



Developing a Model of Care for Challenging Behaviour for Women with Intellectual/Developmental Disabilities in a High Secure Forensic Psychiatric Hospital

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Summary of project

This report outlines how a programme of care was developed for a young woman, A, who was admitted to the State Hospital, Carstairs. The hospital provides conditions of 'special' or high security for those individuals who are seen to pose a significant risk or danger, either to their own safety or to others.

The project was developed after 4 years of caring for A, where little, if any, progress had been made. A's assaultive behaviour had become so severe and frequent that several nursing staff had been seriously injured; Health and Safety representatives were concerned about staff well-being, and the Mental Welfare Commission (MWC) had expressed their unhappiness about the care and treatment approaches that were being used with A.

Having reviewed the available options, the model of "Positive Approaches to Challenging Behaviour," that had been designed by the Institute for Applied Behaviour Analysis, was selected for piloting, with implementation beginning in January 2004.

Background

Some individuals with intellectual/developmental disabilities (IDD) exhibit prolonged behaviours that present a risk either to themselves or to others. The behaviours that most often receive the label of "challenging" include aggressive and/or self-injurious behaviour and harm to property (Allen, 1999). However, there are very few individuals who have IDD and challenging behaviour (CB) to the extent that it has led to offending or other seriously irresponsible behaviours. For this small group, there is little in the way of research that would explain the links between IDD and challenging behaviour, although it has been recognised that the needs of this group have been overlooked (Scottish Executive, 2000).

Care and treatment for those individuals with IDD/CB who present as either at risk of, or who have engaged in, dangerous, violent or criminal actions is usually provided in secure forensic hospitals in the National Health Service (NHS). Of the four 'high' secure or 'special' hospitals in the UK, the State Hospital is the high security forensic psychiatric service for Scotland and Northern Ireland. The hospital admits individuals from anywhere in Scotland/Northern Ireland and individuals are admitted from either a local NHS psychiatric hospital, prison or court and the vast majority of the hospital population is male (94%).

Only 4% of the male population have IDD/CB, yet this diagnosis and reason for admission is applicable for one third (33.3%) of the women in the hospital. Thomson (2001) has identified that overall, the number of women admitted to the State Hospital is less than the other three high secure hospitals in the UK, however, the number of women admitted to the State Hospital with a diagnosis of IDD/CB was found to be greater. The most visible reason for the difference in the admission rates is that the State Hospital is still the only provider of care for women with IDD and challenging behaviour. A lack of medium and low secure services in Scotland means that there is little option about where to admit women who have these difficulties. Conversely, the hospital has been more pro-active in helping to develop medium secure services for men with IDD. While men have been able to move on from high secure care more quickly, women have become entrapped in the only service that is seen as able to manage challenging behaviours in this population.

In the case of one particular woman, A, the care and treatment approaches used at the State Hospital appeared to be having no sustainable positive outcomes, in fact, there had been an increase in her physical and verbal aggression and self-injurious behaviour – her challenging behaviours had worsened.

There may have been several reasons for this. Firstly, the needs of women with IDD are not being met as they are detained in a service that is primarily designed for patients with mental health problems; secondly, the average length of stay of this group is double that of any other diagnostic group; the third point to note is that the restrictiveness of the environment would appear to increase the severity and frequency of challenging behaviour; and lastly, there is a lack of appropriately trained staff to effectively treat this group of women.

Taking the first point, the majority of the hospital population is made up of patients with enduring mental health problems (Thomson et al, 1997) and, as new approaches to care have been developed, this population has been prioritised. This has led to a greater emphasis on pharmaceutical treatments and psychological interventions that are known to be effective in the treatment of mental health issues. Studies of the impact of these approaches on mental health symptoms have shown positive change in negative behaviours (Tarrier et al, 2000). However, for those patients with IDD, and whose

behaviours cannot be easily attributed to an underlying mental health problem, the potential benefits of pharmacological and psychological approaches have been less adequately explored (Thompson, 2001).

