

## WHAT WE SAY...

### About who I am

- *I'm pretty brainy, I just take longer to learn things.*  
(Forgotten People, 1994)
- *I've got a disability and it takes me longer to work things out. But just because it takes me longer doesn't mean that I can't do it!*  
(It doesn't mean I can't do it! 1994)
- *I find things pretty hard - I'm a good person at heart.*  
(Forgotten People, 1994)
- *I might have a learning difficulty and I'm also a kind, good, helpful person.*
- *I have a learning disability which means I have had to have a lot of strength to get by day by day.*  
(Standing Proud Workshops, 1999)

### about learning difficulty

- *[I'm] someone who takes a while to learn things.*
- *I've got a disability and it takes me longer to work things out.*
- *(I) need more time to understand things*  
(Forgotten People, 1994)
- *I think it's being slow and they think very simple.*  
(Standing Tall, 1994)

### about what is difficult

- *Well, I have a learning problem. I'm slow. Developing, y'know. I can't get jobs handling money or anything. I have to get jobs not handling money. I've got a short span of attention. That is my special needs.*
- *I know I've got a learning disability because I'm a slow learner.....With me, reading and spelling. I hate spelling.*  
(Standing Tall, 1994)
- *A bit slow at doing things, sometimes don't understand words, can't write down things like other people.*
- *A bit of a handicap, it's like if people can't read or write. Reading and writing is hard. It's hard trying to figure out in new suburbs where everything is.*
- *A bit slow in reading, writing, because nobody ever showed me. I'd like to read.*  
(Forgotten People, 1994)
- *Need things explained to them in different ways, like me. I don't know how to read bus and train time tables.*

(Standing Tall, 1994)

to help you understand learning difficulty better

- If you don't have respect for people with a learning disability you've got it wrong.
- "Stupid" and "dumb" is not true, is wrong and will never be acceptable, even though name calling is easy.
- I have a learning disability and I am not ever going to accept anyone calling me dumb.
- I have a learning difficulty and am no different from you. I can be hurt and I can be happy.
- I have a learning difficulty but if you can't accept me for who I am you're the one with the problem.
- We're all learning even though some people learn a bit slower.

(Standing Proud Workshops, 1999)

Note: Please see References and Further Reading for publication details of above reports.

## SOME COMMON STORIES

*[I] felt helpless and dumb. Mum was looking after my money. Mum and Dad telling me I couldn't use things like the washing machine: "You don't know how and might wreck it."*

*My parents were taking control, now I am looking after myself. When I was living at home Mum used to do everything for me...she used to do my washing...she had my bank book and I had a key card but she used to take the key card off me because I had trouble budgeting my money.*

*[Now] I feel good inside. Knowing that my friends like me for who I am, I don't have to prove anything to anybody.*

*I hated it [the hostel]. I said I wasn't going to stay in this place. My family just dropped me off, they didn't tell me.*

*The toilets and showers are no good. It gets all blocked up. The house isn't straight. The stumps are loose and they got disturbed in the big raid. The hostel was no good. He [the manager] would tell me to do things. I was washing up and cleaning. He wanted me to run his computer...He said I couldn't stay if I didn't. So I made trouble for him.*

*They [police] push people. They're pushing people into telling a wrong story...they say I'm telling lies.*

*I knew there was something wrong with me. There were certain things I couldn't do in my head. Lots of students just thought I didn't want to go to school. They said things about me behind my back, things that really hurt then. They said I had brain damage. Would have hated to be at Special School because people would tease you, treat you like a fool. Sometimes I would be chased and bullied by two guys, verbally abused. I used to hide.*

*I'd heard of sheltered workshops. I was just interested in getting a full-time job somewhere. They had nothing else to offer me though...it gave me the creeps...they just sit around fixing telephones all day.*

*I had a job making dog and cat food. You have to check the meat for bits of things. I was happy for a while but the workers picked on me.*

