

# Risk and Resilience Factors in the Mental Health and Well-Being of Women with Intellectual Disability

Jennifer Ann Conder, Brigit Frances Mirfin-Veitch and Sue Gates

Donald Beasley Institute, Dunedin, New Zealand

Accepted for publication 8 December 2014

**Background** Women with intellectual disability are thought to be at increased risk of mental illness, yet little is known about resiliency factors supporting women's mental health. This article reports on such factors drawn from a study that aimed to address how women with intellectual disability experience their mental health and well-being.

**Materials and Methods** Utilizing a broad qualitative approach, 25 New Zealand women, aged 21–65 years were interviewed about their life from childhood to the present, including, where relevant, their experience of mental illness. Data were analysed using a general inductive approach.

**Results** Resiliency factors aligned with the theme 'keeping mentally well', subthemes of which were as

follows: the importance of relationships with family and friends; keeping busy; and autonomy and happiness. Challenges for resiliency could be seen in the theme 'mental illness' where subthemes of abuse, long-term stress and medication were identified.

**Conclusions** Many of the women demonstrated remarkable resiliency, despite setbacks and exposure to risks, provided they were nested within a supportive context. Those women who experienced major mental illness shared evidence of both higher risk factors and less support available at crucial times.

**Keywords:** intellectual disability, mental health, resilience, women

## Introduction

Mental health, described as consisting of both the presence of personal contentment and the relative absence of psychological distress (King 2005), is an important contributor to any person's quality of life. With estimations that depression, as one form of psychological distress, will become the second most important contributor to the burden of disease by 2020 (World Health Organisation (WHO) 2000), it is timely to explore prevention strategies including ways to enhance the mental health and well-being of the population.

The New Zealand 2006/07 Health Survey found, on testing, 6.6% of the population sampled had a high or very high probability of affective or anxiety disorder at that time, with women more likely than men to be included in these numbers (Ministry of Health 2008). In addition, people self-reported a diagnosis of mood

disorders (12.8% of women) and anxiety disorders including phobias and obsessive compulsive disorder (OCD) (5% of women) (Ministry of Health 2008). No specific data relating to women with intellectual disability in New Zealand are available; however, it is reasonable to assume that the incidence of mental illness will be similar to that of other Western countries. Leaving aside the high rates when mental ill health of any type is included, among their 461 women respondents, Cooper *et al.* (2007a) found the incidence to be affective disorders (8.0%) and anxiety disorders (4.3%) (specific phobias were excluded and OCD was counted separately at 1.1%). Difficulty accessing women with mild intellectual impairment was one of the stated limitations of Cooper *et al.*'s (2007a) study, suggesting that the figures for affective and anxiety disorders in women with intellectual disability may be an underestimation.

Given these figures, women with intellectual disability living in New Zealand are likely to be at least as at risk of experiencing affective and anxiety disorders as women in the wider population. Contributing to the risk are life events associated with psychological distress that are believed to be encountered more commonly by women with intellectual disability (Lunsky & Havercamp 2002; Cooper, Smiley, Morrison, Williamson, & Allan, 2007b; Hulbert-Williams & Hastings 2008; Taggart *et al.* 2008). Although difficult to establish the direction of association, or the role that other psychosocial events may play in a person expressing psychological distress, there is reasonable evidence that exposure to one or more events over their lifetime significantly increased the likelihood of the person with intellectual disability experiencing a mental illness (Hulbert-Williams & Hastings 2008; Martorell *et al.* 2009). Of note in Martorell *et al.*'s study, life events in the past year, such as bereavement, moving home, relationship break-up and loss of job, were not significant predictors when separated from the traumatic lifetime experiences that included abuse and assault, which were significant predictors of psychiatric diagnoses; however, they caution that the comparative time may be a factor.

From a series of studies in the United Kingdom (Northern Ireland and England), a picture of risk factors that make women with intellectual disability more vulnerable than other women to mental illness has been drawn (Taggart *et al.* 2008, 2009a, 2010). From their literature review, they hypothesized that women with intellectual disability will have heightened risk of mental illness as a result of their social isolation, stigmatization and exposure to sexual and physical violence among other factors known to be associated with mental illness. Interviews with 12 women with intellectual disability, all of whom had a diagnosed mental health condition, and focus groups of staff who work with women with intellectual disability provided identification of both risk and resilience factors (Taggart *et al.* 2009a,b, 2010). Risk factors included feeling less valued than other women, being stigmatized by their intellectual disability and subject to abuse; having unfulfilled hopes for an intimate relationship and children, or, for those who do have children, their removal to foster care. Other life events, such as parents dying, lack of employment, entering supported living or residential care, were noted as having the potential to challenge women's mental health and were thus also recognized as additional risk factors. From the focus groups with staff, dysfunctional family upbringing was

an added risk (Taggart *et al.* 2010). In contrast, protection factors identified from the women's interviews included attention to physical fitness and healthy eating, having structured routines and opportunities for social interaction, contact with family and friends and, for some women, there was recognition of the value of their medication (Taggart *et al.* 2009a). Similarly, but with a slightly different focus, the staff highlighted the need to promote emotional literacy, develop ways to involve women within their community and ensure that signs of mental illness were promptly noted and that women were supported through recovery (Taggart *et al.* 2010).

