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Early Intervention in the Real World

Family peer support work in an early intervention youth mental health service

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Abstract

This paper describes the evolution of a family peer support programme in an early intervention service in Melbourne, Australia. In response to policy directions from Federal and State governments calling for carer participation in public mental health services, and feedback from the families of young people at Orygen Youth Health, the 'Families Helping Families' project was developed. The positive acceptance by families of this innovative programme also warrants further exploration. The programme has overcome many organizational hurdles associated with specifically trained and employed family carers working alongside professional mental health clinicians. This article describes the change processes involved in implementing this programme and documents preliminary expressions of the benefits of family peer support. The contribution of lived experience in treatment and consumer care plans needs rigorous research and evaluation.

Key words: early intervention service, early psychosis, family peer support.

INTRODUCTION

Orygen Youth Health (OYH) is a youth mental health service in Melbourne, Australia, incorporating a clinical programme, a research centre, and a training and communications programme. The clinical programme comprises specialist outpatient clinics, an inpatient unit, psychosocial recovery programmes and an access team.[1]

In 2001, family members of young people who were current clients of OYH's early psychosis clinic, the Early Psychosis Prevention and Intervention Centre (EPPIC), attended a focus group to explore their satisfaction with the service. Information from the focus group revealed that family carers appreciated that their young people were receiving good treatment and care, but they themselves often felt excluded. Although there was some information and support provided to families, this was inadequate. Families still felt they were not receiving the emotional support or the skills they needed to help them manage the difficult behaviours they were experiencing with their young people as a result of the onset of mental ill health.[2]

These carers said that what would have helped them in the earliest stages was communication with other carers who had gone through, or were going through, similar experiences and who could share their stories of learning how to cope. Their main issues, regardless of diagnosis, were a need for increased emotional support as well as for more psychoeducation. Some of the families were also keen to 'put something back into the service'. Having been through the service, they wanted to help families new to the service. They were mindful of the devastating impact they themselves had experienced, and proposed that sharing their experiences and talking about how they had learned to manage, along with what had been helpful and not so helpful, would help minimize the trauma associated with a first episode of psychosis. This phenomenon is described as the 'helper/therapy principle',[3] where those who help others experiencing similar circumstances also feel helped by this process of mutual sharing and support.[4] Most importantly, they wanted to offer hope by showing other families that their situations had improved.

AUSTRALIAN MENTAL HEALTH POLICY DIRECTIONS

In 1996, Standard 3 of the first National Standards for Mental Health Services stated that 'consumers and carers are involved in the planning, implementation and evaluation of the Mental Health Service', and that 'the MHS assists with the training and support for consumers, carers and staff which maximizes consumer and carer participation in the service'. It stated as a specific example of this, 'training in peer support'.[5]

In 2002, the National Practice Standards for the Mental Health Workforce specified that: 'Mental health professionals encourage and support the participation of consumers and carers in determining (or influencing) their individual treatment and care. They also actively promote, encourage and support the participation of consumers, family members and/or carers in the planning, implementation and evaluation of mental health service delivery'.[6] In the same year, the Victorian State Government published the 'New Directions for Victoria's Mental Health Services – The Next Five Years' report,[6] which stated that one of the six key directions for the next 5 years of development of mental health services in Victoria was 'Improving carer participation and support – strengthening support to carers and improving carer involvement'.[7]

FAMILIES AS PARTNERS IN MENTAL HEALTH CARE

Evidence from research over the last three to four decades consistently supports the inclusion of family carers in the treatment and care of their unwell relative. Meta-analyses of these studies are included in Pharaoh *et al.*,[8] Pitschel-Walz *et al.*[9] and Cuijpers.[10] Among these findings are reductions in relapse rates, decrease in hospital admissions, better adherence to medications, and better coordination of treatment and care plans. However, these research studies have been carried out predominantly with 'carers who are more established in their caring role'.[11] The type of family intervention best suited to first-episode mental illness is less apparent, although 'Multiple Family Groups'[12] and 'Single Session Therapy'[13] have been described as effective models for adolescent mental health services.

A programme that implemented multiple family groups found that uptake was low and many families were excluded when only a single model of family psychoeducation was offered.[14] Given that the first contacts with the family can significantly affect the direction and success of a collaborative treatment partnership, Jewel and Smith[15] suggest that a 'spectrum of family services' is desirable to meet the unique, specific and diverse needs of family carers in early intervention mental health services.