*I really wanted to get away from my father...he was dominating me. Parents say, "Don't spend money because you don't have much". I get angry because they don't know what I need.*

*It was hard at first but I learnt to cope. Tax returns, I had not done that before in my entire life, now I'm paying tax for the first time in my life. My parents were taking control, now I am looking after myself.*

*You can do your own thing, roam around, go to the movies or the beach or overseas, and you don't have to ask anyone.*

*I didn't want to leave at first. My parents thought it was a break for them and a break for me. It was scary. I was very attached to home - my mum made it easier by always saying she was there.*

*I've got a disability and it takes me longer to work things out. But just because it takes me longer doesn't mean that I can't do it. I hope to have my own place and to get a job to keep busy and to make friends for myself. Meet new friends. To have long term relationships.*

*I feel lonely a lot. I've got lots of things going on in my head all the time. I feel bad a lot of the time. I'm trying really hard at the moment to work it out. I don't know if I'll ever work it out – do you? I don't think anything is getting better.*

*I've talked a lot to my doctor about this. He's been telling me for ages to talk to someone else outside my family. I've only just started talking to a worker. We talk a lot about things like stress and anxiety and my doubts. I've got some new tablets now – for stress and depression. I'm trying to fight it – “seeing the good times through to the bad times is food for thinking about depression and I don't know if I'll ever feel better.*

*I'd like to have friends. It's really hard. I've tried lots of groups but none have worked out. I get really worried about if anyone is going to like me and if anyone is going to have things in common with me and it goes around in my mind and it's hard to decide to go, so a lot of times, I don't.*

*I have a learning difficulty and I am not ever going to accept anyone calling me dumb.*

**Note:** The preceding stories illustrate some of the issues facing people with learning disability in relation to self, family, school, employment and accommodation. While they have been drawn from statements made by people with learning difficulties, each story is a composite of statements made by different individuals, and come from the following sources:

Brown, C., Jeanneret, S., Morrison, J. and Ringma, C. (1990) Final Report on the Community Living Program Research & Development Project 1989-1990.

Coleman, Anne (1994) It doesn't mean I can't do it.

Conversations with 3 constituents of CLP, 2000.

Ray, Linda (1991) A Collaborative Self-Enquiry Research Project 1991.

Sewell, Sandra (1994) The 1993-1994 Review of Community Living Program.

Standing Proud Workshops (1999 & 2000). Community Living Program, Brisbane.

## AS PEOPLE STILL TO FIND THEIR OWN NAME

One social indicator that a group is marginalised is that other people have names for them. For example, homosexuals used to be called derogatory names like poofers, fruits and queers, and Aboriginal Australians used to be called Abos, black fellers, niggers, and boongs. A sign that a marginalised group is finding its own voice, discovering pride in its identity and becoming organised, is the social moment when the group names themselves, and the wider society accepts the name. Homosexuals named themselves gay, Aboriginal Australians identified themselves as murri, koori, or nyoongah.

While people with a learning difficulty have not yet named themselves, many groups in society compete to name them, a sign of their powerlessness and marginalisation. They are named, variously as intellectually disabled, learning disabled, mentally retarded or mentally handicapped.

In this document we have chosen the term 'people with a learning difficulty', because that is the way most people we work with refer to themselves. We look forward to the time when 'people with a learning difficulty' will claim their own name, that is, move from being objectified to being able to name themselves.

We present these various ways of naming 'people with a learning difficulty' in the knowledge that they reveal, at best, only glimmers of the truth, and sometimes considerable falsehood. The names to be most treasured are the names that people give themselves.

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## AS PEOPLE THROUGH HISTORY

While the self-perceptions of people with a learning difficulty and others' ways of describing their disability have changed across time and across cultures, it has been a constant that they have been considered and labelled "different". Their perceived difference has been the basis of the misunderstanding, the isolation and, often, the mistreatment of people with learning difficulties.

