

# Stream: New Ethnographies and Critical Creativity

*I didn't think I could do art but it's not hard!:*<sup>1</sup>

**Arts based inquiry with women who have an intellectual disability**

**Janette Welsby and Debbie Horsfall  
Social Justice and Social Change Research Centre,  
The University of Western Sydney**

*Kaye: I don't know why you want to know about my life... During the week I go to work and TAFE<sup>2</sup>, I do my community work and on the weekends I just see my friends or spend time with my mum. It's not very exciting.*

## **Abstract**

*Five women who identify as having an intellectual disability came together to share their life stories in a series of creative art workshops. Arts-based research methods were adapted to facilitate creative forms of expression where art was used as a way to spark or focus a memory giving each woman time to reflect and tell the stories of their lives both visually and verbally.*

*The motive for this research was to contribute to feminist understandings about women who identify as having an intellectual disability. This paper uses artwork and stories to open a window into the lives of these women whose voices are not often heard or valued in our society.*

Historically people who have an intellectual disability have not been asked about their stories; they are not often consulted, or asked for their thoughts or feelings. Although there has been a move in recent years to more inclusive research practices (Walmsley and Johnson, 2003; Oliver, 2002; Barnes and Mercer, 1997) people with an intellectual disability are seldom seen as full subjects in their own lives, let alone the research process. Much of the resultant silencing has meant that people who have an intellectual disability are not seen as competent, reliable or trustworthy research participants. It may be that some people are not competent research participants and it may be true of some people who have an intellectual disability. However, the generalised 'incompetent' view of people who have a disability has meant that research has been done *about* them often from a parent, professional or advocate perspective (Grundy, McGinn & Pollon 2005, Oliver 1992, Rambo Ronai 1996).

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<sup>1</sup> Shirley, research participant. All participant names have been changed.

<sup>2</sup> Technical and Further Education Institution in NSW, Australia. These colleges provide certificate and diploma level courses.

We came together as a PhD student and supervisor who were interested in doing research with women who have an intellectual disability. Our interest stemmed from both professional and personal experiences where we had noticed that women who have an intellectual disability have “traditionally gone unheard” (McCarthy, 1998, p. 558); their experiences often unseen, and for us they were obvious by their absence. As feminist researchers we recognised that women have often been silenced so that their stories are not heard in the public domain. Being a woman who has an intellectual disability can mean a double silencing.

As such, a major aim of this research was to provide a space for five women with an intellectual disability to tell their stories in their own way. To have the opportunity to both speak, and be heard. We believed that the narratives of their lives would be as interesting, valid, and as necessary as any other women’s stories. Informed in large part by feminist conscience raising of the 1970’s (Morgan 1992) we believed that change can happen when the dominant societal stories are understood and challenged. This challenging often takes place through the telling of silenced and alternative stories (Freire 1970, Pinn and Horsfall 2000).

Our desire in the research discussed here was to find a way to enable five women, who identified as having an intellectual disability, to tell us about their lives. To tell us what was important to them, in their own words. This is not without challenges. As social researchers we recognised that not all social actors find the more usual forms of interviews and oral histories the best way to tell their stories (see McCarthy 1998; Maynard 2002). This may be the result of never having been asked, and therefore not having the chance to develop the skills. And, sometimes it is physically and intellectually challenging for people to say what matters to them and why. As such, interviews can fall short of enabling multiple voices in society to be heard.

Interviews do privilege the spoken word and with it, those who are able to speak in a particular way. However, the postmodern turn in the social sciences (Bell 2006) has provided us with the opportunity to be creative in our research methodologies and methods. It has enabled us to use multiple textual forms to enable more people to speak for themselves, to begin to define their lives in their own words. We, however, are aware of the inherent paradox that in presenting this paper we are speaking for these women in many ways.

In recognition of the above we developed a creative arts-based research format, in the hope that this would enable the women to both find, and have, a voice. The aim was not to do art therapy, rather to use artistic processes and activities to create spaces which would enable the women to speak if and how they wanted to. And to do research that foregrounded the voices of the women themselves, “to understand what does and does not matter to them and why” (McCarthy 1998, p. 571).

