

Negotiating the Balance Between Recovery and Parenting

Elysia Norris, B.A.
Deborah Ross

The following account illustrates the collaboration between Deborah Ross, who has schizophrenia, and her support worker, Elysia Norris, and their commitment to giving Ms. Ross and her children a voice during recovery.

Deb: I would like to take you back to the very beginning. Ten years ago, when I was 32, I went into my first psychosis, and the merry-go-round started. I was in and out of the acute mental health unit, not knowing what was happening to me; I was in my own world. I have three children who were being cared for by my husband, my mum, and my dad. This merry-go-round lasted for two years, with nobody knowing what would happen next. I went through numerous medications, with many of them leaving me so sedated that I could not get out of bed. Finally, I received the diagnosis of schizophrenia.

Unfortunately, my marriage broke down, and I was admitted to an extended treatment facility. During this time, my children were in constant contact with me, but they were just as scared as I was—their mum just was not the same. It took me 12 months to become well enough to return to the community.

When I did return to community life in 2004, limitations were placed on me, such as being allowed only

short visits alone with my three children, who ranged in age from eight to 13 years. This was very hard and made me think and feel that I was not good enough to be a parent. My children could not understand why they could not stay as long as they wanted to. Gradually, under the psychiatrist's guidance, visitation periods were extended, and the boys were able to stay with me on weekends; this took about 12 months of gradual exposure and confidence building. It was around this time that I became a client of the Personal Helpers and Mentors Program and began working with Elysia.

My son Joshua had other ideas about the amount of time he could spend with his mum; he wanted to live with me full-time. However, the doctors kept saying no because they felt this would put too much pressure on me. This is when the journey back to full-time parenting began.

Elysia: My interest in psychology began when I was 16 and first started thinking about career options. I knew I wanted to work with people, and I knew I was interested in what makes us think and behave the way we do. I completed my bachelor of psychology degree at James Cook University in 2007 and began working for Ozcare as a support worker in their mental health program, Personal Helpers and Mentors.

Ozcare is a nongovernment, not-for-profit organization that operates throughout Queensland, Australia. Ozcare offers a broad range of services across four main areas: aged care, community care, community health, and community support. The Personal Helpers and Mentors Program is part of the Council of Australian Gov-

ernments National Action Plan for Mental Health.

The program focuses on strengths—what people can do, rather than what they cannot do. It also focuses on recovery principles, demonstrating that people affected by mental illness can live fulfilled lives in the community and enjoy the same opportunities as everyone else. Each client of the program is allocated a support worker who assists in identifying recovery goals and providing support to develop strategies to achieve these goals.

During my first few weeks of work in this field, I quickly realized that my degree had taught me a lot about mental illness but not a whole lot about the extent of its impact on people, families, or children. It is through the lived experiences of my clients that I have received my true education in the far-reaching impacts of mental illness.

Let me share with you the definition of recovery that Deb and I agreed on: "Recovery is a life-long journey that is as unique as each individual. It can occur even though symptoms may recur. It requires a holistic view that focuses on the person and the person's lifestyle—not just the illness." Using this as guidance, we focused on confidence building to regain access to the community.

This was our first step toward Deb's recovery. Because of her experiences of panic attacks and intrusive thoughts while completing everyday activities, she required intensive support to manage her anxiety levels. This was achieved through the use of gradual exposure techniques that were approved by her psychiatrist. These techniques were applied to activities

Ms. Norris is an allied health worker affiliated with the Residential Drug and Alcohol Treatment Service, Ozcare, Townsville, Queensland, Australia (e-mail: elysia.leena@gmail.com). Ms. Ross is a consumer consultant for Queensland Health, Townsville (e-mail: deborah.ross@health.qld.gov.au). Jeffrey L. Geller, M.D., M.P.H., is editor of this column.

within the community necessary for everyday life and specifically for a parenting role. Some of these activities included shopping, going to doctors' appointments, working, taking public transportation, and taking parenting classes. Deb did these activities herself; I was not doing them for her, only providing support. Initially, I accompanied Deb during these activities; however, once her confidence became stronger, I simply offered encouragement via phone calls or e-mails. Through my giving Deb the support she required to engage in these activities, she was able to recognize her own potential to effectively parent full-time again.

Deb: In order to build my confidence to participate in my community, Elysia and I first had to establish an effective working relationship. The biggest barrier for me when contemplating this new client-worker relationship was communicating about some of the symptoms of my schizophrenia.

I was able to express my deepest obsessive and intrusive thoughts to Elysia without facing judgment, being ridiculed, or being fearful. It was through Elysia's appropriate psychological training that she was able to understand and take on the challenges of these sometimes extreme symptoms. This was the initial stepping-stone in our journey toward a relationship of trust and mutual respect. Elysia then demonstrated her reliability by keeping prearranged appointment times, following up with phone calls, and so on. It was through this building of trust, respect, and reliability that I was able to tackle the gradual exposure activities required to reintroduce me to the tasks necessary for parenting. Another key point here is that during this time, I felt that Elysia truly understood the importance of her strong support during such activities.

Elysia also took the time to learn who I was as a mother, daughter, employee, and friend. In other words, she looked at me holistically. Dealing with my whole person took into consideration what affects me—every aspect of my life and all of the people around me.

Because of the heavy sedative ef-

fects of my medications, I required consistent motivational support in the form of positive feedback for my achievements—no matter how small they seemed at the time. Elysia was able to help me identify these achievements and support me to keep moving forward.