*Depending upon the ignorance or superstition of the times, the mentally retarded were treated respectfully or cruelly, but always differently (Dickerson, 1981).*

Historically, people with intellectual disabilities were viewed as less than human. Because, in part, of the influence of the classical Greek philosophers who valued rational thought as the essence of humanness, "idiots" and "deranged" persons were considered inferior because of their disability, and had no individual rights. Their well-being was at the whim of government and local communities.

Over time, there have been gradual changes. In 1325, Edward II of England provided a set of guidelines to safeguard the property of "idiots", and to ensure their care. The Reformation saw a rapid growth in humanism and in the scientific understanding of many phenomena which had been previously beyond explanation. However, people with learning difficulties were not to benefit from this change until somewhat later. Thinkers of the time, like Luther and Calvin, considered the "mentally retarded" as possessed by the devil.

By the late 1800's, professionals from a range of disciplines had become interested in the study and training of people with "mental retardation". American studies of the time claimed to have established a connection between "mental retardation", crime and degeneracy. Frank Tate, the Victorian Director of Education, said in 1911:

*The army of unskilled vagrants, habitual inebriates, criminals and lunatics is largely drawn from the ranks of the mentally defective. (Slee, in Vernon & McKillop, 1991).*

Since the development of intelligence tests (IQ testing) in the early 1900s, intellectual disability has been identified by means of a standardised IQ test. Those who have an intellectual disability can be classified as having a mild, moderate, severe or profound disability. The level of disability is determined by an IQ rating.

Mild	50/55	-	70
moderate	35/40	-	50/55
severe	20/25	-	35-40
profound	<20/25		

IQ categories tell us little about the person, their abilities, and their difficulties. For example, while the dictionary definition of mild is 'gentle in effect', people with 'mild intellectual disability' are massively over-represented across most of the social measures of deprivation, exploitation and abuse.

In the early 20th century, many people with learning disabilities were confined to institutions, like lepers and vagrants of other times. By the 1950s, though, the expansion of social welfare policies and an emerging commitment to basic rights for all individuals meant that people began to question the merits of institutionalisation as an acceptable way of responding to those with learning difficulties.

Current policies and attitudes have been shaped by new ideas that emerged in the 1970s. For people with a learning difficulty, mainstreaming, deinstitutionalisation, normalisation and social role valorisation have been important shifts in society's ways of thinking about responses to people with a learning disability. Associated with these policy changes has been the growing awareness of the need to identify areas in which people with learning difficulties may require support, in order to enable them to live a lifestyle of their choice in the community. Identifying support needs is a practice that many service users and service providers find useful. Support needs are commonly categorised as:

- low support needs
  - intermittent support (with some periods of intense support to develop skills and learning)
- medium support needs
  - consistent need for support
- high support needs
  - constant, high intensity support provided across many environments.

Unfortunately there is a tendency to equate low support needs with 'mild' intellectual disability, medium support needs with moderate level of disability and high support needs with severe or profound level of disability. Recent market and managerialist innovations in delivery of disability services have reinforced such errors. In practice, the level of support needed does not neatly equate with IQ level.

People with a learning difficulty may need support in many areas, for example, communication, independent living, community access, safety, decision making and choice, employment, health and leisure.

Even with these supports, people with learning difficulty remain one of the most socially disadvantaged groups in our society.

# AS PEOPLE WHO EXPERIENCE SOCIAL DISADVANTAGE

Recent studies have documented the over-representation of people with learning difficulties in many areas of social disadvantage: homelessness, psychiatric disability, the criminal justice system, unemployment and health problems.

## **Homelessness**

In Australia, The Human Rights and Equal Opportunity Commission Report on Homeless Children (1989), the Burdekin report identified young people with an intellectual difficulty as part of the young homeless population. The young people with intellectual disability were reported as being particularly vulnerable and at great risk of exploitation.

Recent studies and papers have confirmed the findings of the Burdekin report. These studies include those of Difford, Marshall and Rose (1991), O'Connor and Carter (1992), Spencer and Ray (1992), Lindsay (1993), Paterson and Hunter (1993), Underwood, Jackson and Lee (1993), Coleman (1994), O'Connor and Coleman (1995), and Price-Kelly and Hill (1995).

