involved in the client's care. Such CHHRs can serve as an introduction to their future use by the client in a more accessible format. During this project the entries made in each CHHR were hand written and potentially difficult to understand for those with poor literacy. As the project progressed it became clear that CHHRs do not have to be restricted to the format used in this project as they can be flexible as an information carrying medium. If a truly person centred approach is to be taken then it stands to reason that CHHRs can be further refined to fully meet the needs of their owners and need not be restricted to the written word or the use of symbols as a means of recording and imparting information. The use of audio/visual and multi-media technology in such cases could be explored.

Consultation with the client when designing the resource

The use of symbols is only valid as a means of communication when the information they are designed to impart is readily understandable to the reader. When applied indiscriminately the use of symbols to communicate amounts to tokenism. Consequently, consultation

with the client when designing the record is vitally important in order to ensure its content is as meaningful as possible. In order to do so a provision of time and resources must be made.

Training Issues

Encouraging clients to take ownership of their CHHR

All clients participating in the project were encouraged to take full ownership and make personal use of their CHHR rather than treat it as something belonging to or for the sole use of the health professionals involved in their care. For many clients this was a difficult concept to grasp and one that was at odds with their previous experiences of not having to be directly responsible for the ownership of property relating to their care.

Some clients could not see the potential benefits of using a record book, taking the view that they had been able to manage without one in the past. The crucial point here is that although it is true that many have managed previously without the aid of CHHR, it has tended to be with a large amount of support from health and social services which has served to heighten dependency rather than foster independence. The potential benefits of such clients owning a CHHR was highlighted by the fact that during the participant recruitment phase of the study, engaging clients proved difficult. Many struggled to remember the time of appointments and were often not at home at the times for which visits were scheduled. However, the use of photographs proved useful as reminders for

clients as to the days and times of appointments.

Encouraging service providers to use CHHRs

Not only do service users require support in using and maintaining their CHHR, service providers do too. The initial implementation and ongoing maintenance of a CHHR system requires considerable input from professionals for it to work. This support not only includes making available ongoing guidance as to the use of the resource itself, but extends to training in the use of the software and equipment involved in its actual production. Without adequate support and training the CHHR system can not work in the manner intended and can potentially break down altogether.

Practical Application

Health Monitoring

Perhaps those who stand to benefit most from using CHHRs are those with multiple health needs (it is interesting to note that of the 7 Reading CTPLD clients participating in this project, 5 had mental health problems, 5 had physical health problems while 5 of the 7 suffered to varying degrees from both). Often carers and service providers are required to monitor a client's health or behaviour for periods of time. In such instances a CHHR is ideal as it can act as a resource within which such information can be recorded and accessed by relevant parties.

CHHRs for carers

Those with profound disabilities may struggle to take direct ownership of their CHHR. In such cases family and carers could take that responsibility for them as often they are in regular contact with the professionals involved in the client's care with its co-ordination being an issue of direct concern for them.

CHHRs as a research tool

As the pages of a CHHR are potentially accessible to all service providers (with the client's consent) it can enable clinicians to read an 'holistic history' of a client's 'hands-on' care and serve as an additional source of information to the service provider around the time of initial contact with the client. In the same way the system can be used to pinpoint important events in a client's case history and so be of use as a research tool.

CHHRs and clients from Ethnic Minorities

'*Valuing People . . .*' asserts the need to make services more accessible to those from ethnic minorities. Many service users do not have English as a first language and so may make better use of symbols and photographs rather than text as a means of understanding and exchanging information. For this purpose the CHHR is ideal as it is a versatile tool that does not have to rely on written English alone to achieve its aims.

CHHRs and the transition of those moving into the community

CHHRs could prove useful for those who are moving from residential care to supported community living. A record keeping system could act as an aid to facilitate communication between those involved in supporting, co-ordinating and maintaining such a transition. Similarly, a CHHR could prove useful for the client as a means of recording information and concerns for later discussion and as an aid to help readily access their support network if required.

Combined Health and Social Care records

The potential utility of client held records is not just limited to health care. Individual systems could be devised incorporating both health and social care records in order to provide more comprehensive documentation of a service user's care package.

