A parent’s perspective on early intervention

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As a parent and carer I want to share our family’s experience of an early intervention service which helped my son recover from mental health problems he has suffered in recent years.

My wife and I are of Chinese background. Although we originally came from different countries (Singapore and Shanghai, China) our common dialect is Cantonese. Both of us came to Australia in the late 1960s as private students. We did our matriculation in Sydney, finished our tertiary education and settled in our respective professions before having our children. Our experience with our son’s illness may not be representative of other families of non-English speaking background (NESB) who migrated to Australia as a family. By comparison, these families have to struggle with adapting to a new language and a new culture, while at the same time finding employment and schools. However, in recent years more students with circumstances similar to mine study in Australia. Some of these students will eventually stay and get married. It would be reasonable to assume about ten per cent of their offspring will develop mental health problems. So, my view and experience with Jon, hopefully, will help health care professionals to understand and, in turn, help such migrants. I want to stress that my views expressed here are not to be taken as necessarily representative of any carer/parent group.

We have two sons, the first now a young adult and his younger brother a teenager. The elder son, Jon, has been diagnosed as suffering from schizo-affective bipolar disorder. His first episode occurred in mid-1996. Two years later I am very proud and happy that he is able to enrol in a university course and is putting his life back on track.

View of Mental Health Prior to Illness

Prior to Jon’s illness, my wife and I were quite unaware of the prevalence of mental health problems. Now we realise that they are common in the community,

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1 Not his real name.
particularly among young men and women. We associated psychology in practice with straitjackets or 'One flew over the cuckoo's nest', despite the fact that we had some exposure to psychology as students. This was perhaps the main stumbling block for us: to be alert to the possibility of mental health problems in the family and to seek appropriate help. We were never hesitant to seek the best possible help when we were aware of any potential physical ill health in the family. The World Health Organisation defines health as 'a state of total mental and physical wellbeing'. Even though I knew of this definition, I found myself ignoring this with regard to the health of my family!

**A Brief Background to My Son's Illness**

In 1995 Jon showed signs of a lack of enthusiasm with regard to his Year 11 schooling and became extremely disappointed when he missed out on an overseas trip as part of a language exchange program. In the following year his school work deteriorated, he began smoking marijuana and gave up languages, music and sport. He was urging us to let him leave home. Towards the end of that year he began private family counselling. Early the next year (1996) he continued with family counselling, supplemented by individual and group counselling.

In retrospect it seems that Jon may have been showing early signs of illness two years before his first acute psychotic episode. If this is so, these signs were not noted by our private clinical psychologist. I am not pointing an accusing finger at our therapist because I think that without specialised training in youth mental illness and, in particular, prodromal symptoms of early psychosis it is extremely difficult to pick up the signs.

We were motivated to seek counselling from a private clinical psychologist when Jon wanted to leave home. We were very alarmed, as this is quite unheard of in our cultural upbringing. My own immediate reaction was to worry about what our parents and relatives would think. On the other hand, my spouse was more concerned about how he would cope living by himself. We just felt that we were failing as parents in bringing up our child.

Jon's first acute episode of illness occurred soon after his eighteenth birthday. Possible precipitating factors were use of cannabis, the stress of school examinations, and identity and relationship problems associated with his desire to leave home and be independent. He was hospitalised for six weeks and was stabilised on lithium.

A second acute episode occurred some six months after the first, with Jon being hospitalised for three and a half months. The precipitating factor this time appeared to be that Jon was not taking his medication and was continuing his substance use.
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Reaction to Diagnosis

When Jon was provisionally labelled as suffering from bipolar disorder, my wife and I were shocked and disbelieving. We hoped that this was just a one-off drug-induced episode. The explanatory brochures and information sheets lying around in the hospital waiting area were quite encouraging regarding prognosis. Despite this, I seemed to focus much more on the negative feelings I was having and I was probably too ready to read between the lines as well!

My wife was more concerned with issues about Jon’s future life, while I was more concerned with the possible long-term effects of chemical therapy. I had doubts and feared the myriads of side effects of lithium and neuroleptics mentioned in various pharmacopoeia, although if one looked under salicylate (Aspro) some of the side effects could also be said to be quite disconcerting. Both of us became quite irrational when facing this crisis. There was a sense of hopelessness, like a life sentence being imposed on our son, as well as on us.

I will use the foregoing background information, to comment on our experience with the Early Psychosis Outreach Community Health (EPOCH) program.

