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Knowledge Exchange Seminar Series (KESS)

Examining the differences in how residential facilities support adults with learning disability with mental health problems and/or present behaviours that challenge

Background

Considerable progress has been made in supporting people with learning disabilities to live in community settings and move from large hospitals in Northern Ireland. Over 2,000 people with learning disabilities live in various residential facilities and supported living schemes in Northern Ireland. However, Slevin et al. (2011) demonstrated that a high percentage of people with intellectual disabilities display significant levels of challenging behaviours/mental health problems. It is estimated that in Northern Ireland across all settings, over 2,200 people with learning disabilities, including 950 children and 1250 adults, are likely to have challenging behaviours (Slevin et al., 2011). Estimates from three hospitals in Northern Ireland suggests that over a 24-month period 170 admissions or readmissions were because of some form of severe challenging behaviour or mental health problems.

Challenging behaviour is the most commonly used term used to describe people with learning disabilities who present with behaviours that challenge services (Emerson, 2001). This term refers to 'behaviours that might be dangerous for the individual themselves, or to others. Such behaviours also include other actions that are considered inappropriate within society in general' (Hastings 2003). Whereas mental health problems / mental illness has been defined as 'clinically recognizable patterns of psychological symptoms or behaviours causing acute or chronic ill-health, personal distress or distress to others' (World Health Organization, 1996)

Challenging behaviour and mental health problems among people with learning disabilities remains an issue to be addressed by services with respect to the individual, their family and service commissioners and providers (DHSSPS, 2005, 2011a, b; DHSSPS 2015). People with challenging behaviour or mental health problems are more likely to remain in large hospital settings and those who do move to community living arrangements often continue to present behaviours that challenge staff and services (Mansell et al., 2001, 2006; DoH, 2007). Some community based facilities can successfully support people with challenging behaviour or mental health problems but other apparently similar settings the placements of people cannot be successfully maintained.

For people with learning disabilities who present with behaviours that challenge services or have mental health problems, there is evidence that living in supported community settings can lead to an improved quality of life and more participation in meaningful activities in comparison to institutional care (Perry et al., 2011). However, when the person has challenging behaviour or mental health problems there may be a range of difficulties that adversely impacts on community living and can result in readmissions to specialist hospitals for assessment and treatment with concomitant costs not only associated with these services but also in retaining the person's place within the residential facility. Moreover, removing the person reduces the likelihood that the person and the residential services learn to manage better the behaviours in situ. Developing skills to support people who present behaviours or have mental health problems that challenge community services is also important if people previously resettled from hospitals and those yet to move from long stay hospitals are to be successfully supported in community settings. However, it is not clear what features of residential facilities that are most effective in managing the care of people with learning disabilities who challenge services and the supports that are most effective to help them do this is not clear.

Research conducted in Northern Ireland on admissions of people to specialist learning disability hospitals found challenging behaviour and / or mental health problems was a common reason admitted for assessment and treatment (Taggart, 2003; Slevin, et. al., 2008). Information provided from hospitals covering the 2-year period (2010-2011) indicated that 170 admissions, many of which were from residential facilities were because of challenging behaviour and / or mental health problems. Research with community learning disabilities teams in Northern Ireland found high percentages of people on case-loads also have challenging behaviour and / or mental health problems (Slevin et al, 2008).

Rationale for this study

There is a clear gap in research on the effectiveness of residential community based facilities in supporting people with learning disabilities and reduce the need for hospital admissions among people present with challenging behaviour and / or mental health problems. Few studies internationally have compared the effective elements that exist within community facilities that are successful in managing the care of people and preventing hospital admissions. Supporting people with challenging behaviour and / or mental health problems in community residential facilities incurs significant costs to HSC Trusts that may be duplicated when such people require additional or repeated hospital admissions. Also, the social cost to the client in terms of their quality of life can also be adversely impacted upon when they are removed from a facility that to them is their home. Evidence suggests that the workforce to support people with challenging behaviour and / or mental health problems should possess positive attributes, understanding and be confident in their skills (The Judith Trust, 2012).

This evidence indicates four key factors may influence how successfully services manage people who challenge and these are:

- 1) What staff attribute the causes of challenging behaviour to be (Hastings et al., 2003)
- 2) The emotional reaction of staff to such behaviours (Mitchell et al., 1998)
- 3) The self-confidence of staff in dealing with people who present behaviours that challenge / mental health problems (Hastings and Brown., 2003)
- 4) Aspects related to the systems and environment in which care staff work are also important variables in determining the effectiveness of a service in supporting people who challenge (Dilworth et al., 2011).