Psychological well-being has been associated with a combination of resiliency and mastery (Burns *et al.* 2011). Resiliency includes having appropriate psychological coping strategies, including future orientation, problem-solving ability and self-esteem, as well as social supports, such as strong family or other attachments and access to health care when needed (Truffino 2010; Burns *et al.* 2011; van Kessel 2013). Essentially, resiliency is a psychological trait that aids a person's ability to cope and adapt to changes throughout their life. It has been suggested that subjective feelings, such as positive emotions, aid the development of resiliency (Burns *et al.* 2011). In contrast, low positive and/or high negative emotions, either of which may be implicated in depression and anxiety, are more likely when a person has few of the coping strategies associated with resiliency (Burns *et al.* 2011). As a concept related to mental health, building resiliency is recognized in both New Zealand and international policy as a way to both prevent and treat mental illness (Friedli 2009; Ministry of Health 2012).

It is clear in the studies to date that the women with intellectual disability have limited ability to influence or control many aspects of their lives, suggesting that they might be low on mastery. Whilst not a particularly ideal coping strategy, further complicating the significance of life events could be the relative acceptance of a lack of control in one's own life, identified by Stmadová & Evans (2012) in their study of 55 women with intellectual disability. Such passivity (learned helplessness), whilst preventing the women's growth in many ways, may also be protective for some women in terms of lessening their psychological distress. From our interactions with many women with intellectual disability, some of whom have had mental illnesses, the researchers in this study were interested to explore the role of risk and protective factors in the hope that these could inform future practice. Unlike the United

Kingdom studies that were specific to women who had experience of mental illness, this study also includes women who are mentally well, to explore differences in life trajectories of the two groups that may be implicated in their mental health and well-being. The broad aim of the study was to address the question 'how do women with an intellectual disability experience their mental health and well-being?' This paper draws on the findings from the study with the aim of reporting on themes of relevance to mental well-being, risk and resilience for women with intellectual disability.

## Method

### Participants

Twenty-five women were recruited through regional People First meetings, following support from their National body. People First New Zealand is a self-advocacy group led by people with intellectual disability. The women who participate in People First use a range of disability support ensuring representation of residential, vocational and independent support agencies. Initial interest in the project came from local members of People First, with two women members included in the advisory team established to guide the recruitment strategy, interview guidelines, discuss research findings and their dissemination.

The participants represented eight urban or rural areas of New Zealand's South Island and ranged in age from 21 to 65 years. Two women lived with their parents; others flatted with support varying from a few hours a week to 24 h a day. Following a meeting informing them about the research, the women were invited to complete an interest form. Informed consent procedures were conducted with individual women, providing an opportunity for further questions about the research and for the researcher to be comfortable that the woman was certain about her desire to participate. Prior to commencing the project, approval had been granted by the New Zealand Multi-region Ethics Committee, an accredited committee providing ethical oversight for health and/or disability research. An important consideration for this research was the inclusion of protocols for disclosure of abuse, the interview process causing distress to the participants and concerns regarding the mental health of the participant. The protocols included guidance for both immediate action to protect the participant, if necessary, and review and supervision for the researchers.

### Data collection

Taking an ontological narrative approach (Somers 1994; Thomas 2006), a semi-structured interview schedule guided interviews with the women, to build a picture of their life to date and features that may have afforded them resilience in terms of their mental well-being. Ontological narrative approaches acknowledge the embeddedness of experience and the role of narrative in how we know and understand our world. Utilizing that approach meant that, whilst the researcher endeavoured to address all questions on the interview schedule, participants directed the order and emphasis to some extent through the stories they were able to tell. The interviews with 24 women were audio-taped and then transcribed. For the one woman who was not comfortable with being taped, the researcher took written notes.

Each woman was interviewed three times. In the first two interviews, questions explored the woman's childhood, schooling, family relationships, friendships, living arrangements, employment, social activities, self-concept, health and, where relevant, mental health and experience of mental illness. Generally, these interviews took place on two consecutive days. One hour was allocated for each of the meetings but actual time differed depending on the needs of the woman and the amount of information that she either chose to share, could articulate or was able to remember. Such challenges are not uncommon when interviewing people with intellectual disability (Booth & Booth 1996). At the participant's request, support people provided additional data at the time of the interview, or soon after. Predominantly, this was information about medications but sometimes included dates or time frames that they found difficult to remember.

Prior to the third interview, a narrative from the transcripts of the first two interviews with the woman was written. Formulating the information this way assisted the women's understanding of what they were consenting to have included in the analysis phase. At the third interview, their narrative was reviewed, details were checked and consent was gained with regard to that data. Once corrected, the women could choose to have their story sent to them.

### Analysis

Analysis began with writing the women's narratives as the researcher reads and rereads the transcribed interviews to identify main points and generate a

cohesive account of the woman's mental health and well-being against a background of her other life experiences (Goodley 2001). Although the narratives remained recognizable to the women, as their 'story', in the process of writing, they were inevitably influenced by the researcher who chooses what she saw as key points, relevant headings and related content (Harrison *et al.* 2001).