In the arts workshops, detailed below, people moved towards co-created places and spaces where they could tell their stories. Each person around the table moved in and out of teller and listener positions (see Richardson 1997). As a result, both common and unique experiences were shared and discussed, ranging from the things that made us feel good on a personal level to social justice issues such as person’s individual rights.

The five women in this research identify as having an intellectual disability. They were over the age of 21, on a Disability Support Pension, worked part time and lived in the Western Suburbs of Sydney. Three of the women worked in the Business Services Sector; Shirley, aged 43, lived at home with her parents while Jill and Cindy, aged 28 and 52, lived in supported accommodation. The other two participants worked in open employment and lived independently. Kaye, aged 32 lived by herself and Lara lived with her partner of eight years and was 48 years old. Potential participants were approached through established local networks. A number of local disability services agreed to advertise the research project through their networks and it was only after a potential participant expressed an interest in being involved and gave their permission to be contacted that their information was pass onto Janette.

### **Creative Arts-Based Inquiry in Practice**

A series of five workshops were held fortnightly on a Saturday from 10am to 3pm. Door to door transport, all art materials and food were provided. The workshops included four art expression workshops held at the University of Western Sydney's Parramatta campus and a visit to the Art Gallery of New South Wales. Each workshop had a different theme and was designed as a stand-alone unit. Three of the main themes agreed upon by the participants were 'friendships', 'a day in the life' and 'who I am'.

Each fortnight participants were provided with a range of different art mediums and techniques they could choose from to express themselves. Art mediums included clay, charcoal, watercolour pencils, movement, shadow work, paint, photography and crayon. Different styles of art included still life, collage, self-portrait, storyboards, experimental painting and free-form clay sculpture. The idea was to provide as open a space as possible in the workshops where each woman could exercise some level of choice and self-determination. This enabled each participant to experience a more individual way of expressing thought through art.

The workshops were co-facilitated by an experienced art teacher, Moira. Janette took the role of participant-observer. Although video-or tape-recording the workshops would have provided rich data it was decided to keep the workshops as spontaneous as possible so no recordings were made. The workshops produced a rich form of data as the participants' conversations and comments flowed and fed off one another. Detailed field notes were recorded after each workshop as well as one on one discussion. These incorporated observations, details of discussions, insights and what did or did not work. All the workshops were photographed as a pictorial representation of the research process. The photographs were downloaded and made available to the women. They were then either deleted or incorporated into different art expression activities (e.g. collage) throughout the workshops. An album was given to each woman so that they could select photographs to keep as a memento.

### **A note about power:**

No research methodology or method is unproblematic. The postmodern feminist philosophy that women are experts in their own lives (see Lather 1997; Zalewski 2000) lends itself towards a research design that seeks to both make visible and work against power imbalances between the researcher and participants. For the women,

the loosely semi-structured style allowed them to exercise some control over which stories they chose to tell and how they would share them in the workshops. Work and talk happened whilst sitting around a large table. Everyone worked on art expression projects, individually, as somewhat of a collaborative introspection. This then permeated out into group table talk. Working this way helped to promote conversation, individual storytelling and sharing of experiences.

Whilst the informality of this method was effective the relaxed atmosphere put many of the women at ease and potentially off guard. Potentially, this could have resulted in some people saying more than they might in a formal interview. This is of particular concern for women who were perhaps more vulnerable and saw the process not as research but more like friends talking around a table. To address this, informed consent became a continual negotiated process. At the start of each workshop Janette would go through the consent process, foregrounding again, that this was research as well as fun.

### **So what did the women have to say?**

In defining the lives of people with intellectual disability, academics, policymakers and community workers often use terms such as marginalised, socially isolated, excluded, living on the fringe, shadow-dweller. Through the stories the women in this project told, and the art they created, we saw that in many ways these labels *are* descriptive of their lives. For those of us who come from a privileged position or a position of power it can become easy to focus on the everyday restrictive practices within which these women live, and to define their lives by them. This is one truth. However, this is not how the women in this study perceived their lives. Instead they defined their lives and their identities by what they did, not what they could not or did not do.