Secondly, research has found that the length of stay for IDD patients is twice as long as that for any other group of patients. Lamza (submitted for publication, 2006) found that for women with IDD, the average length of stay was 42 months, whereas women with enduring mental health problems stayed on average 19 months. One of the main reasons why this group of women are detained longer than any other group is the lack of 'step-down' facilities – that is, those services which offer medium or low secure care. Additionally, for some female patients with severe IDD/CB such as A, a positive change in their behaviour is usually required before transfer is considered. Change is measured by a reduction in the frequency and severity of the problematic behaviour, yet it can take significantly longer to understand and effectively treat these patients because of the complex combination of factors that maintains either the frequency and/or severity of the challenging behaviour (Moss, 2001). An approach, such as Applied Behavioural Analysis (ABA), that is flexible and naturalistic, supported by a range of practical strategies that have been organised in a clear framework (www.shapingbehavior.com), and delivered by dedicated staff is more likely to make a significant positive contribution when working with this group of patients.

The third reason why progress with A has been erratic and slow moving and why flexible, naturalistic approaches like this are extremely difficult to implement in high secure settings relates to the restrictiveness of the high secure environment. As the safety and security of all patients and hospital staff is the primary aim of the State Hospital, displays of aggression or self-harm are met with physical restraint and further restrictions such as close observation and restrictions on physical/environmental movement are put into operation. Analysis of these problematic behaviours through verbal communication is the initial response of clinicians in mental health practice; however, this is a major difficulty for patients with IDD, who have problems in identifying and verbalising their negative feelings because of their limited linguistic abilities (Moss, 1995).

Lastly, in order that the needs of those patients with IDD/CB are met effectively, a workforce of specialist-trained staff is required (Brown, 2001). Unfortunately for these patients, the majority of clinicians in The State Hospital are specialists in mental health care. The lack of appropriately trained staff severely restricts the scope for potential improvements in the care and treatment of this group. While employing more staff that are specifically trained to work with IDD would be a potential solution, changes in education and training have decreased the number of clinicians working in this field. Most staff that are presently trained to work with people who have IDD are based within community services. The small number of specialist clinicians who are employed in in-patient settings usually have to work across the range of services that the State Hospital provides. This results in these clinicians being more of a resource, limiting their ability to directly impact on in-patient care.

With these points in mind, an examination of alternative approaches to care was considered. Ager et al (2001) meta-analysis found that behavioural interventions for people with IDD enhanced treatment effectiveness and reduced the frequency and severity of challenging behaviour. The most commonly cited approaches were Cognitive-Behaviour Therapy (CBT), Gentle Teaching and Applied Behaviour Analysis (ABA).

Reviews of these approaches finds that in CBT, the delivery differs for IDD patients, as compared to those patients who receive CBT for their mental health problems; there is a notable decrease in pace and quantity of information that is provided (Smith, 2002). Ideally, clinicians should be

specialists in working with IDD patients and have undertaken the specialist training in CBT. While this remains a viable solution in the case of A, it would prove costly and time-consuming for The State Hospital.

Furthermore, there are few studies that relate solely to the use of Gentle Teaching, an approach that has mainly been taught as a non-aversive method for clinicians to manage challenging behaviour (Stirling, 1998).

Finally there was ABA, an approach that has greater recognition in the US, where there is a larger body of evidence related to its effectiveness. Whilst the Institute of Applied Behavioural Analysis (IABA) has recognised that no single strategy or intervention will have complete success with IDD patients who have challenging behaviour, models such as the one developed by LaVigna and Willis (1995) have been designed and tested to reduce challenging behaviour and improve the quality of life of this group of patients.

In the care and treatment of A, and for any future admission of women with IDD/CB, LaVigna and Willis's model has several clear advantages. The multi-element model uses the principles and procedures from Applied Behavioural Analysis, which has been found to make a significant contribution when working specifically with individuals who have IDD and challenging behaviour (Iwata et al, 1996). As ABA uses positive strategies to address challenging behaviour, there is a reduction in the reliance on punitive or aversive responses. For A, this model provided an opportunity to have a tailor-made approach to her care that was more systematic and concise; for clinicians/staff working with her, the model offered empirically supported strategies organised in a clearly defined framework, something that had previously been difficult to achieve.

