

## **Reflections on vocational reintegration through the development of a patient-led café stall in brain injury rehabilitation: The MAK Café**

Leo Parsons, *Assistant Psychologist*

Miguel Montenegro, *Clinical Psychologist*

St Andrew's Healthcare, Northampton

### **Abstract**

*Vocational or activity-based rehabilitation can offer individuals with brain injuries 'normalised' settings to re-learn key skills fundamental for vocational and social re-integration, in particular since some people with more severe impairments may be referred to inpatient rehabilitation to address many of their difficulties, and their vocational reintegration is often halted, or placed in a state of lowered priority. A patient-led coffee stall, named MAK café, was developed aimed at providing an opportunity for service-users to engage in a weekly vocationally and psychosocially orientated activity, which included 'customer' service and financial management of funds and transactions. Four service-users currently involved in the MAK café project were invited to give their views and their cognitive, behavioural and functional data were also evaluated. Staff and 'customers' also provided feedback about the benefits of the MAK café. Data from SASNOS and OAS-MNR suggest a trend of positive improvement in neurobehavioural disability and aggression. Future challenges are also considered.*

### **Vocational reintegration after brain injury**

Typically, an individual who has experienced a brain injury can experience emotional and behavioural changes, cognitive and communication problems, and at times physical disability, to name a few (Headway, 2015). These difficulties can severely impact on people's ability to fulfil previous social and vocational roles, thus affecting quality of life and life satisfaction, as well as everyday psychosocial and cognitive functioning (Channon & Crawford, 2010). Some people with more severe impairments due to brain

injuries are then referred to inpatient rehabilitation to address many of their difficulties, and their vocational reintegration is often halted, or placed in a state of lowered priority. As people are unable to practice such skills perhaps due to unwellness or risk, these skills can decline over time.

Over the past decade, the model of rehabilitation has experienced a paradigm shift to explore the value of the vocational rehabilitation milieu, whereby engagement in everyday activities is regarded as an important therapeutic aim. Vocational or activity-based rehabilitation and re-engagement can offer individuals a 'normalised' setting to re-learn key skills fundamental for vocational and social re-integration. Often classroom vocational skills training programmes are implemented with individuals who lack interpersonal skills and the ability to effectively communicate in a problem situation (Denmark & Gemeinhardt, 2002). However, such skills training groups can sometimes be perceived as 'synthetic' and artificial, as they lack ecological validity and realistic practice on the necessary skills for vocational reintegration.

Relearning vocational and functional abilities can be a long and arduous process, which can in turn lead to dissatisfaction and self-reported ill-being (McMahon et al., 2014). However, it is generally accepted that engaging with vocational and functional tasks can make a positive contribution to an individual's longer-term rehabilitation; not only in the development of skills but it can also be linked to heightened self-concept and self-esteem (Johansson, Hogberg & Bernspang, 2007). A vocation can act as a source of re-identification with the 'previous self', may contribute to feelings of 'normality' and may be a chance to re-socialise and re-acquaint with some 'forgotten' skills (Saunders &

Nedelec, 2014). People who are more actively engaged in a vocational activity, be it through 'gainful employment' or an education programme report higher levels of life satisfaction and recovery (Cicerone & Azulay, 2007; Corrigan et al., 2001). In essence, people value being and feeling productive, and by that to find meaning in what they do, to see results and have personal gains from the activities they are engaged in (Dawson et al., 2007). This article discussed the development of a patient-led coffee stall and the benefits such project brought to all those service-users involved.

### **The development of a patient-led coffee stall: The MAK café**

During Autumn 2013, three service-users residing in a locked slow-stream brain injury rehabilitation unit, with the support of their clinical psychology team, organised and established a coffee stall. This stall was branded with the name 'MAK café', by using the initials of the service-users involved in setting it up. The initiative was aimed at providing an opportunity for those service-users to engage in a weekly vocationally and psychosocially orientated activity, which included 'customer' service, and financial management of funds and transactions.

This project further involved service-users in business and planning meetings to support them to influence the direction of the 'MAK café', including discussing ideas, projects, produce and marketing strategies. The implicit aim of these meetings was to support the development of a range of cognitive and social skills, whilst maintaining stable psychological and behavioural well-being through active engagement. Overtime, the project evolved and has continued as a well-established initiative offering opportunities

for service-users residing within all the locked rehabilitation units wishing to revisit some of the vocational skills offered by the initiative.