At no stage was Elysia's role one of superiority; all decisions regarding my recovery were made together. My challenges were met with understanding, motivating energy, and empathy, not sympathy.

Elysia: It was at this point that we realized that Joshua's desire to return to Deb was now achievable, and the negotiations and planning began. Initially this idea was dismissed by medical staff. The therapeutic benefits of parenting were not being considered, only the stressors. We quickly recognized the barriers we were going to have to face on this journey: stigma, stereotypes, the medical model, and sedation.

During this process, due to circumstances beyond Deb's control, she relapsed and was admitted to the acute unit in Townsville. At this time an involuntary treatment order was placed on her, which prevented her from having any exposure to her children. The effects of this on Deb's children are captured below:

Aaron, then 16: "I just felt really angry."

Joshua, then 12: "I thought Mum must have been dying, because that's what happened when we couldn't see [Grandmother] Nanna."

Matthew, then 11: "I didn't know what I felt."

Deb's method of managing her illness while raising her children was taken over by the medical model, which prohibited visits. With Deb's high level of insight about her illness, she had educated her children on how schizophrenia affects her and what to expect when she is unwell. If the children had been allowed to see her, they probably would have understood what was happening and had many of their concerns alleviated. They had experienced this before and were prepared and well supported, both within the family and by professionals.

Deb: During our preparation stage,

we realized that we needed like-minded professional supports who would also take the time to realize my capabilities as a parent. We were lucky enough to come across a case manager at the community mental health center who shared our vision that parenting is a positive outcome of my recovery. Key people who shared this vision were also selected from community organizations and departments to support Joshua's wishes and my recovery journey.

Each of these organizations collaborated with Joshua and me and with each other to develop multiple care plans, action plans, and case plans. These were put in place to ensure both Joshua's and my safety and well-being. For example, I know that if I have two nights of disrupted sleep or no sleep, my intrusive thoughts are not far off, which if not dealt with appropriately can develop into a full-blown psychosis. Part of my action plan is to contact the community mental health center, Ozcare, or my general practitioner, and, depending on the circumstances, we will negotiate a course of action. My ex-husband is also contacted and if necessary will pick up Joshua until my sleep returns to normal. He also shares my vision of becoming a full-time mother again, and at no time was he a barrier to this plan.

While preparing for Joshua's return, I continued my own recovery maintenance, including keeping regular medical appointments, advocating to decrease sedative medications, and persisting with personal challenges and achievements, such as obtaining new employment.

Elysia: What Deb and I were doing together required advocacy. We believe that advocacy is a three-way process in which the support worker creates the initial pathways of effective communication and negotiation. The client can then facilitate her own changes and express her needs in a supported environment with her clinician, employer, or some other person or organization.

Because of negative past experiences in which Deb was dismissed, ignored, belittled, and disempowered, she had lost the confidence to address issues about parenting and

her illness in general. These experiences began in the years leading up to and after her diagnosis. Deb was told by a treating psychiatrist that she could not expect to parent, live independently, or obtain regular employment. She experienced this disempowerment not only within the medical profession but also within the wider community.

When faced with each hurdle, Deb and I would meet and discuss who needed to be involved, who was affected, and what outcomes we required. Stakeholders were then involved. The level of advocacy used depended on who the stakeholders were.

For example, when recognizing that an alternative to Deb's heavily sedating medication was necessary in order for Deb to be able to parent effectively, Deb and I met and decided that her case manager from the community mental health center needed to be involved. At this stage of negotiation, minimal advocacy was required on my part, because Deb had a good partnership with this worker.

However, it was at the next level, when Deb and I brought the issue to the treating psychiatrist, that the intensity of advocacy stepped up. In this meeting, I presented the issues

and needs on behalf of Deb and in her presence. This style of advocacy was received well, and there was a shift from a one-way communication from the psychiatrist to an open forum of comfortable exchange with Deb, the psychiatrist, and myself.

Once our preparations for Deb to return to the role of full-time parent were complete, she and I brought the issues to the table in a meeting with her mental health professionals, rather than accepting that the clinicians would discuss the issues among themselves, without Deb's presence. This meeting was a success, and after approximately one month of supported reintegration, Joshua returned home.

Deb: Since the reintegration, like any relationship between a teenager and parent, there have been bumps in the road. However, that is what our action and care plans were devised for. We implemented them, and they have been successful. My journey is not unlike any other parenting experience. It is never smooth sailing, and each family has its challenges—my mental illness is ours.

Since becoming a full-time parent again, my reliance on sedative medication has ceased completely. I have had no hospital admissions related to mental health for over 18 months. I

have recently obtained a position at Queensland Health in the acute unit as the consumer consultant coordinator—not bad for someone who was told she couldn't parent or expect to obtain regular employment, eh?

Elysia: Because of the high turnover of staff in this field, it is vital that whenever possible, a new support worker is oriented to the specific needs, goals, lifestyle, and experiences of the client. The client also needs to be given as much time as possible to adjust to the news that her support worker is leaving (as I did when promoted) and to be assured that the new worker will be sufficiently trained to continue to support her appropriately.

This commitment to working together toward recovery has not only resulted in Joshua and Deb's regaining control of their relationship, it has also begun a steady stream of positive effects. Deb's confidence and passion to improve the mental health system have led to multiple career opportunities for her. I have also learned many valuable professional lessons along this journey, including the power of collaboration. Deb and I were partners. Deb, Joshua, and I, as well as the Queensland mental health system of care, are better for it.