

# Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/ Challenging Behaviour:

## Technical Document -

### Chapter 4.5 Literature Review – Summary of Papers on Accessing Healthcare

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## **Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/Challenging Behaviour Chapter 4.5 A Summary of the literature regarding accessing health care for people with learning disabilities**

**Hames, A., & Carlson, T. (in press) Are primary health care staff aware of the role of community learning disability teams in relation to health promotion and health facilitation? *British Journal of Learning Disabilities***

### **Background**

People with learning disabilities often have greater health needs than the general population. Previous research has established that individuals with learning disabilities are more vulnerable to epilepsy, sensory impairments such as sight and hearing impairment and mental health problems. Additional health worries arise from a reduction in reported dental checks and use of health screening services for individuals with learning disabilities compared to the general population. While these individuals have the same rights as the general population in accessing health services, many experience barriers in accessing the appropriate care, particularly in accessing primary health care.

The Government White Paper Valuing People (DoH 2001) recommends primary health care teams must take a more active role in meeting the health needs for people with learning disabilities. The responsibility has fallen particularly on members of learning disability teams to work closely with the individuals to promote health awareness and facilitate access to primary health care services.

### **Aims and Methods**

This study examined the implementation of recommendations within Valuing People, within primary care teams in and around the Newcastle area. The authors particularly examined:

1. The extent to which local primary health team members were aware of learning disability teams and understood their role within the service.
2. The extent to which local primary health care team members were aware of the role of the learning disability teams in health facilitation and health promotion.

This was achieved through administering questionnaires to 15 GP practices within the local area. A total of 44 questionnaires were returned, predominantly by GP's (43%), practice nurses (27%) and health visitors (18%).

### **Results and Conclusions**

Of all the respondents only 36% had some contact with their local learning disability team leaving 63% of respondents who reported never having any contact with their local learning disability team. The remainder of results are organised

according to the responses from ‘contact’ and ‘noncontact’ with learning disability groups. These results are summarised in the table below.

<b>Questions asked to respondents.</b>	<b>‘Contact’ Group (Percentage response rate)</b>	<b>‘Noncontact’ Group (Percentage response rate)</b>
What is the role of the local learning disability team?	Support for people with learning disabilities (50%)  Assessment of needs or skills (50%)	Support for people with learning disabilities (50%).
What services are available from local learning disability teams?	Psychology, physiotherapy and links with social workers. (no percentage given)	Psychology, physiotherapy and links with social workers. (no percentage given)
How do you identify the health needs of patients with learning disabilities?	Ask patient directly (37%)  Ask patients family or carer (37%)  Through community learning disability team (6%)	Ask patient directly (28%).  Ask patients family or carer (43%).  Through community learning disability team (11%).
How could learning disability teams help with health screening, health promotion and facilitation?	Majority had no idea (25%)  Suggested they could provide workshops, training and advice to the GP practice (19%).	Had no idea (82%)

The results indicate that the majority of respondents had no contact with learning disability teams. Those that had been in contact with their local learning disability teams were unable to indicate the team’s specific role within health promotion and facilitation for people with learning disabilities.

There also appeared to be a lack of awareness as to the type of services a learning disability team may provide. Respondents from both the ‘contact’ and ‘noncontact’ group failed to acknowledge the type of professionals (and therefore the type of input) that contribute to a learning disability team (i.e. community nursing and speech and language services).

A high proportion of respondents indicated that they asked either the family carer or the individual themselves when trying to identify health needs. Many family carers or individuals with learning disabilities fail to understand and recognise arising health needs. This therefore questions the reliability of solely asking the patient or the patients carers for information regarding health needs. Very few respondents from

both groups indicated they used input from learning disability teams in addressing health needs.

Together the results indicate the lack of knowledge primary health care staff have of the role of learning disability teams in facilitating health promotion for individuals with learning disabilities. In particular the study highlighted the confusion over exactly which professionals make up the team and how this team could facilitate access to primary care for individuals with learning disabilities.

### **Implications for our subject**

With Valuing People requiring that all people with learning disabilities have a health facilitator and consequently a Health Action Plan offered during the transition process, this study highlights the significant steps that need to be taken in order to raise awareness of the role of health facilitators to primary care teams as well as other professionals involved in transition. In particular, a Connexions PA, SENCO, parents or the young person would benefit from understanding the role of a health facilitator in embracing mental as well as physical needs. This would in turn facilitate better access to health care, particularly mental health care, for people with learning disabilities.