The MAK café opens once a week for about 90 minutes and service-users are on a rota to take charge in setting it up, running it, clearing it at the end of the afternoon. It is located in the main open reception area of the Brain Injury Rehabilitation building, thus in the way of a busy and commutable area. The MAK café also transformed to follow seasonal and festive trends, and has germinated into a less regular 'cake stall' (Dhalia Cakes) with baked produced by service-users residing in the active rehabilitation unit, and into an occasional book and CD stall with items from local donations. The MAK café has been represented in staff recruitment open days, family and carers events, and has also been fundamental in the integration of seasonal and charity events at the brain injury department.

The aim of this paper is to reflect on the development of the MAK café initiative, and to provide qualitative and quantitative updates from the service-users involved in this project.

## **Method**

A discussion was held with four service-user-members of the MAK café team to determine their views about the initiative. Some time was taken outside of the usual running of the MAK café and each participating member of the team was individually approached to express their views and opinions about the 'MAK café'. Cognitive,

behavioural and functional data was also gathered from their records to evaluate service-users rehabilitation progression within the service. The measures revisited were the 'Functional Independence Measure and Functional Assessment Measure' (FIM + FAM), the 'St Andrew's Swansea Neurobehavioural Outcome Scale' (SASNOS), and the 'Overt Aggression Scale – Modified for Neurorehabilitation' (OAS-MNR). Admission and the two most recent SASNOS and FIM+FAM scores for each person currently involved in the MAK Café were analysed using the Friedman non-parametric test. As for the OAS-MNR, the first 3 months and most recent 3 months of frequency and Aggregate Aggression Score (AAS) data were included in the analysis using the Mann-Whitney *U* test (Alderman, Knight, Stewart, & Gayton, 2012).

Members of staff supporting the service-users have also offered their views on the project's progress and development. In addition to this, the opinions of café 'customers' and of staff supporting the MAK café were also included.

### **Service-user progression**

Of the three initial service-users involved in the development of the MAK café, one was discharged to another service. The remaining two service-users continued their involvement as they moved to one of the pre-community rehabilitation units that are part of the same service. Other service-users were introduced to the initiative, and some of these too progressed from the active rehabilitation and/or slow-stream rehabilitation into the pre-community rehabilitation units. This progression was facilitated by positive changes in risk, behaviour and social skills. The predictability of the MAK café, and of

specific job roles, motivated service-users to continue with their presence, but there were visible positive changes in memory recall and sustained attention for those service-users who had initially presented with many difficulties. Service-users also learned to tolerate ‘quiet periods’ but also sudden influx of customers, often using that time to discuss positive aspects of life and goals. Two service-users also progressed to attend the MAK café without the need for staff escorts as they received unescorted leave around the hospital grounds.

When exploring data for the four service-users mostly involved in the MAK café project, the most evident change was in the SASNOS and OAS-MNR data (Table 1).

**Table 1.** Individual comparison of % improvement scores\* for each individual involved in the MAK café when analysing admission and latest SASNOS, FIM+FAM and OAS-MNR AAS scores.

	<b>SASNOS</b>	<b>FIM+FAM</b>	<b>OAS-MNR-AAS</b>
	<b>% improvement</b>	<b>% improvement</b>	<b>% improvement</b>
<b>Service-user 1</b>	21.3%	4.3%	17.8%
<b>Service-user 2</b>	-4.9%	-14.8%	92.9%
<b>Service-user 3</b>	-13.5%	7.7%	96.7%
<b>Service-user 4</b>	225.4%	-3.7%	68.2%

\* Negative (minus) scores suggest a negative decline for that particular measure

The SASNOS data experienced an average of 23.5% improvement over time, and the OAS-MNR experienced an average of 78.8% improvement when using the AAS.

Despite these results being statistically non-significant, the data suggest a trend where

people involved in the MAK café have shown a generalised improvement in their neurobehavioural disabilities, but most importantly in their behavioural control and reduction in aggression as measure by the OAS-MNR. The FIM+FAM results have not resulted in any obvious change.

