

Caring in Families: a Case Study

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Editors' introduction

This is an extract from a study of 22 adults with learning disabilities interviewed about their experiences of care and caring. Lynne's story was the one which raised the most complex issues about being a woman, about having the label of 'learning disability' and about being both carer and cared-for.

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Interview situation

The local MENCAP secretary told me about Lynne as a woman with learning difficulties who cared for her father. A lengthy attempt to make contact followed. I was helped in this by Rita, the disability employment worker whose job was to look after people with learning difficulties in work. She tried to arrange an interview at Lynne's workplace and failed. In the end we met at the hostel near Lynne's flat. At Lynne's request Rita was to be present.

At the hostel I was introduced to the officer in charge who had known Lynne for 20 years. She told me Lynne's father, like many others, had difficulty accepting self-advocacy. Lynne's sister, she said, 'doesn't do much', and Eddie, Lynne's boyfriend had been harassed by Lynne's father: for example he would ring him up to do errands when Lynne was unavailable. Staff had stepped in to defend Eddie. All agreed that Lynne's father should not be told about the interview and helped Lynne rehearse a story about visiting a friend, as a reason for being out that evening.

Lynne's life story as she told it

Lynne was 43. She was nervous: 'I don't know what I'm going to say tonight.' In fact, she was reticent about the past, and the facts are briefly recounted.

She was born in L— and once lived 'up Burley Hill'. With difficulty I obtained the information that she'd been to Fivetrees (an occupation centre opened in 1959). (The minutes of the Mental Treatment Subcommittee dated 12 September 1957 record that she was put on statutory supervision at the age of eight.) She said firmly it was a school. She later went to the centre, from where she obtained her job. Her mother died:

I was down the Salvation Army when she died and Dad had to go up the hospital with me uncle and it was too late so someone told me down the Salvation Army. On the quiet before they gave it out . . . she'd got cancer . . . she kept falling over and I went to work.

She was unable to give any indication of when this happened. When pressed to give details she did not want to recall she changed the subject. However, it did result in her father taking over the cooking in the family, something that Rita referred to more than once when arguing that Lynne owed caring obligations to him.

The only event which was dated was her starting work:

Been there seven years, nearly eight years . . . I wanted a job. I worked in C & A for a month's work experience and me dad said there's a factory up near where he works.

She said her social worker had found the job (though Rita said it was the officer from MENCAP Pathway, a specialist job-finding service).

Family

Throughout her life Lynne had lived with her family. Her mother died, her sister left home to marry, and she remained. She began the first interview by saying:

I know I'm not very happy at home at the moment . . . I'm a bit fed up with me dad. He doesn't know where I am tonight. He thinks I'm going round a friend's. I daren't tell him.

Fear of her father, and dislike of living with him, were recurrent themes, a graphic illustration of a care relationship which was felt to be burdensome and restrictive.

It took some time to ascertain the precise nature of the tasks Lynne did for her father. Rita questioned her persistently to discover what these were. One was shopping:

Dad writes a list out and we have to get what he wants. He likes his stew and dumplings and I don't.

Lynne handed her 'board money' to her father and he gave some back for his shopping. Money was a matter of contention:

Well every Thursday night I usually give him me board money. I didn't this week cos I didn't draw me money out till Saturday. 'Where's me money, where's me money.' I give up. He wanted his money for shopping Friday night, I think. He didn't know we was doing it on Saturday.

Other than shopping, Lynne said her work in the home included 'cooking his dinner and washing up what I normally do'. Lynne prepared her father's dinner the night before, and left it ready for the home help to put in the oven. She had to monitor what he ate because of his diabetes: 'He's only allowed potatoes when he doesn't have stew and dumplings cos of his diet.' She peeled all the potatoes for the week on Saturday nights.

She said she spent little actual time with him:

Jan: You scared of him?

Lynne: I am. I'm always in me bedroom. Part from tomorrow. I goes to the club.

Jan: But you don't actually spend any time with your dad?

Lynne: No.

Jan: Is that, do you choose not to?

Lynne: I have me dinner with him. Sometimes if it's hot I have to wait for it to cool down.

Jan: But you don't sit and talk to him at all?

Lynne: No.

Jan: Would you like to?

Lynne: No, I'd rather go out.

The tensions in the relationship came to a head in between our two interviews. Rita brought the subject up, and Lynne said she'd prefer Rita to tell the story:

The way I understand it is that Dad was having a go at Lynne and Lynne lost her temper. She was peeling the potatoes. And she waved the knife to her dad. So he told the home carer and the home carer fetched the social worker.

Lynne corroborated this and said:

I wouldn't really do it. I was upset at work, wasn't I . . . he was going on . . . he said do something while I was peeling the potatoes . . . he [social worker] said he'd put me away next time . . . social worker said to me dad you won't be staying here, you'll be going a long way away . . . he said if I tried that again to call him, he said I won't be in L—— . . . I heard him.

This incident summed up Lynne's situation with her father, and her social worker. She felt that her father asked too much of her, that he tried to stop her going out, and that the social worker was on her father's side. It was perhaps unsurprising that she wanted to leave home. She was a single daughter at home with an invalid father, and worked a double shift, at home and at a full-time job, yet remained infantilized by her father, a view shared by staff at the hostel.