Project aims

The aims of the project were firstly, to identify an approach where staff could work with A to reduce the frequency and severity of her assaultive behaviour and secondly, to ensure that the quality of A's life on a day-to-day basis was sufficiently stimulating whilst a safe environment was maintained and lastly to move A to an environment that was less restrictive.

Developing a model of care using the IABA principles and strategies

After a review the literature on CBT, Gentle Teaching and ABA (specifically the multi-element model of IABA - the service run by LaVigna and Willis) the project leader/innovator presented options appraisal paper to the women's service clinical team and thereafter to the directors of the hospital. Support was given to develop and implement the multi-element model of IABA.

The initial step was for the project leader/innovator and the first team member to visit the IABA services developed by LaVigna and Willis in Los Angeles, USA. The purpose of the visit was to observe how the service ran in its natural environment and to have an opportunity to discuss establishing the model in a high secure setting such as the State Hospital. This visit helped to establish how many staff would be required to deliver the model and the training needs of those staff; how the model would be set up in the ward environment and lastly the delivery of the model, including all of the necessary stages and documentation that was required to support it.

Creating a team

Initially, the decision was made by the clinical team to have a dedicated team of six qualified nurses to work as co-ordinators/advisors to the all ward staff to assist in implementing the model. The team of six were registered mental nurses but all had an interest in the model and working with A. By having six full-time staff involved, most shifts covering morning, afternoon and early evening would be covered by one of the six (taking annual leave and

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sickness into consideration) so that consistency and continuity of the model's strategies would be better adhered to, and six staff was agreed to be a good enough number so that they could provide support for one another whilst managing the very challenging behaviours of A. Each of these members of staff attended a week-long training course on the model.

After the six staff had completed their training, a 'support plan' day was organised where the group identified the main problem as A's physical aggression. As the support plan for multi-element model has four main parts – ecological changes, focused support, positive programming and reactive strategies, and each of these parts has specific strategies and skills that have to be tailored for every individual through the drafting of a support plan, it took considerable time and input of all members of the clinical team (namely the psychologist, psychiatrist, social worker, occupational therapist and clinical nurse specialist) to finalise the first plan.

The care environment

As the ward environment itself was going to be one of the major challenges to the success of the model, six qualified nurses were selected to be trained in the IABA model in order to manage A's physical aggression whilst maintaining her quality of life. The ward that A resides in is the sole unit for all women who are admitted to The State Hospital, therefore, women in the ward vary in terms of clinical diagnosis, forensic histories, age and social backgrounds and make a diverse and complex group to care for. A's main problems with hostility and aggressive behaviour, that was usually directed at nursing staff but on occasions it was towards other women, meant that she had very few peers in the ward. One further issue relating to all the ward staff, especially the nurses, was that they were understandably cautious during contact time with A as over the period of her admission, A's violent behaviour had ranged from unpredictable and impulsive to well-planned and orchestrated.

In January 2004, it was agreed that to begin with, A would be cared for in the smaller admissions area of the women's ward, and then gradually re-integrated into the main unit where the majority of the women spent their time. During the next four months, steady progress was made with A spending time in the main unit; a significant reduction in the number of physically aggressive assaults on staff and a programme of daily activities. A was even able to have an outing in the local area for something to eat. However, after the outing the number of assaults directed towards staff, some of which resulted in serious injury to the nurses involved began to increase. This coincided with two of the team of six being off on long-term sick leave, another two members of the team had to move onto nightshift leaving only two members of the original six. The strategies in the support plan were used less and less as the frequency and severity of A's assaults increased and from June 2004 until March 2005, the work of multi-element model was put on hold. During this time, A returned to the admissions unit, and at one point had to be nursed in her bedroom with staff seated outside the room due to the daily occurrence of aggressive behaviour.