**Melville, C. A., Cooper, S, A., Morrison, J., Finlayson, J., Allan, L., Robinson, N., Burns, E., & Martin, G. (2006) The outcomes of an intervention study to reduce barriers experienced by people with intellectual disabilities accessing primary health care services. *Journal of Intellectual Disability research*, 50 (1), 11-17.**

### **Background**

Individuals with learning disabilities have significant unmet health needs compared to the general population. Many barriers have been identified in preventing these individuals from accessing relevant health services. Of these barriers, the training needs of professionals working with people with learning disabilities have been consistently identified as an important one. In particular it appears that the training needs of practice nurses needs greater attention. These professionals have frequent contact with people with learning disabilities but very little specific training of working with these individuals or of understanding the types of health needs that pose significant risks to this population.

### **Aims and Methods**

The research tested the hypothesis of the effectiveness of a purpose specific training intervention for practice nurses working in Greater Glasgow. In particular the effectiveness of the training intervention on the nurses' knowledge of the healthcare needs of people with learning disabilities and self-efficacy in working with individuals with learning disabilities was examined.

### **Training intervention**

The training intervention consisted of a 45 page training pack and a 3-hour face-to-face training event.

### **Participants**

- Altogether, 201 practice nurses were asked to participate in the study and completed the first questionnaire.
- Up to 79 of these nurses were allowed to opt for the training intervention.
- 42 of these nurses received the training pack and attended the training event (Group1).
- A remaining 21 nurses just received the training pack (Group 2).
- 60 nurses did not participate in the training intervention but completed questionnaires at Time 2 (Group 3).

### **Study Design**

A three group, pre- and post-intervention study design was used.

At Time 1 of the study the training needs of all practice nurses was established using a purpose-designed questionnaire. The questions were concentrated within the domains of knowledge and skills. Presenting a list of 24 frequently occurring health needs assessed nurse's knowledge of the health needs of people with learning disabilities. Nurses were asked to indicate which health needs they thought were common among individuals with learning disabilities. There were additionally 3 questions measuring the self-efficacy of practice nurses in their work with people with learning disabilities.

At Time 2 of the study, all nurses were again invited to complete the research outcome measures. The outcome measures were completed 3 months after the training intervention. The questions assessing nurses health knowledge and self-efficacy were again asked at Time 2 to measure any changes in either of these domains. The nurses that took part in the training intervention were additionally asked specific questions regarding the components of the training.

### **Results and Conclusions.**

#### **Effects of the Intervention on Knowledge**

Overall a repeated measure ANOVA revealed a significant difference between the scores obtained from the different groups of nurses and the time at which knowledge scores were obtained.

At Time 2, there was a significant difference between the knowledge scores obtained from Group 1 and Group 3 ( $p=0.0006$ ). There was also a significant increase in knowledge of the nurses that received either both components of the training pack or just one component (i.e. Groups 1 or 2) between Time 1 and Time 2 of the study ( $p<0.001$ ). However, no significant differences in knowledge were found between Groups 2 and 3 or between Groups 1 and 2 at Time 2.

#### **Effects of the Intervention on Self-efficacy**

A repeated measure ANOVA did not reveal a significant group by time interaction.

There was a significant difference in self-efficacy between groups 1 and 3 ( $p=0.04$ ) at Time 2 of the study. There was however, no significant difference in self-efficacy scores between groups 1 and 2 and groups 2 and 3.

### **Practice Nurses Findings of the Training Pack**

Practice nurses from groups 1 and 2 combined stated that the training pack had made changes in their clinical practice on meeting the health needs of people with learning disabilities (67%). Additionally, nurses reported that they had referred to the training pack since the training intervention (61%) and that they were likely to refer to it in the future (83%).

The authors conclude that the training pack alone appeared to have a positive impact on the nurses knowledge of health difficulties for people with learning disabilities. The training pack and event combined additionally produced increases in nurses self-efficacy in working with these individuals. Additionally, the training intervention produced changes in nurse's clinical practice.

### **Implications for our subject**

For the subject of our interest, this study is important and could be further extended to establish practice nurses knowledge and understanding of mental health needs in young adults with learning disabilities. Exactly, what the training pack consisted of is unclear from the paper, nonetheless a separate study looking specifically at the impact of mental health training on access of mental health services for people with learning disabilities would be beneficial. However, this study establishes that a health based training pack significantly impacts nurses' knowledge and can impact on the health care received by an individual with learning disabilities.