### **Service-users' reflections**

*“The MAK café is somewhere you can go to get a drink or a snack and it is very reasonably priced at only 50p. Patients volunteer to run the MAK café with staff support. Whilst working on the MAK café I have become friendly with the staff that support the MAK café as well as the patients that volunteer with me. Importantly, it teaches you how to make a decent cup of coffee! You have to be flexible and make tea and coffee according to individual customer's taste. If someone else was interested in starting a similar initiative, I would advise them to listen to what the customer wants. I would also say they would need to have a friendly attitude towards other people”.*

*“We sell coffee, hot chocolate, ice cream and tea, it's always bloody good. I enjoy finishing the coffee, helping out to clean and tidy. I really have just enjoyed it”.*

*“The MAK café is a place that we all get together, the boys who run the café. The best thing about the MAK café is being able to get out and work as I used to. It shows that people with brain injuries are able to work. Advertising is important making sure people know that we are here”.*

*“It’s a place where we sell coffee, tea and a variety of other stuff. It keeps my mind busy and I see friends and staff. I just enjoy taking part and have gained a lot of knowledge. All of us benefit from the MAK café”.*

### **Staff and ‘customers’ feedback**

*“The MAK café has been a fantastic initiative within the brain injury service and is now very much an established part of the weekly routine. It has always been run once a week but has recently undergone change to allow service-users to participate for a longer period of time. It has been fantastic to see how much the service-users value being a part of this initiative and in my time supporting the MAK café over the last two years or so I don’t think anyone has ever declined to support the running of the stall. It is also great to see the skills that some of the patients have developed, which includes interpersonal skills, planning, organising, attention and memory. The MAK café is, on the surface, a bit of fun and an enjoyable experience for both patients and customers, however at the root of it the service-users are developing core functional skills to support their rehabilitation and wellbeing”.*

Below are just a few of the comments that the MAK café has received in the feedback book from customers who have visited the MAK café;

- **“Amazing friendly staff – keen to help. Great service”**
- **“I look forward to my coffee each week. [Patient] even remembers what I have now!”**

- **“Great service from friendly people. Great this is led by our residents – twice a week would be even better”**
- **“A lovely little café! Very friendly and great service, keep up the great work”**
- **“How handy! And what a great idea! Service is always with a smile”**

## **Discussion**

The MAK café has played an important role within our brain injury pathway. For the ‘customers’ it offers some light refreshment at the end of a busy week. For the service-users managing the stall every week it offers a chance to be a part of an initiative which focuses on opportunities to socialise and develop cognitive and social abilities in a naturalistic environment. The project provides opportunities for service-users to develop a sense of self and identity during their stay in hospital by being engaged in a meaningful activity (Johansson, Hogberg & Bernspang, 2007).

The initiative has become an important symbol to those who have attended in the past and for those who still support the project, offering the opportunity for productivity and cognitive-behavioural control. From the accounts given by those who have taken part, it is clear to see the meaning this has brought to them and the satisfaction they get from supporting the MAK café each week. It is also valuable to integrate cognitive and behavioural data from the same service-users and consider how much they have positively changed over time. Service-users have reported that they have had the opportunity to *“become friendly with the staff that support the MAK café as well as the*

*patients that volunteer with me”, “get out and work as I used to” and “enjoy taking part and have gained a lot of knowledge”.*

Offering the chance of a ‘normal’ activity and the chance to socialise is important after brain injury to support someone’s rehabilitation (Saunders & Nedelec, 2014) which the MAK café offers to all involved. No matter the skill or ability there is an opportunity for people to find their own place and have a paced time in the MAK café. It is clear from the comments of both staff and service-users that the initiative is a highly valued and desirable activity to be a part of, and can make a difference.

### **Future challenges**

As with any service initiative, the MAK café is not immune to challenges from service-pressures, priorities, and developments. At present, the MAK café project resides within the domain of the clinical psychology team directly involved with the respective service-users taking part in the initiative. The main challenge to this is ensure that clinical psychology staff are consistently available on a weekly basis to support the service-users accessing the equipment and produce for the MAK café, but to also provide with enhanced cognitive and behavioural observations to prevent any risk to the service-users involved or to ‘customers’. The responsibility is enlarged though if we take into account that it can take about 2.5 hours to setup and clear the equipment, plus time to plan for ideas and go shopping for products to sell in the stall. Advertising also takes time, as it does the ongoing service justification as to what is the benefit of having such initiative, involving service-users in it, and encouraging people to support the stall with their presence. Often staff resources are scarce, due to clashing of priorities, but so far

the psychology team has managed to support the event reliably and consistently for the past 3 years. For the initiative to continue to flourish, it would require support from the extended multidisciplinary team to take turns with the task in staffing the MAK café. So far, the most successful MAK café by-product was the development of the “Dhalia Cakes” stall, which has already grown its reputation by being an Occupational Therapy-led stall providing cakes baked by service-users on the ward. However, this “cakes stall” is still very infrequent and affected by staff availability.