The process of art-making was used to give time for the women to reflect on their lives visually and verbally. The art works themselves were not primary data, in that they were not analysed or interpreted by anyone other than the composer of the work. The works were used as a way to spark or focus a thought or memory. Used as a creative form of expression, art was the vehicle for the women to tell and share stories about their lives, and as such the art work and stories need to be viewed together (see below). The following creative works and accompanying stories illustrate the women from their point of view. The stories are compiled from words the women said over the course of the project, as recorded in field notes. While they are not a verbatim transcript, we have attempted to write the stories as each woman spoke, to stay as true to their voices as possible.

## Jill's story



**Fig 1.**  
**Artist: Jill**  
Title: Friends  
Year: 2005  
Medium: Poster  
Paint

I am 52 years old and the eldest of 7 children. My mum is still alive, she is getting very old and she has bad arthritis so it's hard for her do things now. My sister wants me to move back home after Christmas to look after mum. I really love living here we look out for one another but someone has to help mum. It's a big decision so I need to think about what I should do.

We used to have Christmas at my mums but now we go to my nephew's house for lunch. Everyone gets together and we have a good time. There is lots of noise and laughter and we always eat too much turkey, ham and chocolate. I love my nephew we are really close. I made this card for him.

I am a good worker. I mainly fold handkerchiefs and put them into packets. It's very boring. We haven't had any work for weeks so every day we just sit around and watch TV. Last week I wore my new sandals to work and my supervisor sent me home because it's against OH & S to wear open toe shoes in the warehouse. I could understand if there was work to do but I was only going to be reading a book.

My dream is to work with children. I told my supervisor a long time ago that I want to find another job. I have to be patient and wait until they sort something out. I like where I work because I get to see my friends but the supervisors are always shouting at people and telling us to keep quiet. I would love to leave.

My boyfriend is a bit of a ladies' man he flirts with all the girls. He really makes me laugh and he is a good dancer. It took me a long time to go out with A... my last boyfriend died a couple of years ago. I still miss him. I can't walk past his house or see his parents it's just too hard. Sometimes I get so sad I have to get out of the house and go for a walk.

### *Lara's story*



**Fig 2.**  
**Artist: Lara**  
**Title: Untitled**  
**Year: 2005**  
**Poster Paint**

This is different to the other research I was involved in. They just asked me lots of questions. This is better – it's fun – and I've made some new friends. I was a bit anxious at first because I haven't done any art since I left school. I felt more confident after we went to the Art Gallery. Even I can do better than some of those artists. I'm not worried about putting up my paintings up in the lounge room now not after seeing some of those pictures.

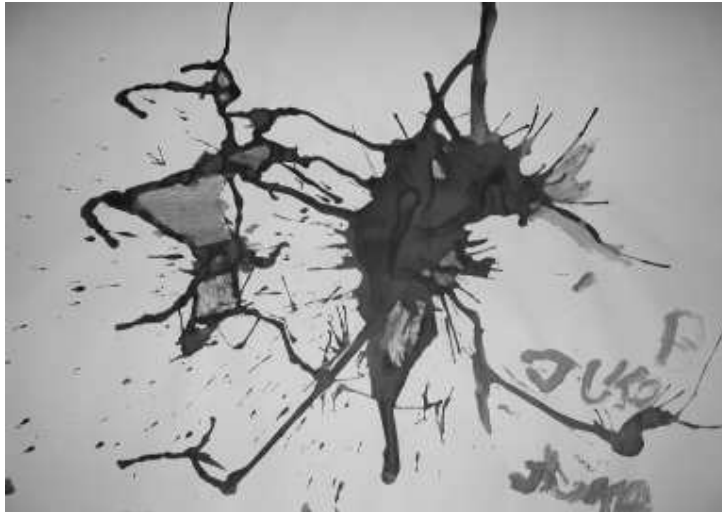
I live with my partner. We've been together for about 8 years. I have one son and two grandchildren who call me Nana. I take my grandchildren for the weekend every fortnight. They can be a bit of a handful but I love having them.