These studies have variously reported:

- the over-representation of people with an intellectual disability amongst the homeless
- their vulnerability to exploitation and abuse
- their health risks (including sexual health and psychiatric health risks)
- the relationship between deinstitutionalisation and homelessness
- the difficulty the group has in accessing services
- the difficulty which agencies who work with homeless people have in responding appropriately to the needs of the group.

## **Psychiatric Disability**

The Report of the National Inquiry into the Rights of People with a Mental Illness (1993) suggested that people with an intellectual disability are more likely than the general population to have a psychiatric disability. Tonge, quoted in the Report, estimated that between 30-50% of intellectually disabled persons have a severe emotional or behavioural problem (Tonge, 1993). The report's findings are also supported in papers by Einfeld and Tonge (1992), O'Connor and Carter (1992), Paterson & Hunter (1993) and Coleman (1994).

These studies have variously reported:

- lack of appropriate services, either through mental health systems or intellectual disability services
- lack of appropriate accommodation and support services
- over-medication and inappropriate medication of people with an intellectual disability.

### **Criminal Justice System**

The Law Reform Commission of NSW Issues Paper 8 (1992:8) cited studies which indicate that people with an intellectual disability are over-represented in the criminal justice system, both as offenders and victims. Some of these studies include Hard (1986), Johnson et al (1988), Wilson (1990), NSW Women's Co-ordination Unit (1990), McCarthy (1993), McCabe and Cummins (1993), Law Reform Commission of N.S.W Report 3 (1993), and Klimecki, Jenkinson and Wilson (1994).

These studies have variously reported:

- the over-representation of people with intellectual disabilities as victims of crime
- the over-representation of people with intellectual disabilities as victims of assault
- the over-representation of people with intellectual disabilities (both male and female) as victims of sexual assault
- the over-representation of people with intellectual disabilities as victims of fraud
- the over-representation of people with intellectual disabilities in appearances before local courts
- the over-representation of people with an intellectual disability in jail
- under-reporting of crime against people with an intellectual disability
- physical and mental abuse of prisoners with an intellectual disability
- high recidivism rate amongst people with an intellectual disability.

### **Unemployment**

Ierace (1989) noted that people with an intellectual disability are likely to be affected both by unemployment and underemployment. This view is supported by data from Difford, Marshall and Rose (1991), Community Living Programme (1993), and Coleman (1994).

- Difford, Marshall and Rose (1991), in a study of forty-five unemployed homeless people with an intellectual disability, found 22% were on unemployment benefits, 76% were on sickness benefits or invalid pension, 2% received other allowances, and none were employed.
- Community Living Programme (1993) found that only three out of sixty-six people with a mild intellectual difficulty were employed.
- Coleman (1994), as part of a study of young homeless people with a learning disability, found that one person out of seventy interviewed was employed. Six had no independent income at all.

## Health Problems

Research by Hammond, Lennox, O'Connor and Davis (1995) indicated that health problems which would normally attract the attention of a parent, carer or health professional tend to be under-diagnosed or under-managed in people with intellectual disabilities. The authors note the specific health issues for people with intellectual disabilities, including:

- hearing and vision impairment (these problems remain unrecognised and unmanaged in up to 40% of people with intellectual disability);
- psychiatric disabilities (the lifetime prevalence of psychiatric disorders may be as high as 50%);
- people in this group are often over-medicated and medication regimes are not adequately reviewed;
- pain often presents in a complex way, such as disturbance of behaviour (when the behaviour is the only way of communicating the pain); also some people with intellectual disability have high pain thresholds;
- dental infections are more prevalent in people with intellectual disability;
- 20 to 30% of people with intellectual disability have epilepsy, which may go undiagnosed or inadequately managed, and people with intellectual disability are more likely to have more severe forms of epilepsy;
- nutritional problems, including obesity;
- undiagnosed constipation is often a problem for people with intellectual disabilities.