Impact of services

Lynne's career until she got her job seems to be fairly typical of a woman of her age who was certified as ineducable, and whose family were prepared to take responsibility for her: certification, occupation centre, then training centre. There are many examples of such a life course in the records of the Mental Treatment and Mental Health sub-committees.

However, what is missing from these written accounts is the subjective meaning of such a biography. She did not mention the process of being certified. Her reference to Fivetrees Occupation Centre as a school reflects, perhaps, an attempt to normalize her situation, or possibly the well-meaning efforts of family and staff to do so. The importance of her job was reflected in the fact that this was the only event she was able or willing to date. Even the means by which she got the job was presented as a family initiative, not an intervention by MENCAP's Pathway.

Getting a job set her apart from all the people I interviewed, and made her situation uniquely complex. I examine this below.

Identities around gender, caring and dependency

Lynne seemed to have three distinct social identities: as an employee; a woman with learning difficulties; and an unpaid carer.

Lynne talked of her work at a pharmaceuticals factory with pride. She washed her own uniform, got herself up and off to work by rising at 5.20 every morning. As an employee she spent her working day in the company of non-disabled people with minimal specialist support. The company were, according to Rita, anxious to treat Lynne like any other employee. Some interventions, such as Rita's visits, were accepted, and there had been special efforts to ensure she was well fed, and that her wages were accessible to her. But it was not sheltered employment. Lynne was expected to pull her weight, packing drugs with the other workers. She herself made reference to this.

Possibly as a consequence of her status as a working woman Lynne had more casual community contacts than many I interviewed:

I get me money out in town now If I want a prescription I ask sometimes the library to do it for me . . . I go in the estate agents next door too, I still pop in to say hello [this was where she used to draw her wages], Thursday nights I still go down to pay me rent.

The need and the opportunity to meet people in the course of running her life seemed to give Lynne confidence in these transactions. It was an obvious benefit of her employment.

However, she remained a person with learning difficulties in many respects. She did not acknowledge this openly, but it was clear from her social contacts that she was still part of the network. Service providers lingered in Lynne's life from her days as a client. The officer in charge at the hostel where we met knew Lynne well. She had contact with professionals through Eddie, still a user of services – for example she was anticipating going out to eat with Eddie and his key worker. The one worker who currently had responsibility for Lynne was Rita. Lynne appeared to trust her, as she insisted on her being present at both interviews. Rita assumed the role of co-interviewer, and used the opportunity to pursue in some detail those areas which concerned her as disability employment officer – Lynne's diet, her health, her teeth ('I think you're having trouble with your teeth, you know. They're falling out all the time').

Lynne's leisure time was largely spent with other people with learning difficulties. She went to the club on Wednesday evenings, and on the outings organized for its members, she went to the gardening classes at the hostel. Above all, she knew people. This network, shared by Beryl and many others I interviewed, was long-standing and durable. Its significance was illustrated by an incident at the hostel. I had brought a gift for Rita and while we awaited her arrival a hostel resident tried to grab it. I could not cope with the situation, but Lynne said 'Sit down, David' and he did. Later we talked about the incident. Lynne said she'd known him from the centre and he used to talk 'but now he don't'.

Lynne was also a carer, for her the least welcome identity. This entailed relationships with a number of professionals who were there for her father. He had home aides and home care assistants coming into the home, including at weekends. It was a home care assistant who called in the social worker after the knife incident. Lynne had mixed feelings about the home care assistants:

Sometimes Dora comes at weekends. She's all right. She does say hello to me But sometimes I just want to keep out of the home care's way and go out.

In this respect, her home was the site of someone else's care, and this compromised her autonomy within it (Gavilan, 1992).

Her caring role was most complex in relationship to the social worker. He was Asian and she claimed to be unable to understand him. There also seemed to be a greater difficulty; he was both her father's social worker and hers [. . .] and they had different and irreconcilable interests. Lynne was keen to leave home and live on her own 'before I get too old'. The social worker may have been the key person to achieve that, but their relationship was such that she could not imagine making contact with him to talk about rehousing.

It seemed that for the social worker she was part of her father's network of support, not a person with needs of her own, a classic conflict of interest.

As an adult daughter at home Lynne was under pressure to take on the role of caring for her father. This was clearly spelt out by Rita, who told Lynne that the fault in the relationship was not one sided:

I think sometimes Dad gets cross cos you aren't doing the things you really should do. Cos you just want to go out. Am I right? It's not always Dad's fault he gets cross, is it? It's sometimes your fault . . . Well I say to Lynne sometimes that hard as it is for her to have to have someone like Dad dependent on her to a certain extent he took care of her when she was young and helpless and needed someone and now she is grown up and able to cope in life she should help if she can.

It is a clear exposition of a commonly held view on daughterly obligations to elderly parents, though some of the language ('now she is grown up') seems inappropriate for a woman of 43.