THE NEEDS OF FAMILIES IN FIRST-EPISODE PSYCHOSIS

Distress and burden associated with caring for a mentally ill family member has been well documented.[14] The symptoms of first-episode psychosis and the stigma of mental illness produce 'a maelstrom of emotions' – anxiety, confusion, guilt, blame, helplessness, a sense of isolation – as family members struggle to understand what has happened to their loved ones.[16] Research undertaken by Gleeson *et al.*[17] indicated that a majority (56%) of family members scored at or above a total mean of 5 points on the General Health Questionnaire, recognized as the standard threshold for 'caseness'. Family members themselves were suffering from anxiety or depression of severe enough intensity to warrant the need for treatment. Data from the Family Questionnaire showed that nearly one-half of family communication styles were within the high expressed emotion category (criticism, hostility, emotional over-involvement). This creates a high proportion of at-risk family environments. Family members or carers with high levels of expressed emotion often behave in negative ways towards their unwell relatives, which creates interpersonal stresses that may trigger vulnerabilities and increase symptomatology.[18]

In spite of the obvious need of families for intensive and extensive help and support, the research literature reports that family carers largely feel as though they are the 'invisible and silent partners' and are generally undervalued by mental health services.[11] Leavey *et al.*[19] define the needs of families with a young person experiencing a first episode of psychosis as 'a mixture of characteristics described as psychoeducational, behavioural, problem-solving, family support and crisis management; these also need to be modified to embrace the needs of culturally and linguistically diverse communities within diverse metropolitan, rural and remote locations'. In summary, the emotional trauma associated with first-episode psychosis is profound; unhealthy emotional reactions and behaviours are deleterious to a young person's recovery. The focus group strongly expressed the need for emotional support and felt that contact with other carers would be invaluable. An exploration of an effective way to address these issues became the driving force behind the development of OYH's family peer support programme.

THE EVOLUTION OF THE FAMILY PEER SUPPORT WORKER (FPSW) PROGRAMME

'Families Helping Families' as it exists today has evolved over a period of years. Prior to its onset, clinicians at OYH were having some contact with families through individual meetings and the 'Family and Friends' psychoeducation and support group. Group sessions were often poorly attended for reasons to do with stigma, long distances to travel or other responsibilities and commitments. In an effort to have early contact and to facilitate engagement with families, 'cold-calling' of new admissions to EPPIC was commenced. This involved a FPSW phoning the family as early as possible to enquire how they were and asking what help would they like. There were concerns that phoning families without always having the consent of the young person would breach his/her confidentiality; however, in keeping with national and state policy directions it was successfully argued that families needed help and support in their own right. Furthermore, it was also recognized that it was in the young person's best interest to have informed and supported family members. In fact, the primary focus of these calls is to establish how the family members are managing rather than making any enquiries about the young person who is unwell. FPSWs do not ask clinicians for information about the young person, only the young person's family. They then endeavour to make contact with the family either face-to-face or by telephone.

In some circumstances, there may be valid reasons for not wanting the family involved; for example, if the family has a history of extreme difficulties such as intrafamilial abuse, or a young person had been admitted and knew that his/her family would not agree to treatment. In these cases, the clinician informs the FPSWs that the family should not be contacted until further notice.[20] In reality, this has been a very rare occurrence. More often, young people are pleased that their family is being supported. Their concerns around confidentiality are sometimes about personal secrets being revealed, or not wanting their parents to worry. Sometimes they fear losing independence and are therefore not fulfilling age-appropriate responsibilities.

TRAINING AND INTEGRATION INTO A CLINICAL SERVICE

In keeping with policy directions, thought and effort was given to the integration of this service into the youth mental health team. It was recognized that the FPSWs would require information, education and training about how people who did not have a professional mental health qualification, but who were 'qualified by experience', could work alongside clinical staff in a service environment. For the clinicians, an understanding was needed of what families had to offer because of their experience.

Two fathers and four mothers who wanted to put something back into the service were invited to undergo training on how to share their experiences with families new to the service, and how to work alongside, and be supportive of, clinicians in their work with families.

THE TRAINING PROGRAMME

A training programme for FPSWs was developed, consisting of seven fortnightly 90-min sessions interspersed with support and supervision of the peer support workers as they began to implement the project. The most effective method of training the workers was to intersperse the formal training sessions with an apprenticeship approach; that is, 'learning by doing'. Issues that arose during the course of telephone support or face-to-face contacts were discussed and resolved as soon as possible. In this area of intense emotional distress, it was important that the peer support workers felt they were supported when they felt inadequate, when their own emotional distress was reawakened, or when they felt they had not handled a situation effectively.

The training includes:

1. Ways to use 'lived experiences of psychosis' to help other families. This involves a comparison of the differences between mental and physical illnesses; and of experiential and professional knowledge.
2. Telephone and face-to-face support. Active listening for telephone and face-to-face support, making cold calls, working with culturally diverse families and reducing emotional tension through active support.
3. Helping family carers cope in first-episode mental illness. Utilizing a general and first-episode coping strategies checklist.
4. Management of illness behaviour. Learning to manage difficult behaviours; finding the fine

dividing line between under- and overstimulation of the young person; developing a calm response; reaching mutual agreements.

5 Helping families understand the mental health system. Setting up a resource room with many helpful ‘tip sheets’; for example, tips for visiting a young person in hospital.
6 Managing boundary issues. Understanding the relationship between FPSWs and the family being supported; working alongside clinicians; self-care and supervision.
7 Facilitating a support group. Optional.