A separate and deeper level of analysis using a general inductive approach (Thomas 2006) was then applied to the transcribed first and second interviews to expose relevant themes and to inform a comparison and contrasting of the women's lives and their personal experience of mental health. The general inductive approach is not associated with any one tradition of research, rather it is a broad method of analysis that assists researchers to draw qualitative data into a meaningful summary responding to, but not limited by, the objectives of the study. Following the guidelines offered by Thomas (2006), the three researchers conducted a first level of coding through reading the transcripts of their own interviews and a selection of other interviews. These codes were then discussed and themes relevant to the research objectives agreed; subsequently, one researcher (JC) coded all transcripts with reference to these themes. Once a preliminary list of themes was identified, the advisory group met to discuss the results and comment upon whether or not they reflected their own experience, or that shared with them by people whom they have supported. The advisory group agreed that there would be no changes at that point.

## Results

The 25 women in this study had very diverse life experiences, with five having been admitted to inpatient psychiatric services in the past while many others apparently maintained good mental health throughout their lifetime. The findings are presented in two sections: firstly, identifying those factors that appeared to keep the women well and secondly, the issues that may have led to women becoming mentally unwell or to impact on their recovery. With the agreement of the women, all names have been changed and pseudonyms used.

### Section one: Keeping mentally well

The majority of women reported being mentally well most of their life. Three themes were identified as

contributing to their wellness. These themes were close relationships with family or friends; keeping busy; and autonomy and happiness. Whilst all women did not necessarily make direct links from these themes to their individual mental health, they typically identified them as contributing to their happiness with their life.

#### 1. Close relationships with family or friends

Positive relationships with family and friends provided a major source of happiness and affiliation for the women. Most of the women shared the pleasure they found in the company of friends and family and in the experiences that they were able to have as a result of these relationships. Friends were loosely defined, as expressed by Eva when she asked 'Are staff friends?'. Friends therefore included flatmates, people from their day activities, paid or volunteer support people, family friends and others that the women met through clubs or church groups. For the women who had a parent living within their vicinity, support from that relationship was common. Furthermore, these women appeared to have stronger links both with wider family and their community, presenting greater opportunity for a range of experiences.

A few of the women had boyfriends with whom they had a special relationship and although two were engaged, none were currently married. The importance of their boyfriend to their mental well-being was expressed as follows by two participants:

*Georgia:* My boyfriend cares about me. ... Yeah, he wants me well.

*Barbara:* Yeah, the first time I met him he looked gorgeous. ... He was someone I always wanted. ... Yeah, that's important in my life.

Georgia, who was coping with a major medical illness, felt her boyfriend provided her with emotional support, whilst Barbara frequently referred to the sense that fulfilment of her relationship with her boyfriend added to the quality of her life.

For most of the women, positive relationships had grown from their family or support setting, whereas Quiana and Xena sought opportunities to widen their circle of friends and noted the benefits in terms of enjoyment:

*Quiana:* Every second Wednesday night and every Monday night ... I usually go to a group ... then usually every month I go to a women's group which they call 'Women's Aglow' ...

and they're all fellowship type of meetings and ... they're all sort of things I enjoy doing and mixing with other people.

*Xena:* I've got... you know I'm in a... sort of friends that I go out with [for] coffee and that a friendship ring. .... To [have] fun with.

For the two mothers in the study, their relationship with their children was an important source for happiness; however, both had significant histories of mental illness and connection with their children and wider family had been intermittent over the years.

Most women focused on current relationships, often providing a stoic response to loss, for example Marika 'I feel sad because my parents died recently. I got over that quickly'. For some, sibling and other family relationships became particularly important when there was no parent alive. However, while parents had often lived nearby, siblings were more likely to live some distance away and the relationship relied on routine arrangements of phone calls, initiated by either the women or the family member. Visits to siblings did, however, provide holiday opportunities.

When the woman had no close familial relationships, friends were particularly important. Whilst holding good memories, few friendships from school days survived into adulthood, although exceptions could be found in some of the younger participants who had left school relatively recently and in one woman in her fifties who had occasional contact with a friend from boarding school. Despite many sources of friendships, there remained individual women for whom there seemed to be little opportunity to make new friends on their own. Frequently, new friends were either people being paid to support them or volunteers. It was clear that these people played a pivotal role in maintaining the woman's mental health through their relationship. Provided they were interested and supportive, they became both the woman's confidant and the initiator of many of the pleasurable activities the women enjoyed.

Whether it was family, friends or partners, having a relationship that gave them a feeling of being cared about as well as being able to offer something to that person in return was important to the women's sense of emotional and psychological well-being.

## 2. Keeping busy

One of the most common responses from the women to questions about how they kept mentally healthy was that they liked to be busy. A number of the women had diaries filled with activities for each day. For example

*Kura* ... 'I like going fishing, going out with (friend) ... going to the centre ... my bit of work ... going to the pictures ... and shopping'.