Before this I worked at SW it was a bookbinding company. I did a number of different jobs and ended up being the union rep, 'you got to love the power'. We went on strike a couple of times the company had to listen when we down tools and stopped working. It was a good company and they did care about their workers it's a shame it's closed down now. Now I teach self-advocacy and interview staff for workplace audits. I really love listening to people's stories. My job is fantastic. I love clothes shopping and I get my hair done every 6 weeks. It's important when you're a trainer to look your best.

When I train, I tell people, 'If I can, so can you'. Sometimes people say, 'You don't have an intellectual disability'. I tell them you can't always tell by looking. It's important to have role models. If they know that I can do it then it makes them think, 'Hey, maybe I can'. It's hard for people with an intellectual disability, people always tell you what to do and make decisions for you.

You go to these meetings and you have all these "normal" people standing up and talking about us as if we are not there. What we should and shouldn't do. If somebody just stopped and asked us they would find out that we actually know a lot.

### *Cindy's story*



**Figure 3**  
**Artist: Cindy**  
Title: Butterfly  
Year: 2005  
Ink and paint

I don't go to work for the money. It's the only way I get to see my friends. Well I don't see my family very much. I have two sisters. My sister called me for my birthday we had a long chat. I didn't get a cake on my birthday this year. Can I take what's left home? I'll hide it at the back of the fridge so I don't have to share it with J... Thanks this is great. It was a lovely surprise.

The best job I had was working at Target<sup>3</sup> for work experience. I stayed there for a while. I loved that job. Everyone was happy and nice. I could talk to the customers and the people that worked there. My boss called me a social butterfly. I like that. I like to think of myself as a butterfly. When I moved to Sydney I had to leave. I really loved that job.

It's hard to make friends in a new place but Jill I remember my first day at ... you asked me to come and sit at your work table. I didn't know anyone. You made me feel like one of the gang. You showed me what to do and where to go. I'll never forget that you were so friendly. I pack my lunch every day but I like to buy a chocolate éclair from the Tuck Truck most days for morning tea.

Oh yer I get shouted at a lot for talking at work even when there is no work we have to sit quietly. I'm always in trouble for something... say something to who? There's no use even the big boss shouts at us. We are always being shouted at for going too slow or making a mistake or talking.

I like to go line dancing, its good exercise and lots of fun. No-one gets cranky or shouts when you do the wrong thing. Its lots of fun. You should try it. Sometimes I forget the steps but we just laugh. You only have to look at the person either in front or beside you and you soon pick it back up.

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<sup>3</sup> Target is a large general retail chain

### *Shirley's story*



**Fig 4**  
**Artist: Shirley**  
**Title: A Starry Night**  
**Year: 2005**  
**Acrylic paint**

I love to go to my sister's house in the country. Of a night I stand outside and look up at all the stars. There are so many stars you don't see many stars in the sky at home. This is a picture of all the stars in the sky and the flowers that grow in the paddock.

I like to spend my money on lipstick and music. I love The Rat Pack, Tom Jones, Shirley Bassey, anything really. I went to John Paul Young and he signed a poster for me. I have it on the wall of my bedroom. To my greatest fan love JPY. Do you remember his songs? "I love the music" "Yesterday's Hero"... we danced all night.

My favourite recipes are beef casserole, lasagne, spaghetti bolognese, meat loaf, chicken marinade and apricot chicken. I love to cook. I'll cook for you if you like. I did a course with Centacare<sup>4</sup> they helped me put together this recipe book. They came here to my home and taught me on the stove in the kitchen. See this is a picture of our stove and that's my hand stirring the pot, the recipe lists the ingredients and then what to do. I tell mum what I want to cook and she buys the ingredients when she goes down the street.

I go to gym and do the treadmill and stretching. Mum and I go every Wednesday. I am learning my money skills every Wednesday half past three and finishes about 4 o'clock. We just count notes like five dollar notes and you count five cents. It's not pretending money it's the packet real money. It helps me when I go out shopping or for coffee or dinner. So I can pay for things and to make sure I get the right change.

I go to Coffee Club. Once we went to Tasmania on a holiday it was lovely. I shared a room with L... she is my best friend. She will ring me up and say hello but she doesn't talk much but she does talk to me. We talk about her dog and this and that.