The other issue potentially affecting the longevity of the MAK café pertains with the steady influx of service-users ready and willing to accept the vocational role of staffing the MAK café. So far, only seven service-users have been reliably involved in the project since its inception. However, as people move along the rehabilitation pathway, and hopefully out of the service into the community, those who still remain in the service often have their timetables reprioritised with other activities which may take priority over the MAK café. Such priorities are often re-negotiated with the service-users’ and their new teams, but most often it is the very nature of those new activities, which can also be of a vocational nature and externally provided, thus presenting as inflexible due to limited availability of timetable slots. In this instance, it can only feel natural for service-users involved in the MAK café to progress to other vocational activities, thus ‘opening the door’ for new people to experience the initiative. At this point, the aim would be to focus our energy on ‘recruiting’ other service-users who may not immediately see the value of being engaged in the MAK café.

A further challenge may lie with the continuous presence and flux of 'customers' who provide real meaning to service-users regularly involved in the MAK café. There are regular 'customers', who visit the stall every week, and their presence is acknowledged by the service-users who react positively to such familiarity and consistency. Such regular flux of 'customers' is also important for the ongoing motivation of service-users to engage in the MAK café, but also to ensure that they gain the required skills from such interactions. The most difficult task so far has been getting the consistent support and involvement from other wards to ensure that other service-users are brought over to experience the MAK café as 'customers'. Most often than not, limited staffing levels and other ward-based crisis interfere with the opportunity for staff and service-users to come along to the MAK café. An outreach, delivery type, service was already considered but unable to be developed due to staffing issues discussed above. Support is thus required from each ward to ensure that attendance at the MAK café is prioritised in service-users timetables and that staffing levels represent the required need for those few hours once a week. The MAK café can then be fully experienced as a leisure time for service-users to come along, buy a hot or cold drink, a snack or even take part in a seasonal event or fayre.

## **Conclusion**

A brain injury of any type can have a profound effect on all aspects of life and may mean for some people that they are unable to return home or to meaningful employment. Offering an opportunity for a vocational experience, such as the MAK café, provides the individual an experience of a vocation in a controlled environment where

they are able to receive individualised support, and using their strengths to guide what level of support they provide. The MAK café is based on providing those who take part with a positive opportunity to show what they can do as opposed to what they may no longer be able to do as a result of brain injury. Those who take part are always truly grateful to be involved and to show what they have learned and what they can do and their desire to do it more.

## **References**

- Alderman, N., Knight, C., Stewart, I., & Gayton, A. (2012). Measuring behavioural outcome in neurodisability. *British Journal of Neuroscience Nursing*, 7 (6): 691-695.
- Channon, S., & Crawford, S. (2010). Mentalising and social problem-solving after brain injury. *Neuropsychological Rehabilitation: An International Journal*, 20(5), 739-759.
- Cicerone, K.D., & Azulay, J. (2007). Perceived self-efficacy and life satisfaction after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 22(5), 257-266.
- Corrigan, J.D., Bogner, J.A., Mysiw, W.J., Clinchot, D., & Fugate, L. (2001). Life satisfaction after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 16(6), 543-555.
- Dawson, D.R., Schwartz, M.L., Winocur, G., & Stuss, D.T. (2007). Return to productivity following traumatic brain injury: Cognitive, psychological, physical, spiritual, and environmental correlates. *Disability and Rehabilitation*, 29(4), 301-313.
- Denmark, J., & Gemeinhardt, M. (2002). Anger and its management for survivors of acquired brain injury. *Brain Injury*, 16(2), 91-108.
- Headway (2015) Effects of brain injury. [Online] Available at: <https://www.headway.org.uk/about-brain-injury/individuals/effects-of-brain-injury/> [Accessed 24/11/2015].
- Johansson, U., Hogberg, H., Bernspang, B. (2007). Participation in everyday occupations in late phase of recovery after brain injury. *Scandinavian Journal of Occupational Therapy*, 14(2), 116-125.
- McMahon, P., Hricik, A., Yue, J. K., Puccio, A., Inoue, T., Lingsma, H. F., Beers, S. R., Gordon, W. A., Valadka, A. B., Manley, G. T., Okonkwo, D. O., Casey, S. S., Cooper, S. R., Dams-O'Connor, K., Menon, D. K., Sorani, M. D., Yuh, E. L., Mukherjee, P., Schnyer, D. M., & Vassar, M. J. (2014). Symptomatology and functional outcome in mild traumatic brain injury: Results from the prospective TRACK-TBI study. *Journal of Neurotrauma*, 31, 26-33.
- Saunders, S. L., & Nedelec, B. (2014). What work means to people with work disability: A scoping review. *Journal of Occupational Rehabilitation*, 24(1), 100-110.