As a source of being busy, work presented a number of challenges. It generally meant part-time, voluntary positions in shops, health and social services or industry and was often sourced through work experience opportunities from school or polytechnic courses. The women demonstrated incredible patience and willingness to continue to seek employment despite many rejections. For example, Barbara was clearly disappointed about missing out on a recent job application but held any emotion related to that disappointment in check:

*Barbara:* I was supposed to clean up and tidy up the little office area there.

*Interviewer:* Right.

*Barbara:* But they were supposed to contact me on Thursday but they never did, someone else got it.

*Interviewer:* Oh that was a bit disappointing was it?

*Barbara:* Yeah.

*Interviewer:* Yeah. You're smiling.

*Barbara:* Yeah, smiling.

*Interviewer:* But it was disappointing?

*Barbara:* Yeah, disappointing.

With few work opportunities, being busy for most women meant finding alternative satisfying activities. Either through their day base or other avenues, the women engaged in a range of activities, including sport or other exercise, such as swimming, walking, biking, riding for the disabled, activities at gymnasiums and yoga. Sport and exercise also provided support for the women's self-esteem, with a number very proud of their achievements at local, national and international Special Olympic events. For example, Patricia commented on her opportunity with Special Olympics 'And I was chosen to go to USA, which was my dream'.

For the more independent women, the day service was often seen as a 'base'. Julia, for example, explained 'I like going out and about, I like music, going for a coffee with a friend - that's it. Just out of the base. I don't really want to stay at the base all the time'. Thus, whilst some women depended on the arranged activities of their day base to satisfy their desire to be 'busy', others chose activities for themselves, including home-based hobbies, such as knitting, painting, card making and collecting.

For those women who had experienced mental illness in the past, mention was made of the mental as well as

physical health benefits from being active, for example Vera identified the importance of 'going for walks ... Listening to music and reading books' as her way of lifting her feelings of depression.

Barbara summed up the importance of being busy, 'Yeah, I'm just an active person on the go. No, just keep on working and making myself happy'. While perhaps best expressed by Barbara, many of the women either directly, or through implication, identified with the belief that personal happiness and mental health were related to self-responsibility and could be maintained through being busy and having a happy disposition.

### 3. *Autonomy and happiness*

For most people, a sense of autonomy is important for their overall happiness. In contrast, some women in this study appeared to forgo their autonomy, including disappointments, to emphasize their overall happiness. As noted above in Barbara's comment about happiness, while Marika said 'I feel really, really happy all the time'. Patricia also stated in colloquial terms that she was as 'Happy as Larry', suggesting that some of the women felt they might have a duty to be happy. Furthermore, it appeared that this duty should come before the woman's wants and desires, such as Barbara who said she really wanted to marry her fiancé, so that she could 'feel more secure, more happier'.

Some women, however, were less willing to keep smiling through disappointments. For these women, it often appeared that a significant challenge to their autonomy was central to their unhappiness. Xena, for example, said 'when I moved into this place, I didn't even know there was boys in this place, until they all walked in ... And like me on my own, the only girl, it's just lonely'. Similarly, independently living Quiana wanted better recognition of what support would be most helpful to her to enable travel to a nearby town for People First meetings but ...

... a lot of us ones who've been sort of, well, supposed to have been supported but we're supposed to have been independent on everything but I mean with there being no sort of proper transport in [town] there's not a lot of travel or anything that you can get to and from to places ...

Despite the challenges they faced, these women could see the importance of being able to influence their own life; thus, they did not simply accept their situation in the same way that some others did. They expressed

their dissatisfaction and, in the case of both, Quiana and Xena had been able to make changes to their living arrangements by the time of their third interviews.

### Section two: mental illness

Of the 25 women interviewed, eight provided information that might indicate risk of mental illness. None of the women who had experienced mental illness were able to remember events that immediately preceded their admission to hospital. In retrospect, some recognized that they had been depressed for a while and could trace those feelings to earlier events. Analysis for this section draws on common predictors of mental illness that were evident in the interview transcripts, and thus the themes of experience of abuse, long-term stress and medication.

#### 1. *Experience of abuse*

For this analysis, abuse is being loosely defined to include bullying, physical, sexual or emotional abuse. Experience of abuse or bullying was not limited to the women who had a diagnosed mental illness; however, that group of women were all able to recount stories of repeated events, often beginning with bullying at school. Interview transcripts provided many examples of ongoing bullying, physical and emotional abuse with perpetrators including other people in their homes, both flatmates and support staff, and hospital staff for those who had been admitted for psychiatric care. Nadia, for example, spoke about a person who had recently moved from her flat saying 'I didn't like her picking on me all the time, bullying me all the time'. Despite reporting fear, anger or powerlessness, the women generally tolerated these behaviours; however, Francesca had a more direct approach. When asked what she did about a flatmate who annoyed her by constantly coming into her room, she responded 'I was like this. ... I booted him in the bottom, told him off'. When asked how she felt at such times, she was unable to put it in words but made a fist, and agreed when the researcher asked whether she meant she was angry and tense. The long-term impact of living with such concerns is difficult to measure, and while it might be expected to contribute to mental ill health, or a diagnosis of challenging behaviour if they responded with similar physical attacks, whether or not it actually did so was invisible in our interviews with the women.