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<sup>4</sup> Centacare is a Catholic non-government organisation providing a variety of services in the community.



*Kaye's story*



**Fig 5**  
**Artist: Kaye**  
**Title: Self Portrait**  
**Year: 2005**  
**Pencil and Texta**  
**colour**

I'm an Admin Assistant in our office. I like my job. Before this I worked in Business Services you know a sheltered workshop. It was horrible I never want to work there again. It was very boring. I know some people have to work there but they are not very nice places.

I am an only child. No I wasn't spoilt my parents were very strict. I got meningitis when I was 50 days old that's how I have an intellectual disability. Some people tell me that I don't look like I have an intellectual disability. I ask them "what am I supposed to look like?" I have difficulty with numbers. I go to TAFE at the moment I'm learning to do spreadsheets then at work I can do petty cash and my time sheets on the computer. This will help me with my maths.

The best thing about my job is understanding what I have to do and learning new skills, otherwise I know I will feel bored. Oh, I shouldn't have said that. The worse thing is when I don't know. When communication breaks down. One thing I hate is to be told five minutes before they need it. You should tell us beforehand not two minutes ago or slide me this. This doesn't work.

I don't live with mum any more it was far away from this job. I spoke with Housing and they found me a flat around the corner. Now I live by myself and I walk to work. I can't have my computer there because it's on the ground floor and someone might look in the window and steal it so I have to keep it at mums.

## Reflections:

The opening of a conversational space, using a variety of creative arts processes yielded a deep understanding of the women: who they were; what was important to them; what they wanted to talk about. They talked of work, lost loves, food, and friendship. In many ways they spoke of the usual everyday things and they talked of their dreams and achievements. Laura, for example was in the process of moving to the country to live with her partner who had just purchased a house. She was moving into a new and exciting phase of her life and was eager to talk about it: *'I never in my wildest dreams ever thought I would have my own home. My place to paint whatever colour I want and put any hook anywhere on the wall. It's H's home really but he calls it ours. Our home. Can you believe it?'*

Two things emerge as significant about these stories. The first is that now they have been told, and in this paper, introduced into the public domain, available for scrutiny and public debate – they are no longer silenced. And secondly, what is significant about the content of the stories is the everydayness of them. While the issue of 'disability' came up at times, it was not the predominant theme. Instead the women talked about what was good, or bad, about particular work they did, hobbies they pursued. They spoke of their families, and relationships that were significant to them. They talked about where they lived and why, what made them happy and sad, how they liked to be treated. Perhaps what is surprising is this everydayness; these women, rather than being consumed with their 'disability' identity, were instead a lot like any women in what they chose to talk about. They spoke about their identities as friends, lovers, consumers, children, aunties, workers, parents.

Reflecting on the arts based method, like Judith Davidson we found that producing an art work first did appear to help the women to "organise their thoughts so that in describing their drawings (or other artworks) they can elaborate on their ideas to an extent that they could not have done without an opportunity to present the idea visually ... in addition the drawing or photograph (or other artworks) in question may provide an opening for elaboration" (2004, p. 60). It also enabled us, and the women, to notice what is often taken for granted. In our busy lives many of us just get on with living, doing what needs to be done to get through this day, the next day, the day after that. Our lives become so familiar to us that we do not see them, or ourselves. In this research the women were asked to notice themselves, to glimpse, and then articulate, the familiar and to see what emerged (Van Halen-Faber & Diamond 2002).

This project has raised some questions for us around the role of the researcher. In the actions of interviewing and transcribing the spoken word, the analytic territory of the researchers is usually carefully mapped out. But how does a social science researcher read an art piece or a creative work? Does the researcher want to read it? We don't have the answers but in the research project outlined here, it was left to the women themselves to read their work and tell their story. The women talked in a visual language first, then noticed what emerged, and then decided what to tell. In this way there was a movement towards emancipation, as a deliberate sharing of meaning-making was taking place. Through this research we have glimpsed these women as women with multiple identities. Our hope in writing this paper in the way we have

done, centring the women's words and art, is that we have enabled you to glimpse them this way too.

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