This project was a two-stage project that contrasted these four areas of staffing in residential facilities that are successful in preventing admissions to hospital with similar matched community residential

facilities from where people are admitted to hospital. Establishing the evidence of outcomes to shape future services is a key principle of the Crompton Review and the Mental Health and Learning Disability Frameworks (DHSSPS, 2011 a, b).

Study Aims:

The aim of the study is to investigate potential differences in staff cultures between two groupings of residential homes for people with learning disability and challenging behaviour and/or mental health problems, one of which has experienced higher rates of hospital admissions, and one of which has successfully maintained people in the community settings and has low rates of hospital admissions.

Study Objectives

Stage 1

1. To examine staff perceptions on the behavioural/mental health characteristics of the adults with learning disability and variations across residential settings;
2. To assess staff perceptions on aspects relating to community participation and leisure activities.
3. To ascertain levels of staff training and how this relates to the management of people with challenging behaviour and/or mental health problems;
4. To identify staff attributions of the causes of challenging behaviour and/or mental health problems for persons with learning disability;
5. To explore the emotional reactions of staff to challenging behaviour and/or mental health problems;
6. To examine staff self-confidence in dealing/managing with challenging behaviour and/or mental health problems;
7. To ascertain if aspects related to the systems and environment in which staff work are also important variables in determining the effectiveness of a service in supporting people who present with challenging behaviour and/or mental health problems.

Stage 2

1. To identify the most salient factors that staff in residential and supported living services and managers perceive as helping them to support a person with learning disability who has challenging behaviour and/or mental health problems?

Methods

The study will have two main groups:

Group 1: Placement Maintained Group: involves adults with learning disability with challenging behaviour and/or mental health problems living in residential facilities where staff are currently supporting them to reside with no hospital admission in the past two years.

Group 2: Admissions Group: involves adults with learning disability with challenging behaviour and/or mental health problems living in a residential facility where their behaviours have led them to being hospitalised.

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Stage One was a quantitative study that will use a number of standardised questionnaires that staff will complete on two groups of adults with learning disabilities and challenging behaviour / mental health problems in order to investigate the characteristics and the key factors that may influence hospital admissions. Group 1 will involve adults with learning disabilities with severe challenging behaviour / mental health problems living in residential facilities where staff are currently supporting them to reside (i.e. preventing hospital admission). Group 2 involves adults with learning disabilities with severe challenging behaviour / mental health problems living in a residential facility or supported living scheme who have been admitted to a learning disability hospital.

Admissions Group ($n = 78$) where residents have been admitted into hospital over a four-year period (Jan 2012-2014)

Placement Maintained Group ($n = 43$) where a matched sample of people who had placements maintained in the community during the same period.

There were 465 questionnaires completed by staff members in Stage One.

Stage Two was a qualitative study using 1-1 interviews with adults with learning disabilities who have challenging behaviour / mental health problems, and also interviews with their family and residential carers across these two groups to explore the perceived reasons for hospital admissions in greater detail. This information will be compared with similar data to be collected from adults with learning disabilities, their family and residential carers drawn from 'effective' residential settings in Camden/Islington Foundation Trust, London. Having data from Northern Ireland and Camden/Islington, will allow the research team to gain a deeper insight on what staff and service users experience as effective supports for people with challenging behaviour / mental health problems.

	Focus Group Managers	Focus Group Staff	Focus Group Family Member/Client Rep	Interviews Service Users
Admissions Group Northern Ireland	6	4	3	12
Placement Maintained Group Northern Ireland	5	5	2	7
Placement Maintained Group London	2	5	4	9
Total	13	14	9	28

Key Findings

Stage 1:

Staff in services who managed to support people with learning disabilities to stay in their community services had:

- Less experience
- Less knowledge about challenging behaviour / mental health problems
- A higher positive emotional reaction to challenging behaviour and/or mental health problems.
- More confidence
- Less difficulty
- A greater positive effect
- More satisfaction
- A higher sense of being in control
- Felt appropriate resources were felt to be in place
- Made more reference to communication as a technique. From the Word Cloud's we can see that similar behaviours were reported as displayed by service users in the admission group and the placement maintained group.
- Rated their managers' performance significantly more positively than the Admissions group in two of the three tasks, namely Task related functions and Individual related functions
- Rated their managers in the Placement Maintained group were reported as more likely to be using Supportive, Participative, Achievement orientated or Other style.

In the Admissions group

People with learning disabilities admitted to hospital were more likely to be reported as have higher levels of aberrant behaviours and more likely to have organic mental health condition, but less likely to have affective or neurotic mental health problems, in comparison to people within the Placement Maintained group (only for people with moderate learning disabilities).

Staff made more reference to methods such as medication, PRN, different professionals such as psychologist, psychiatrist and multidisciplinary team.