Ten women experienced either sexual harassment or sexual abuse. Both the level of abuse and the response of others appeared to make a difference to the woman's

subsequent mental health. Three women who spoke of sexual harassment had received immediate support from a friend, their support service, the police or the education institution and resolution through either institutional policy or the justice system. Such responses appeared to strengthen their self-confidence. Patricia expressed the following:

I saw someone down the street the other day and he said 'I hear your friend's back' ... I said 'He's not my friend ... he's the one that abused me and I don't want to see him' and he said 'Well I'm afraid he is back in [the town] till the end of February' and I said 'Well whatever he does he can keep away from me' That is what I said to him.

The likelihood of a serious sexual abuse case being successfully upheld through the justice system appeared low, with just one woman having the satisfaction of seeing her abuser convicted and sentenced. For that woman counselling had been pivotal in coping with both the abuse and questioning by both prosecuting and defence lawyers at court.

Perpetrators of sexual abuse included parents, grandparents, partners, family friends and neighbours of the women. For various reasons, few of these women appeared to have had their case dealt with through the courts, despite complaints being laid with the police. Although the abuse may have happened many years ago, there was a sense of unfinished business as the women often raised the topic with the researcher. Among this group were two of the three women with prolonged mental illness both of whom were abused by a family member as adolescents. The third woman had been sexually assaulted during her recovery from her first admission for mental illness. Family supported the only other participant who shared the experience of abuse during adolescence; however, whilst she had not become mentally ill, she expressed psychological distress reporting that the abuse she experienced in her youth meant 'even now still I find it hard to trust men'. Although it is not possible to make direct links, none of the women without a history of mental illness or psychological distress reported being sexually abused in their youth.

## 2. Long-term stress

Most of the women reported stressful events they had experienced without necessarily developing mental illness. However, multiple stressors combined with a lack of support appeared to be a common factor for the

women who did experience mental illness. For example, both Ophelia and Carla noted difficulties at school that seemed to leave them bored and isolated. Ophelia stated 'I just was left behind in class and by those days you'd get left – sent to the back of the room and they'd forget about you'. Similarly, Carla noted school was boring because she 'Couldn't handle it. ... Work was too hard'. In contrast, however, even though Patricia found school 'Very hard to learn. Yeah. When it came to the fourth form I was really quite – no, I couldn't do maths, I couldn't do science...', her strong family network and support provided by the school ensured alternative learning experiences.

Leaving school and entering the workforce was a further challenge. There appeared to be little support for the women who found work in processing or factory settings, with the result that they lost their jobs. Whilst unemployment was common among all the women, the addition of other events, including abuse, a parent dying and moving towns, was evident in the stories of those women who subsequently experienced mental illness.

Two of the women were mothers, and the expectations that surrounded their parenting roles appeared to provide a further stressor. Recognizing that she needed family support to raise her child, after her relationship with her partner ended, one woman felt she had little option other than to return to the family home where she had previously been abused. Although married, the other woman appeared to lack other social connections. When asked whether she had been involved with any of the children's activities she replied, 'Well just couldn't understand anything, those sorts of things, and you know'. When asked whether she and her husband had friends, she answered 'Sort of, not very much though'. To her mind she felt that her marriage 'started off very well but then I think I started to get sick', at what stage during the birth and raising of her three children she first experienced symptoms of mental illness was not clear; however, her youngest child was at school by the time she was admitted to a psychiatric hospital.

Those women who were admitted to psychiatric hospitals faced further stressors after they were discharged. The standard of care during their recovery differed widely and relationships with family were often strained. Rural towns provided limited mental health services and women living in these more remote areas were often reliant on support staff who lacked knowledge of mental illness and recovery. The women felt frustrated and worried about the lack of confidence shown by support staff. For example Carla, when asked whether she would contact her support person if she

was feeling really sad, commented, 'No, we can't get hold of them'. Ophelia described an incident where she had been acting strangely but her staff did not recognize her behaviour as being related to mental ill health. She said 'they didn't know why I was acting like that... one time I lied down on the floor at the centre... and K [support person] said to me: get up, get up'. Given the lack of, or inappropriate, response to early warning signs, it is not surprising that some women had recurrent admissions to hospital.

### 3. Medication

For the women who had experienced major mental illness, an important contributor to their recovery and maintenance was their medication. The women had few memories of counselling or other therapies, although Ophelia remembered diversional activities being helpful during a more recent hospital admission. It appeared that the women were offered few opportunities for therapies aside from medication. Reinforcing the importance of medication, two women thought that it was when they stopped their medication that their mental health deteriorated more rapidly. The reason that they had stopped taking their medication was not clear in the interviews but there was some suggestion that they were already becoming unwell and therefore not necessarily making reasoned decisions at the time.

Services monitored medication for the women who were perceived at risk of recurring mental illness; however, the women appeared to accept that as being in their best interest. For example Ophelia reported on the service's response to a previous episode where she had stopped taking her medication and was showing behavioural changes '...that's why they've given me the pills just every day and just enough for the weekend, you know Friday till Monday, you see'.

When asked what medication they were taking, the women commonly referred the interviewer to their support person. However, Vera knew that 'One stops the voices and I don't know what the other wee ones are, I'm not too sure about them'. While Yolanda identified 'My Paroxetine does that' in response to a question about feelings of sadness, adding that she did not think her medication was helping and that she intended to talk to her doctor about this.