The Early Psychosis Outreach Community Health (EPOCH) Program

The EPOCH program as a whole included a variety of services: medical intervention; family counselling; individual counselling and occupational therapy; a group program called Youth Advocacy Program (YAP); a family forum; and professional education for all health professionals dealing with youth (e.g. general practitioners, dentists, nurses, social workers, and school counsellors). The EPOCH program ended in June 1997 at the conclusion of its funding period.

The EPOCH team was made up of the following experienced staff: a psychiatrist; a clinical psychologist; an occupational therapist and a social worker/family therapist. The last three, under the direction of the psychiatrist, were affectionately known as ‘the three musketeers’. The medical staff was very responsive to the needs of client and parent. A senior registrar often had to do house calls in order to review the changing situation.

In addition to the hospital and community health centre, the early intervention team provided for young people suffering from first episode psychotic illness. The three musketeers were made up of (i) a very capable family therapist with more than ten years’ experience, (ii) an occupational therapist who instilled a sense of fun in the young people, and (iii) a clinical psychologist with extensive experience in dealing with mental illness and substance abuse. They had the knack of showing the young men and women some purpose and fun in life. This way of boosting a young person’s self-esteem is something that I, as a parent, was unable to do.
There is always room for improvement, of course. I think a nurse in the team would have been beneficial, especially to assist with supervision of medication (although a nurse may have detracted from the romantic notion of the three musketeers!).

As a parent/carer I was not involved in the activity of the Youth Advocacy Program (YAP). My understanding of YAP was that it was a venue for young people to meet others with similar problems, boosting each other's self-esteem as well as giving each other encouragement. It was run by one of the three musketeers, the facilitator, plus a volunteer who organised social functions, such as outings and sporting events. This provided a base for a young person to engage with the service during the period of his or her recovery from an acute episode.

I can recall a very heartening experience when Jon was hospitalised for the second time. There were quite a few letters of encouragement and hospital visits from the YAP members. In one letter it said something like: '(Expletives deleted) Jon stop messing with drugs, get on with other stuff you wanted to do!' I don't think a parent or therapist could ever be so direct with a young person.

I have already implied that a multidisciplinary and wholistic approach to early intervention of psychotic illness is needed. My experience with private practitioners and the EPOCH Program convinced me of that. I do not think a single private practitioner has the time or resources to deal with all the ramifications of psychotic illness, especially in young people — not to mention the cost of such a service provided privately to clients. For example, there is the effect on family and social life to be dealt with, the psychological wellbeing of siblings to consider, and the sufferer's future study and employment prospects to be taken into account.

It would be hard for a single private practitioner to maintain trust and confidentiality with every family member. There is likely to be some conflict of interest in providing needs for the client and supporting the concerns of a parent. Meeting the mentally ill person in a less threatening non-clinical environment, including home visits, is a more effective way of delivering a mental health service. In my opinion no amount of conversation in a counselling room can reveal a family situation better than a home visit.

My wife and I were able to receive emotional support and professional guidance from the EPOCH team. This was much appreciated as, apart from friends, neither of us has any relatives in Australia. The EPOCH team was very approachable and the members were virtually at our beck and call when the real need for them was apparent. The following were some of the significant services provided by members of the EPOCH team to my family: explanation of the nature of illness; stress reduction in the family; and conflict resolution among family members. The centre of attention was, naturally, Jon. The team helped him to cope with depression, with issues such as leaving home, drug use, and our relationship problems.
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When Jon was undergoing a stage of severe depression, for example, my wife and I were given appropriate advice and counselling. When Jon was too lethargic to eat or too uninterested even to talk with my wife, he surprised me by being able to summon all his energy to see an EPOCH team member or to go to a YAP meeting. This speaks volumes for a supportive team like EPOCH. Each member of the team certainly developed a rapport with the young person.

The Family Forum Conducted by EPOCH

An important lesson my wife and I learnt from the forum offered by EPOCH was to understand, as well as to accept, that when there is a mentally unwell person in the family, it may be long term. We had to plan to cope with the illness by changing our attitudes as well as our lifestyle.

Following the family forum, there was a family group program running for eight weeks. The following topics were presented, each one leading to group discussion:
- Drugs and Alcohol
- Relapse Prevention
- The Mental Health Act
- Sibling Issues
- Stigma, Youth Suicide
- Family Relationships
- Change of Outlook in Life
- Looking after Oneself

Initially, the time of meetings and topics to be discussed during the eight weeks were decided by general consensus. Various speakers conversant with the topic were invited. In particular, I recall the evening that a larger than usual number of parents/carers met to discuss the issue of suicide. The facts and figures given in the course of that meeting made it a sobering experience for a parent/carer. There was a stony silence after the presentation and no one seemed to be in a mood for the usual tea break that night.