**Wong, J. G., Clare, I. C. H., Holland, A. J., Watson, P. C., & Gunn, M. (2000) The capacity of people with a 'mental disability' to make a health care decision. *Psychological Medicine*, 30, 295-306.**

### **Background**

The capacity of an individual with a 'mental disability' to make a valid, informed decision regarding health care is much debated. Given the variety of conditions that fall under the umbrella of mental disability, the capacity of these individuals cannot be classified as the same. There are many factors that affect an individual's ability to make a health care decision other than the presence of a mental or learning disability. These factors include the language used to present information regarding the health need, as well as how easy to comprehend the material is.

### **Aims and Methods**

The present study primarily aimed at examining the performance of three 'mental disability' groups on a making a decision about a blood test. It was expected that performance of all of these groups would be poorer than the general population.

A second aim examined whether modifying the material presented to participants so that it relied more on visual interpretation, significantly improved capacity to make an informed decision. It was predicted that significant benefits to all three groups would be observed.

### **Participants**

Groups of participants were separated according to whether they had a mental illness, learning disability or dementia. In this study participants were allocated to the mental illness group if they had ‘at least a 5 year history of diagnosed schizophrenia or schizoaffective disorder, using ICD-10 criteria.’ The learning disability and dementia groups were decided from previous health records and by the use of established assessment measures. The general population group were also screened for mental illness.

There were roughly an equal number of participants in each group with the ‘mental illness’ group containing 21 participants, the ‘learning disability’ group containing 20, the ‘dementia’ group containing 21 and the ‘general population’ group containing 20.

### **Assessment of decision-making capacity**

An information sheet and a semi-structured interview were devised using templates from similar previous studies and in consultation with medical practitioners and lawyers. The structures of the information sheet and semi-structured interview are presented in Tables 1 and 2 respectively, below:

**Table 1: The Information Sheet.**

<b>Number of Elements in the Information Sheet</b>	<b>Elements of information regarding a blood test</b>
1	‘The purpose of the test’
2	‘Description of the procedure’
3	‘Risks associated with the test’
4	‘Risks associated with not having the test’
5	‘Voluntariness (the principle of a free choice in making a decision about the procedure).

**Table 2: The Semi-structured Interview**

<b>Number of Stages in the interview.</b>	<b>Elements of the interview assessing patients’ ability to understand and communicate information.</b>
1	Baseline knowledge of blood tests was established (‘Spontaneous Account’)
2	The information sheet was read by and read to participants. They were subsequently asked to give an account of its content in their own words (‘Uninterrupted Disclosure’).
3	Participants were asked to repeat stage 2 of the interview

	but stopping after each element of the information sheet ('Element Disclosure').
4	Participants had to demonstrate the procedure of a blood test ('Non-verbal demonstration').

An experienced psychiatrist scored all responses using a scoring system derived from one of the previous studies. Additional psychological assessments were also carried out in order to establish characteristics of patient groups.

### **Results and Conclusions**

Judgements were made regarding individuals capacity to make a health care decision before presenting participants with the information sheet and interview. It was found that the 'general population' group were judged as having greater capacity than the 'learning disability' and 'dementia' groups. However, the 'mental illness' group showed no statistical difference in capacity regarding a decision over a blood test compared to the 'general population' group.

A within group comparison was carried out to identify which of the abilities was difficult for the 3 'mental disability' groups. For the 'mental illness' group there was a significant difference in the ability to 'make a decision based on the information provided'. This was similar in the 'learning disability' and 'dementia' group.

It was also found that some items of information provided were easier to retain than others and that this differed significantly between the mental disability groups. It was found that the 'mental illness' and 'learning disability' group followed a similar pattern of understanding elements of the interview. The pattern for the 'dementia' group was slightly different. Across the 3 groups it seems that understanding of the procedure was easiest to understand, with risks of the procedure and risks of saying no being difficult to comprehend.

Finally, as expected the capacity to make a health care decision improved as the decision making task was simplified, but this improvement was only significant for the 'mental illness' group.

### **Implications for our subject**

Although the results are not generalizable to all individuals with any 'mental disability' these results show that taking into account a persons disability can have a significant effect on the adequacy of health care they receive. For some of the individuals taking part in the study, modifying information sheets and interviewing patients significantly improved their capacity to make an informed decision regarding a health worry.

Similarly, providing young adults with learning disabilities and mental health problems accessible information during the transition process can significantly improve their experience of transition and lead to gains in achieving personal goals. The main message from this paper highlights that the need to adopt more user-friendly approaches in information sharing with people with learning disabilities.