## Discussion

Our intention with this study was to explore differences in the lives and disposition of women who have and have

not experienced mental illness to expose protective and risk factors for mental health. As noted in the introduction, both resiliency and mastery are considered important for psychological well-being (Burns *et al.* 2011). While most studies that have examined these issues are based on populations of people who do not have intellectual impairment, the current study was focused on women with intellectual disability. Strategies aligned with resilience, such as being future orientated, having positive emotions and in some cases problem solving, can be seen throughout the themes. Furthermore, the importance of social support resonated both in the women's day-to-day lives and at times of heightened stress. For those women who did experience mental illness, the availability of health care was an issue.

### Coping strategies

As an overall impression, it was clear that the majority of the women had internalized a level of self-responsibility related to their mental well-being, predominantly expressed in the themes of 'keeping busy' and 'autonomy and happiness'. From the perspective of resilience factors (Burns *et al.* 2011), the women demonstrated amazing coping strategies through lives that were, for many, externally controlled and offered limited opportunities, including where and with whom they lived and with regard to the daytime activities that were available to them. Some women in our study were conscious of having been different throughout their schooling and into adulthood, reflecting social isolation and stigmatization (Taggart *et al.* 2009a, 2010; Stmadová & Evans 2012). In addition, some women expressed unhappiness with their current living arrangements or with the lack of meaningful work that was available to them. However, despite these seemingly negative experiences, the majority expressed tolerance of their situation, often reframing it in a positive way. Positive emotions appeared to be influential, and, whilst there was a sense in which it seemed to be aligned to duty, being happy and smiling was deemed by many of the women as the key to mental well-being. Daily timetables for some, dreams of a future including marriage to their boyfriend, persistence with applications for employment, or a better living arrangement for others, indicated some level of future orientation. Although Quiana and Xena were able to demonstrate problem-solving skills both in terms of widening friendships and changing living arrangements, most were more like Barbara, who despite wanting to marry, remained relatively passive in

terms of making that happen. It seemed that for most women, support from family or others was essential to achieving their goal. As Taggart *et al.* (2009a) found such support, along with the relative stability many experienced in their day-to-day lives, contributed to their mental well-being. Even when it seemed that the woman had small social circles and intermittent contact with family, the limitations on their autonomy within support services appeared less influential than the benefit they gained from the support (Taggart *et al.* 2010; Stmadová & Evans 2012). The general optimism and happiness of the women, an ability to celebrate opportunities that others might see as insignificant (also seen in Stmadová & Evans) and a belief that they do have some self-responsibility does suggest that they share characteristics identified with resilient people (Burns *et al.* 2011). From this perspective, there would appear to be value in encouraging self-awareness of capabilities (Lunsky & Havercamp 2002), developing self-responsibility and teaching young women positive strategies for managing life's challenges and disappointments. Further, any strategy that can strengthen meaningful relationships and offer some stability in their lives would be advantageous.

#### Support through transitions and heightened risk

As also noted in the introduction, there are various life events that may contribute to psychological distress for women with intellectual disability (Lunsky & Havercamp 2002; Cooper *et al.* 2007a; Hulbert-Williams & Hastings 2008; Taggart *et al.* 2008; Martorell *et al.* 2009). Whilst exposure to risk factors differed for the women in this study, having available quality support at transitional points in their lives was a key indicator of difference in outcomes for them. For the majority of the women who experienced mental illness, there was limited support both at school and on leaving school. Despite their schooling being in special classes, when they left school they did not appear to access disability services, becoming invisible as Cooper *et al.* (2007a) found with their prevalence study of mental ill-health in people with intellectual disability in Scotland. Lacking support networks, the women in the current study could not independently manage when they entered the workforce and then subsequently lost their jobs. For the two parents, missing natural extended family support and mainstream services not recognizing and responding to their parenting needs meant additional stress, as seen in previous research with parents with intellectual disability (Conder *et al.* 2010). Furthermore,

there is well-documented evidence that removal of children is a traumatic event and, as is all too common for parents with intellectual disability, the two women who were parents lost the day-to-day care of their children (Booth *et al.* 2005; Conder *et al.* 2008; Taggart *et al.* 2009a, 2010). While interview data suggest their mental illness contributed to the separation, it was notable that they received little support to maintain their relationship with their children at the time and it is only in more recent years that they and their now adult children have begun to re-establish contact. Overall strong natural family support provided the connection between women and services, but when that connection was missing women were more likely to become isolated and did not appear to seek out alternative support. While women with mild intellectual disability do not necessarily need regular support, having a person available to them who can assist them to negotiate for necessary support at times of transition could be beneficial to preventing mental distress. Given the emphasis that is placed on building resiliency as a means to prevent mental illness (Friedli 2009; Ministry of Health 2012), it is important for mainstream health and education services to be aware and responding to the needs of these women who will not necessarily be accessing specialized disability services.