CREATING A NEW CULTURE

Employing family members as staff in clinical services is new territory for some organizations, particularly as clinicians have to adjust their perceptions and feel comfortable with family members as staff and not only as family carers of clients.

FORMAL EMPLOYMENT OF FPSWs

FPSWs are officially employed and paid. Their formal employment also requires the signing of a confidentiality agreement and an agreement to the mandatory checks expected of all newly employed staff.

THE ROLE OF SUPERVISION

To facilitate integration with clinical services, FPSWs were required to liaise closely with clinicians as well as families. To do this, OYH positioned FPSWs within the Psychosocial Recovery Services team. This programme comprises a multi-skilled team of clinicians and other workers offering recovery group programmes, including psychoeducation groups for families, educational support, vocational guidance and support, youth participation and an autism spectrum disorders clinic. Young people who access this service are provided with a clinical key worker to assist with their goals in addition to case management. Families may also be provided with support from clinicians within this team. The team is managed by a senior clinician.

As part of facilitating integration, ideas and possible concerns about embedding FPSWs into the clinical programme were discussed in multiple OYH forums, including meetings with management and clinicians. FPSWs were also requested to express their concerns and to comment on possible barriers to integration. All parties were informed about each other’s roles and responsibilities, and were encouraged to talk openly. Feedback from all strongly supported the initiative. It was embraced with goodwill and a belief that working together would provide a better service for young people and their families.

Service guidelines were written with input from senior clinicians within the EPPIC clinical programme. These were disseminated, discussed and fine-tuned. Orientation and a newsletter describing the role of the FPSW are now provided for all newly employed clinicians.

FPSWs provide face-to-face and telephone contacts to any families of clients registered with OYH. They are respectful and provide support and information as required. They are mindful that not all families want this support, and they also take guidance from clinicians if it is deemed inappropriate or not timely for them to make contact with a family member. Any concerns that they have are addressed in supervision. If these concerns are urgent, they are referred to duty workers or relevant clinical staff immediately. An example of how the team operates, one practice guideline states that FPSWs will inform clinicians when the first contact has been made with a family member. This is usually done via email or is documented in the clients’ clinical notes if the young person is in the inpatient unit. Any concerns for family members or clients at any time are fed back to clinical staff.

Ongoing training and professional development is provided every week in a 2-h formal session with the supervisor (a senior clinician). These occur in a small group format, where time is available for clinicians to present referrals or to discuss family issues. New staff, students and visitors can attend as part of their orientation to the service. Areas of discussion that commonly arise in supervision include:

- Boundary issues: how often to make contact and limit-setting are among a range of issues discussed
- Self-awareness and looking after yourself as a FPSW
- Managing confidentiality
- Acknowledging how small gestures of support and listening can be vital for maintaining hope and confidence in families
- Strategies for empowering families
- Being cautious about giving advice and information, as every family’s journey is unique; emphasizing that the process is about listening, sharing and not being prescriptive with ideas
- Exploring ways to improve services.

The weekly supervision meeting has encouraged open discussion between clinicians and the FPSWs, thus dispelling any hesitations about the role the service provides. Having an experienced clinician acting as a support for both the clinical team and the FPSWs by following up queries, facilitating discussions, providing supervision and feedback has assisted in drawing the clinical and peer support services together.

More recently, with the support of philanthropic funding, the OYH FPSW service has been able to offer additional work hours. This has included a trial of increased contact hours in the inpatient unit, targeting different time slots such as after business hours and during weekends. Anecdotal findings indicate that face-to-face contact is more likely when FPSWs are available on site after business hours during the week. There was no increase in contacts on Saturdays. It was hypothesized that families often take their young person for an outing or for leave on weekends and do not sit in the unit as often as they do on weekdays.

EVALUATION

In 2009, a small quality assurance project was conducted, which entailed a brief analysis of the notes written by the FPSWs. In all, 86 cases were explored. The aim of this was to identify the areas that FPSWs and families commonly talked about. The findings showed that FPSWs most commonly spoke with mothers. Topics were varied and influenced by the style and experiences of the individual FPSW. Providing support for distress was a common theme. Some families wanted direction and required encouragement to speak to the clinical team. There were also questions related to understanding and managing behaviours, along with discussions around medication. Families welcomed and expressed a need for emotional support, describing a range of emotions, including initial shock, frustration, needing to be reassured, exhaustion and sadness. There were many occasions where thanks were expressed to the clinicians and the service as a whole, with only one person making a request that no further contact be made.

CONCLUSION

FPSW is now a well-established programme at OYH. Its strength lies on the close collaboration with both families and the clinical team to provide family members with a range of interventions to assist recovery. Most importantly, family members are contacted and encouraged to be involved as early as possible. FPSWs are positioned in the service assessment area and in the inpatient unit to ensure this. Future recommendations for the programme include expanding the service and evaluating it more rigorously in order to determine the specific benefits to families and the young person for whom they care.

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