Review of model

In January 2005, a review of all possible treatment approaches, including the IABA's multi-element model, found that the model had shown some degree of effectiveness during its short implementation time. After agreement with the hospital's management team, it was decided to re-establish a dedicated team, but there would be four staff, and they would work solely with A. Re-introduction and updating of the support plan took place in March 2005, and an evaluation day was held recently

Below is an evaluation of one of the tools used to monitor A's behaviour over the last 11 months. The Green/Amber/Red (GAR) chart (See Figure 1) monitor's A's behaviour on an

hourly basis, between the hours of 8am (the start of the team's shift with A) until 9pm (when A goes to bed). Green behaviours are when A is settled, interacting well and generally compliant; Amber is when there are indications of a change in presentation but A's behaviour has not deteriorated to aggression; Red behaviours are when A is very unsettled, hostile, threatening and her physical presentation indicates that staff should be aware.

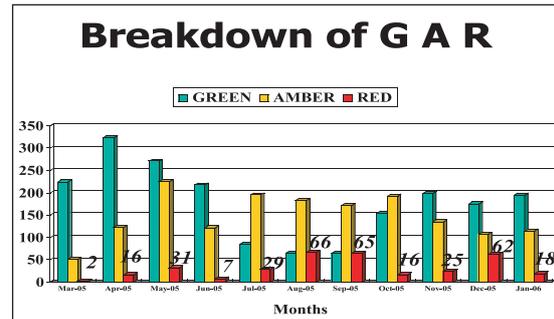


Figure 1. Green/Amber/Red Chart.

The number on the chart indicate the actual numbers of hours during that month that A was noted to present with Red behaviours

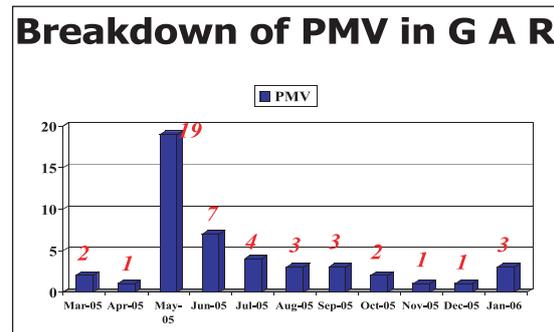


Figure 2. Use of Preventive and Management of Violence Techniques

Figure 2 indicates the number of times it has been necessary to use Prevention and Management of Violence (PMV) techniques. These were also recorded on the GAR charts.

As can be seen from the chart, there was a significant rise in A's assaultive behaviour in May 2005. At this time physical contact with the team was adapted to ensure nurses' safety and prevent A from assaulting. The unit where A has been nursed has the ability to become self-contained, and at times when A's presentation began to change and physical violence either appeared imminent, or was expressed, nursing staff would withdraw and secure the area between themselves and A. During these periods, A was still able to converse and was coached and taught to use skills until her aggressive behaviour had lessened. This approach has resulted in a gradual decrease in staff having to use PMV techniques.

Overall, progress is steady yet slow. A's behaviour fluctuates on a daily basis, where she can only offer limited explanations as to the cause. There is daily contact, although the proximity of staff to A varies. There is a full range of activities in place, however there are restrictions in terms of the environment and the materials that can be used. Despite this, A has regular contact with an occupational therapist and a rehabilitation instructor, with the pet therapy and sports and fitness service, with her psychiatrist, psychologist and psychology assistant and with the clinical nurse specialists. All of this happens in conjunction with the ongoing daily

support, education and coaching provided by her dedicated team of nurses.

Implications for practice

The most challenging aspects of working with A, a woman who has such extreme challenging behaviours and a diagnosis of IDD, is the difficulty in remaining positive, consistent and supportive in our clinical practice. As the team are mental health nurses, they have had to adapt the skills they gained during their training and post-registration experiences to work with a markedly different approach and a diagnostically different patient. The pace at which the nurses have to work is much slower, the way information has to be presented is much simpler and the received responses from A can often cause frustration and confusion. Furthermore, not all the existing team have had the benefit of the principles of ABA, the education and knowledge that is integral to the IABA's multi-element model, so staff are having to learn the strategies as they go.

On a practical level, the long-day shift system can be draining, especially if A has been particularly disturbed and aggressive, and there is always the very real threat of being assaulted. In addition to this, contact with the other women in the ward is very limited, so there is potential for some skill loss in terms of managing mental health issues.