Lifetime experience of abuse further puts women at risk of mental illness (Martorell *et al.* 2009). Comparison of outcomes for the ten women who had either been sexually harassed or abused identified some interesting differences. Resilience following exposure to sexual violence appeared to be more likely if the woman received helpful counselling at the time and justice in terms of the perpetrator being found guilty within the courts or, in the case of harassment, through processes appropriate to the context. For those receiving counselling, the quality and availability of counselling services differed, with formal counselling reportedly rarely offered and when it was there were mixed results, reflecting a similar situation to the United Kingdom (Taggart *et al.* 2009b). The two women sexually abused by family members as adolescents had ongoing mental health concerns, whereas the other woman abused as a teenager was left wary of men but did not become mentally ill, possibly illustrating other research that has found that resiliency and psychological distress may co-occur (Anderson & Bang 2012). Contributing to resiliency in this latter case might be the different relationship (family versus neighbour) but also the recognition and responses from others either at the time or when the abuse came to light.

### Responsiveness of services

The experience of significant illness is in itself a risk factor, raising the likelihood of a repeating process of mental illness and recovery. Recognition of relevant signs and symptoms is a protective factor for preventing this cycle (Taggart *et al.* 2009b, 2010); however, the services supporting the women appeared to differ in their capacity to understand the women's mental illness. Services that struggled with recognizing relevant changes in the women's mental health were unlikely to be familiar with best practice in mental health recovery, and particularly for rural services, it was evident that they had little access to assistance or advice from a community-based mental health service familiar with the needs of people with a dual diagnosis. Repeated hospital admissions identified the women as vulnerable, with the services predominantly responding with high levels of supervision, as seen with control of their medication. Whilst somewhat understandable given the women's apparent lack of understanding regarding their medication, an important point to consider is whether or not their intellectual disability was providing justification for a level of care that may be increasing dependence and not building their self-esteem or other characteristics of resilient people, therefore contradicting principles of recovery espoused in health policy (Ministry of Health 2012).

### Study limitations

Firstly, the cross section of women with intellectual disability in terms of living arrangements, service provision, rural and urban, age range and fulfilling our desire to promote citizenship rights by recruiting through People First was a strength of this study, however, that resulted in an imbalance of women who declared a mental illness versus those who did not meaning that conclusions drawn regarding mental illness rely on few women. Despite a number of women identifying counselling and being medicated for mental health on their interest form, at interview few disclosed a mental health issue, with many being clear that mental illness was not an issue for them. The findings of previous research including the broad Health Survey of New Zealand women (Ministry of Health 2008) and the more specific study of people with intellectual disability (Cooper *et al.* 2007a) might have suggested more women to either self-report mood disorders or identify with having received mental health services. The reason for the discrepancy between the data on

interest forms and interviews was not evident, and out of respect for the women, the interviewers did not challenge their self-report at interview. For this research, there had been a purposeful decision not to perform mental health assessment with the women; however, such a strategy may have identified more women with either mild affective or anxiety disorders and would therefore be worth considering for future research.

Secondly, in addition to discrepancies between interest forms and interview data, some of the women found it difficult to remember or express aspects of their life that may have provided deeper understanding of their resilience. Similar to strategies documented by Booth & Booth (1996), the interviewers did find themselves rephrasing many questions and at times using closed questions. Whilst these strategies are contested for perpetuating acquiescent behaviour, we found that the women in this study were very clear about whether or not they agreed, with many being quite persistent in terms of getting points they felt were important across to the interviewer, seemingly contrary to their relative passivity when reporting lifetime experiences. Whilst the women appeared able to stand up for themselves, as one might expect of People First members, it seems likely that such behaviour differed with context.

### Conclusion

In terms of future practice with women with intellectual disability, this study highlights relationships and opportunities to engage with their interests as significant to fostering a positive attitude and ultimately the woman's happiness. Reflecting other studies, the women who had experienced mental illness reported social isolation, stigmatization and exposure to sexual violence (Taggart *et al.* 2009a, 2010) seemingly with a higher lifetime exposure to traumatic events than the women who remained mentally well despite experiencing periods of recognized life events, such as a parent's death or loss of a job, that might cause increased mental distress (Hulbert-Williams & Hastings 2008; Martorell *et al.* 2009). More responsive services, including justice, education, health, social and specialist disability support, could prevent or minimize harms. It was particularly notable that childhood abuse from within the family was a major risk factor for later mental illness, reinforcing the importance of early recognition of signs of abuse and having in place appropriate reporting and supporting strategies. It was evident that these women relied on their wider

community, such as their school, to be alert to them being abused. Furthermore, the vulnerability to mental distress for women with mild intellectual disability should be noted by mainstream services as this group is not necessarily known to specialist intellectual disability services, yet may not be able to initiate support when they are in need.

### Acknowledgments

Thank you to the women who volunteered to share their life story with the researchers. Thanks also to Lotteries Health for funding the research.

### Conflict of Interest

None.

### Ethics Statement

The research was approved by the Health Research Council of New Zealand Multi-region Ethics Committee. All participants provided written consent following full explanations and opportunities to ask questions.

### Correspondence

Any correspondence should be directed to Jennifer Conder, Senior Researcher, Donald Beasley Institute, 44 Dundas Street, Dunedin, New Zealand (e-mail: jconder@donaldbeasley.org.nz).