Stage 2:

Overall analysis of the content of the Focus groups and interviews added depth to the findings from the quantitative analysis and highlighted the important factors in positive leadership and relationships between staff members, with each other and people with learning disabilities. The following key aspects were identified as important for successfully supporting people with intellectual disability in community settings and equally so the absence of these factors was seen as a challenge:

- Clear and supportive leadership
- Connections between people
- Working with family members
- A confident staff team

Conclusions

The numbers of people with learning disabilities are projected to continue to increase within Northern Ireland (DHSSPS 2005), including the number of people with behaviours that challenge services to provide high quality, safe and effective care. The stated policy aim is that people with learning disabilities will be supported to live inclusive and valued lives within community settings. Prior to now much of the emphasis has been on the education of direct care staff and their level of experience as a means of improving care and these are important considerations. However, attention has been given to the role of the manager of services and how they are prepared for their role and the care environment they create. This project has provided quantitative and qualitative evidence to demonstrate that the leadership of staff teams to promote confident and personal centredness, relationships with people with learning disability and family members are critical factors in successful community residential services that support people with intellectual disabilities who present with challenging behaviour or mental health problems. On the basis of the findings of this study, it is argued that these factors are more important than staff education or length of time in post.

Key Recommendations

- The development of leadership skills that result in the engagement of staff teams and developing their confidence and their perceived sense of control should be considered a priority for staff appointed into roles to manage residential services for people with intellectual disabilities.
- There is a need to a regional agreed process for preparing people appointed into the position of managing residential services for people with intellectual disability who present behaviours that challenge or who have mental health problems.
- Managers of residential services at a local and regional levels should create a strong sense of team work by ensuring the team has articulated a clear vision of the team's work.
- People managing residential services for people with intellectual disabilities who present behaviours that challenge or who have mental health problems should recognise the need to work closely with people with intellectual disabilities who use services and family members and actively build relationships with them and involve them in decision making.

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Appendix 1:

Questionnaires used in this study:

- 1) **Demographic information about person with learning disability:** Staff completed this anonymized questionnaire about the demographics of the person with learning disability. This included gender, age, physical health, mental health, medications, previous hospital admissions, length of time in residence, and recorded incidents of challenging behaviour and/or mental health problems in the previous 12 months.
- 2) **Aberrant Behaviour Checklist (ABC)** (Aman & Singh, 1994): The ABC is a 5-Factor structure: 1) Irritability, agitation, crying (15 items); 2) Lethargy, social withdrawal (16 items); 3) Stereotypic behaviour (7 items); 4) Hyperactivity, non-compliance (16 items); and 5) Inappropriate speech (4 items). Each item rated from 0 (not at all a problem) to 3 (the problem is severe in degree).
- 3) **PAS-ADD Checklist** (Moss et al. 1998): The PAS-ADD can be used to collect symptom information directly from the key worker on the basis of knowledge already possessed about the individual.
- 4) **The Guernsey Community Participation and Leisure Assessment (GCPLA):** This is an instrument designed to gather quantifiable information regarding the quantity and quality of community-based activities, contacts and leisure activities both individual and social. This scale has been robustly developed and evaluated and has strong psychometric properties- reliability (0.83), and good content and concurrent validity (Baker 2000).
- 5) **Demographic information on staff:** All staff completed a questionnaire regarding demographics. This included gender, age, qualifications and training.
- 6) **The Challenging Behaviour Attribution Scale (CHABA)** (Hastings, 1997; Hastings et al., 2003): This is a 33 item Likert scale in which participants are asked to rate each item related to what they attribute to be the cause of the individuals challenging behaviour. The scale consists of six-subscales on attributions to challenging behaviour i.e. learned behaviours (positive), learned behaviours (negative), biomedical, emotional, physical environment and stimulation. This was completed by all staff.
- 7) **The Emotional Reaction to Challenging Behaviours (ERCB):** This is a 23-item scale in which participants rated their emotional reactions to the persons challenging behaviour on a 4-point Likert scale. The scale has two sub-scales within it allowing identification of negative and positive emotional reactions to challenging behaviour by staff. This was completed by all staff.
- 8) **The Difficult Behaviour Self-Efficacy Scale (DBSE)** (Hastings et al., 2002): This is a 5-item questionnaire in which respondents rate their confidence and how difficult they find it to deal with challenging behaviour in the particular clients on a 7-point Likert rating. This was completed by all staff.

- 9) **The Services System Assessment (SSA):** This scale assesses three organisation aspects (i.e. having appropriate resources, the internal organisation, and the quality of leadership). The scale consists of 22 categorical questions requiring a yes/no response on resources and organisation with additional questions on leadership and management using a 5-point Likert scale. This was completed by all staff.