Yet, even as new members join the team, there continues to be close communication between the members, weekly opportunities to reflect upon practice, individual clinical supervision and regular contact with the other professionals involved in the care of A have meant that there are many occasions where formal and informal discussions about A's care and treatment can take place.

Having the opportunity to freely discuss issues with one another, to practice techniques and reflect on their effectiveness and to give support and honest feedback have been the main reasons why the team have worked together so effectively. As there are weekly consultations where all other disciplines attend and have input into discussions, the whole team has an opportunity to discuss and plan the key targets for that week, as well as give feedback on their own work with A.

Using such a multi-professional approach, where all disciplines work visibly with one another has offered us an opportunity to view each other in practice, to ask questions and to build our own skills, which we can then use in other relevant clinical situations.

Reflections of project leader

Given the restrictiveness of the State Hospital environment, and the lack of appropriate services elsewhere in Scotland, I believe that this approach is the most appropriate and safest for this woman. I have had an opportunity to observe the model working effectively however, this was in a setting where greater resources and learning experiences were available to individuals with IDD/CB, and the staff group were fully qualified and trained in the model.

Despite this, I have learnt more about ABA using this approach than at any other time in my professional career; I have observed nursing staff, who previously felt frustrated and a loss with what to do for A, demonstrate proficiently a range of skills that they have had to develop as a result of caring for this patient, and doing so very effectively. Lastly, I have seen nurses take a lead role on the development, delivery and evaluation of an evidence-based approach in health care – a personal aim of mine since I took up this post.

References

- Ager, A. and O'May, F. (2001) Issues in the definition and implementation of "best practice" for staff delivery of interventions for challenging behaviour. *Journal of Intellectual and Developmental Disability*. Vol. 26, No. 3, pp243-256.
- Allen, J. (1999) Contemporary and New Horizons in Learning Disability Research.
- Brown, J. (2001) Future directions – initiatives and agendas *In*: Thompson, J. and Pickering, S. (2001) *Meeting the Health Needs of People who have a Learning Disability*. London: Bailliere Tindell, Harcourt Publishers Ltd.
- Iwata, B.A., Dorsey, M.F., Slifer, K.J., Bauman, K.E. and Richman, G.S. (1982) Toward a functional analysis of self-injury. *Analysis and Intervention in Developmental Disabilities*. Vol. 2. pp 3-20.
- Lamza, C. (2006) A survey of women's characteristics in a high security forensic hospital. Submitted to the Journal of Forensic Practice.
- La Vigna, G.W. and Willis, T.J. (1995) Challenging Behaviour: A Model for Breaking the Barriers to Social and Community Integration. *Positive Practices*. Vol. 1. No. 1. pp1-14.
- Moss, S.C. (1995) *Methodological issues in the diagnosis of psychiatric disorders in adults with learning disability*. Thornfield J. University of Dublin. 18. pp 9-18
- Moss, S. and Lee, P. (2001) Mental Health. *In*: Thompson, J. and Pickering, S. (2001) *Meeting the Health Needs of People who have a Learning Disability*. London: Bailliere Tindell, Harcourt Publishers Ltd.
- Scottish Executive (2000) *The Same as you? A review of service for people with Learning Disabilities*. Edinburgh: The Stationery Office Bookshop.
- Stirling, C. and McHugh, A. (1998) Developing a non-aversive intervention strategy in the management of aggression and violence for people with learning disabilities using natural therapeutic holding. *Journal of Advanced Nursing*. Vol. 27. No. 3. pp 503-509.
- Smith, S. (2002) *Psychological Interventions*. London: Estia Centre, Guy's Hospital.
- Tarrier, N (2000)
- Thomson, L.D.G., Bogue, J.P., Humphreys, M.S. and Johnstone, E.C. (2001) A survey of female patients in high security psychiatric care in Scotland. *Criminal Behaviour and Mental Health*. Vol. 11. pp 86-93.
- Thompson, J. and Pickering, S. (2001) *Meeting the Health Needs of People who have a Learning Disability*. London: Bailliere Tindell, Harcourt Publishers Ltd.

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