### References

- Anderson K. M. & Bang E.-J. (2012) Assessing PTSD and resilience for females who during childhood were exposed to domestic violence. *Child & Family Social Work* **17**, 55–65.
- Booth T. & Booth W. (1996) Sounds of silence: narrative research with inarticulate subjects. *Disability & Society* **11**, 55–69.
- Booth T., Booth W. & McConnell D. (2005) The prevalence and outcomes of care proceedings involving parents with learning difficulties in the Family Courts. *Journal of Applied Research in Intellectual Disabilities* **18**, 7–17.
- Burns R. A., Anstey K. J. & Windsor T. D. (2011) Subjective well-being mediates the effects of resilience and mastery on depression and anxiety in a large community sample of young and middle-aged adults. *The Royal Australian and New Zealand College of Psychiatrists* **45**, 240–248.
- Conder J., Mirfin-Veitch B., Sanders J. & Munford R. (2008) "I've got to think of him..." Relationships between parents with an intellectual disability and foster parents. *Developing Practice*, **21**, 17–25.
- Conder J., Mirfin-Veitch B., Sanders J. & Munford R. (2010) Planned pregnancy, planned parenting: enabling choice for adults with a learning disability. *British Journal of Learning Disabilities* **39**, 105–112.
- Cooper S.-A., Smiley E., Finlayson J., Jackson A., Allan L., Williamson A., Mantry D. & Morrison J. (2007a) The prevalence, incidence and factors predictive of mental ill-health in adults with profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **20**, 493–501.
- Cooper S.-A., Smiley E., Morrison J., Williamson A. & Allan L. (2007b) Mental ill-health in adults with intellectual disabilities: prevalence associated factors. *British Journal of Psychiatry* **190**, 27–35.
- Friedli L. (2009) *Mental Health, Resilience and Inequalities*. World Health Organisation, Europe, Copenhagen, Denmark.
- Goodley D. (2001) 'Learning Difficulties', the Social Model of Disability and Impairment: challenging epistemologies. *Disability & Society* **16**, 207–231.
- Harrison L., Johnson K., Hiller L. & Strong R. (2001) "Nothing about us without us": the ideals and realities of participatory action research with people with an intellectual disability. *Scandinavian Journal of Intellectual Disability Research* **3**, 57–70.
- Hulbert-Williams L. & Hastings R. P. (2008) Life events as a risk factor for psychological problems in individuals with intellectual disabilities: a critical review. *Journal of Intellectual Disability Research* **52**, 883–895.
- van Kessel G. (2013) The ability of older people to overcome adversity: a review of the resilience concept. *Geriatric Nursing* **34**, 122–127.
- King R. (2005) Proceeding with compassion while awaiting the evidence: psychotherapy and individuals with mental retardation. *Mental Retardation* **43**, 448–450.
- Lunsky Y. & Haverkamp S. (2002) Women's mental health. In: *Health of Women With Intellectual Disabilities* (eds P. Noonan Walsh & T. Heller), pp. 59–75. Blackwell, Oxford, UK.
- Martorell A., Tsakanikos E., Peredaa A., Gutierrez-Recacha P., Bouras N. & Mateos J. (2009) Mental health in adults with mild and moderate intellectual disabilities. *The Journal of Nervous and Mental Disease* **197**, 182–186.
- Ministry of Health (2008) *A Portrait of Health: Key Results of the 2006/07 New Zealand Health Survey*. Ministry of Health, Wellington.
- Ministry of Health (2012) *Rising to the Challenge: The Mental Health and Addiction Service Development Plan 2012–2017*. Ministry of Health, Wellington.
- Somers M. (1994) The narrative constitution of identity: a relational and network approach. *Theory and Society* **23**, 605–649.
- Stmadová I. & Evans D. (2012) Subjective quality of life of women with intellectual disabilities: the role of perceived control over their own life in self-determined behaviour. *Journal of Applied Research in Intellectual Disabilities* **25**, 71–79.
- Taggart L., McMillan R. & Lawson A. (2008) Women with and without intellectual disability and psychiatric disorders. An examination of the literature. *Journal of Intellectual Disabilities* **12**, 191–211.

- Taggart L., McMillan R. & Lawson A. (2009a) Listening to women with intellectual disabilities and mental health problems. *Journal of Intellectual Disabilities* 13, 321–340.
- Taggart L., McMillan R. & Lawson A. (2009b) Predictors of hospital admission for women with learning disabilities and psychiatric disorders compared with women maintained in community settings. *Advances in Mental Health and Learning Disabilities* 3, 30–41.
- Taggart L., McMillan R. & Lawson A. (2010) Staffs' knowledge and perceptions of working with women with intellectual disabilities and mental health problems. *Journal of Intellectual Disability Research* 54, 90–100.
- Thomas D. (2006) A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation* 27, 237–246.
- Truffino J. C. (2010) Resilience: an approach to the concept. *Revista de Psiquiatría y Salud Mental* 3, 145–151.
- World Health Organisation (WHO) (2000) *Women's Mental Health: An Evidence Based Review*. World Health Organisation, Geneva.