Conclusion

The piloting of CHHRs illustrated their potential utility and highlighted a number of practical issues to be addressed if the initiative is to be successfully developed further. What becomes clear is that:

1. The appropriate implementation of a CHHR system will take some time and that the success of such an initiative hinges on health professionals' abilities to identify and support those who can benefit most from using such

a system. The successful introduction of CHHRs with such individuals will provoke more flexible thinking as to their potential use with other clients and so ultimately encourage further innovation.

2. A provision of time and resources must be made in designing individual CHHRs and promoting their use amongst clients and health professionals alike. A provision must also be made in order to ensure that staff are adequately trained and supported in the use of CHHRs. Staff will also need to be knowledgeable in the use of the technology used in the production of CHHRs, such knowledge must be shared amongst professionals in order for the initiative to flourish.

Footnotes

- ¹ Hebron and Wooldridge Study - a report on the use of Client Held Health Records in East Gloucestershire Learning Disability Service can be obtained from: Cirencester Community Learning Disability Team, Grounds of Cirencester Hospital, Tetbury Road, Cirencester GL7 1UY, UK. Tel. +44 (0)1285 884676.
- ² Reading CTPLD provides a service to the GP population of Reading, Berkshire, UK.

Summary

This paper details an initiative by a multidisciplinary community team for people with a Learning Disability assessing the potential utility of Client Held Health Records for use with its

clients. Central to this paper is the exploration of making information as accessible as possible to clients with recommendations being made regarding the future development of such systems by service providers. Particular emphasis is paid to the presentation, content and format of Client Held Health Records and issues of client and staff training in their use. Suggestions for potential future uses of Client Held Health Records are made.

Acknowledgement

Thanks to the participants in the study for their time and co-operation and all those who gave their input and support to the project, specifically the staff of Reading CTPLD and Eileen Davis. Special thanks to Daphne Banat, Paula Hughes and Chris Traynor for their support and guidance throughout.

References

- Borthwick-Duffy, S.** (1994). Epidemiology and Prevalence of Psychopathology in People with Mental Retardation. *Journal of Consulting and Clinical Psychology*, 62, 17-27.
- Curtice, L. and Long, L.** (2002). The Health Log: developing a health monitoring tool for people with learning disabilities within a community support agency. *British Journal of Learning Disabilities*, 30, 68-72.
- Department of Health** (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. www.doh.gov.uk/learningdisabilities/strategy.htm.
- Elbourne, D., Richardson, M., Chalmers, I., Waterhouse, I. and Holt, E.** (1987). The Newbury Maternity Care Study: a randomized controlled trial to assess a

- policy of women holding their own obstetric records. *British Journal of Obstetrics and Gynaecology*, 94, 612-619.
- Essex, B., Doig, R. and Renshaw, J.** (1990). Pilot study of records of shared care for people with mental illnesses. *British Medical Journal*, 300, 1442-1446.
- Johnson, R.** (1981). *Picture Communication Symbols*. Solana Beach, CA: Mayer-Johnson.
- Laugharne, R. and Stafford, A.** (1996). Access to records and client held records for people with mental illness. A literature review. *Psychiatric Bulletin*, 20, 338-341.
- Lee, H. and Goodburn, A.** (1993). Developing an integrated strategy to meet homeless families' health needs. *Health Visitor*, 66, 51-53.
- Lovell, A. and Elbourne, D.** (1987). Holding the baby - and your notes. *Health Service Journal*, 19, 335.
- McLaren, J. and Bryson, S. E.** (1987). Review of Recent Epidemiological Studies of Mental Retardation: Prevalence, Associated Disorders, and Etiology. *American Journal of Mental Retardation*, 92, 243-254.
- Reuler, J. B. and Balazs, J. R.** (1991). Portable medical record for the homeless mentally ill. *British Medical Journal*, 303, 446.
- Stafford, A. and Hanningan, B.** (1997). Client Held Records in Community Mental Health. *Nursing Times*, 93, 50-51.
- Stafford, A. and Laugharne, R.** (1997). Evaluation of a client held record introduced by a community mental health team. *Psychiatric Bulletin*, 21, 757-759.
- Woodcock, R. W. and Davies, C. O.** (1969). *The Peabody Rebus Reading Program*. Circle Pines, MN: American Guidance Service Inc.