During the forum three or four parents/carers of NESB required the assistance of an interpreter to help them understand the topic under discussion and to enable them to participate in the group discussion. This had the disadvantage, I thought, of slowing down the proceedings. Also during a speaker’s presentation the background voices of interpreters speaking to their respective clients was quite disturbing to other listeners. One interpreter circumvented the problem by writing down the key points and explaining them to his client during the tea break. The main benefit derived from the forum, I feel, is that all parents, including parents of NESB, were made to feel welcome and were supported by other parents.
Deeper Dimensions – Culture, Youth and Mental Health

As a result of the parent group lecture series, parents/carers identified the following needs of their son or daughter:
- increased self-esteem/confidence
- need for independence
- recognition and strategies for coping with anger/aggression
- stress relief
- illness education.

For children of NESB, one might have to add that self-identity is an important issue. I was troubled by Jon’s constant complaints of me speaking poor English with a heavy accent and not having a lot of friends, especially Aussie friends. To me, this may indicate that he was not quite sure with which culture he should identify. He seemed to have lost a sense of belonging. I posed the question to a psychiatrist once in relation to possible precipitating factors leading to psychotic illness. He cited a study in the USA on first-generation Jewish migrants from Europe. The incidence of psychotic illness was the same as for the general population. Perhaps a study would be needed specially tailored for the Australian situation.

Early Psychosis Parent Support and Advocacy Network (EPPSAN)

EPPSAN was originally known as FAN (Family Advocacy Network). The EPPSAN group was founded as a result of initiatives from the family forum and parent support group conducted by the EPOCH team. This parents’ group is fortunate to have a very capable and dedicated volunteer who is knowledgeable about mental health issues. She acts as a resource person, helps with running the group and coordinates EPPSAN meetings.

As I mentioned earlier, the EPOCH program was funded by the government for a limited time of two years. The establishment of EPPSAN ensured that the early intervention program for youth did not cease when the EPOCH program finished at the conclusion of its funding. I believe EPPSAN has a pivotal role to play. I view its role in mental health services as follows:

- Advocacy for primary and secondary recipients of mental health services.
- Support for parents to share experiences and talk freely with other parents in similar situations (the buddy system). The special needs of parents of NESB are to be recognised and supported.
- Education of relatives and friends, school and community at large regarding the nature of mental illness, with emphasis on early recognition and the role they can have in supporting the young person experiencing a mental health problem.
- Liaison with hospital and community treatment teams in order to achieve the best outcome for youth with a first episode of psychosis.
Barriers to other parents with a similar background in terms of seeking help

My wife and I feel very fortunate that we have been given the appropriate support and that Jon was given the best treatment once the mental illness was recognised. We have spoken with other parents who witnessed their child's first episode of mental illness. It appears that not all parents were as well served as we were. They told of the difficulty of finding the right contact. It seems likely that parents of NESB would have more difficulty due to language problems.

I feel that the greatest barrier for any parent or carer would be early recognition of the onset of a mental illness. There is insufficient community education in this regard, especially in languages other than English. It would be best if parents or carers were aware that some out-of-the-ordinary speech patterns and demeanours in their children may be possible signs of pending mental ill-health — and not just the more obvious indicators of anti-social behaviour.

Looking to the future, as EPPSAN develops and expands with enthusiastic parents' support and with funds canvassed from government and the private sector, I hope the EPPSAN group will be enabled to develop a useful resource library, an informative website and a helpful network of enthusiastic volunteers.

Conclusion

Jon and our family are grateful beneficiaries of this health service. I believe a well-informed carer/parent can act as a vital support and link between the hospital and the community health team for effective early intervention. It will often be the carer who monitors medication compliance, personal hygiene and eating patterns in the home as a gauge to pending episodes and can provide feedback of observed efficacy and side effects of medication.

In my experience, the multidisciplinary approach to early intervention, such as the EPOCH Program offered, meets the needs of young men and women with mental health problems, as well as the needs of their carers. Ideally, one would like to see psychosis recognised in its prodromal stage and an acute episode prevented. Therefore, interaction and networking among community health centres, hospitals and families will help to lessen the burden on available mental health care resources, to the benefit of both the providers and receivers of the service.

Epilogue

Jon's illness changed our outlook on life significantly, and certainly our priorities in life. My wife decided to decline a promotion offer from her current senior executive position and I decided to enrich my career by enrolling in a fascinating university course. I hope Jon will graduate before I do!