Lynne also had a boyfriend, Eddie. She met him at the Adult Training Centre and they had been friends for 13 years. In answer to a question from Rita she said he had asked her to marry him, but she'd said no because he was too old. It was not described as a sexual relationship, but it did give both practical and affective support. He did the shopping with her and they met most days after she'd finished work. She described how he made sure she ate:

Eddie took me straight down town to have two beefburgers. I said 'Eddie I only want one beefburger.' 'You're having two, you got to eat.'

Eddie had been banned from Lynne's flat because her father was trying to get him to run errands.

Lynne was exceptional. Beryl told me she was the only person from the centre to have got and kept a real job. But this change in status was in some ways superficial. She still did not enjoy the autonomy that having her own income might be expected to bring. Her father, according to her and others, still treated her as if she was a dependant, took 'board money' and expected her to obey him and account for her movements. She was expected by him, and others, to carry out daughterly obligations, and her wish to be an independent householder was not taken seriously. In terms of care, she was both carer and cared-for. The formal care she received was very much geared to sustaining her ability to carry out her job. Rita was responsible for overseeing her health – food, spectacles, teeth were all matters of interest to Rita. The care work Lynne did for her father was actually quite substantial, but she got little credit for it and no rewards. Her history as a woman with learning difficulties had followed her into the world of work. The consequences for Lynne were

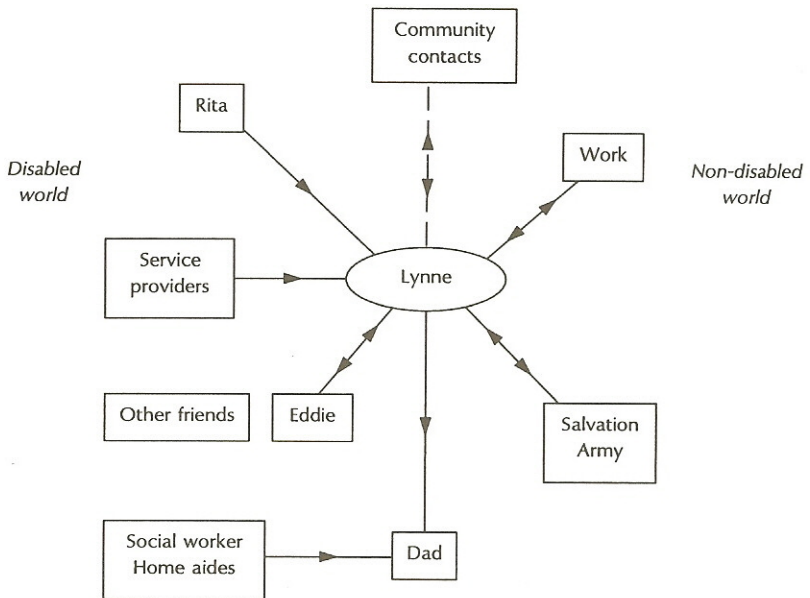


Figure 4.1

that she uncomfortably straddled two worlds, and had few of the benefits of either.

'Lynne' case study: issues around care and caring

Lynne is a woman with learning difficulties, a label which implies dependency and excludes her from a role as a 'carer' or a worker. But she is also:

- a woman who has a classic 'double shift': full-time work and caring duties at home;
- a daughter whom Rita sees as having an obligation to care for her dad to repay him for caring for her when she was younger;
- a single daughter at home on whom the obligation to care often falls (Lewis and Meredith, 1988);
- a full-time worker;
- a recipient of 'care' herself in a limited fashion from Rita whose role as disability employment officer has been adapted to support Lynne, and a person in whom learning disability service providers take an interest.

Her social relationships are complex (see Figure 4.1).

What does Lynne's story tell us about 'care'?

- (1) It depends on who you ask and how you ask. Had I asked Lynne's father, social worker, Rita, home aides about her life I'd have got a very different picture. What if I'd used a questionnaire?
- (2) Care relationships change over time: 10 years earlier it would have been a very different picture – Lynne at a training centre, Mum alive, and out at work. Five years later, different again, maybe.
- (3) Caring services went into the household for individuals. Rita did not know much about Lynne's home life. She used the interview to find out. The social worker, home aides and care assistants apparently saw their role as supporting Lynne's dad, not Lynne. There is no evidence of a holistic approach: indeed Rita was not employed by Social Services at all and felt she had no leverage with Lynne's social worker over, for example, Lynne leaving home or resolving differences between her and her social worker.
- (4) There are gender issues here: would Rita have said what she did to a man? Class issues, also?
- (5) Lynne's views of her social worker, and her ability to communicate with him, were complicated by race. She claimed to be unable to understand him, and was, by implication, racist.
- (6) What sorts of services might help?
 - allocating a social worker to Lynne as well as to her father;
 - Dad's social worker to act as broker between Lynne and her father rather than advocate for him alone;
 - a gender perspective for Rita – did she recognize her role in reinforcing gender stereotypes?
 - training for the home carers/aiders in working with Lynne rather than around her, and recognizing her contribution to the household;
 - someone to listen to Lynne and respond to her clearly articulated wish to have a home of her own;
 - a carers' support group for Lynne.

References

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