Research carried out by the New South Wales Women's Co-ordination Unit (1990) also indicated that many people who worked with people with mild and moderate intellectual disability perceived their clients to be at risk of contracting HIV, primarily because their clients lacked information concerning the virus, or had incomplete or incorrect information.

# AS PEOPLE WHO ARE INVISIBLE

Learning difficulty is sometimes referred to as a 'hidden disability' or 'invisible disability'. We suggest three reasons for that invisibility. Firstly, people with a learning difficulty put energy into hiding that they have a disability, into 'passing' as 'normal'. Secondly, many people in society exhibit 'false consciousness' about learning difficulty: when people recognise the person with a learning difficulty is somehow different, they do not usually understand the lived significance of that difference. Thirdly, what can be referred to as 'closing off' - emotional and physical detachment - may occur when people realise that someone is 'different'

## **Hiding Disability**

It is understandable that people with a learning difficulty try to hide it from others. They have experienced the name calling, the put downs, the nasty belittling terms - 'mongol', 'idiot', 'retard', 'moron', 'brain damaged', 'spastic'. Not surprisingly people try to avoid being called these names: "They said things about me behind my back, things that really hurt then, they said I had brain damage."

Society values and rewards people who are smart, clever, intelligent. When people want to fit in, they try to be like everyone else. They're not going to volunteer that they are different by, for example, using a pension concession card on public transport or letting on where they went to school. Often they will say yes to questions they don't really understand.

Edgerton (1993), in his classic study of the lives of a group of people with 'mental retardation' who had been deinstitutionalised, noted that their fundamental problem in living in the 'out' was 'passing' (that is, attempting to pass as 'normal') and 'denial' (that is, denying to others they had a disability).

*Don't tell anyone you've got a disability. Act normal. Don't let too much out. If you let too much out then they'll judge you* (Spork 1994:14).

*Telling about it [intellectual disability] bothers me now and again* (Law Reform Commission of NSW Report 3, 1993:29).

*Sometimes I wouldn't ask for help* (NSW Law Reform Commission Report 3, 1993:29).

## False Consciousness

What we here call 'false consciousness' occurs when a member of the community perceives that someone with a learning difficulty is different, but is not aware of the true nature of the disability. The following illustrations are from police officers:

*[Intellectual disability, that's like.....]*

*Walking sticks...wheelchairs, they usually have a disabled label on their car.*

*Intellectual disability? Do you mean they're actually retarded?*

*Not the full quid. They're not intellectually handicapped.*

*Certainly some were what we term 'slower' than others, but I wouldn't call that as intellectual disability.*

(Brennan & Brennan, 1994)

The comments of these police officers demonstrate 'false consciousness' in regard to people with learning disability. While conscious that people were somehow different, the police were not aware of the lived significance of their disability.

## Detachment

Ralph Ellison, the African-American author, wrote The Invisible Man (1952) based on the experience of being black in the United States of America. The theme of his book was that black people were invisible to white people because white people only saw 'black', they did not see the person, did not see the human being.

It seems that a similar situation exists in relation to people with learning difficulty. When people became aware of 'difference', they become blind to the person, to the human being.

*Looking back on fifteen years of community work I realised that I had come in contact with a number of people with an intellectual disability. I wasn't conscious at the time that they had an intellectual disability. I thought of them as a bit slow, a bit different. I realise now that as soon as I thought of them as being different I started to detach emotionally, energy wise. They became less human, less real, less visible to me. I didn't really listen to what they were saying, I didn't really work to assist their understanding, my communication became a sort of pretend communication. Now it seems to me that this detachment is a common response of people in the community, professionals etc. to people with an intellectual disability (Community Living Program, 1995).*

## AS PEOPLE IN FILMS AND VIDEO

Most films provide a vehicle for us to project ourselves and our fantasies into. What is it, if anything, that is different about films which deal with someone with a learning difficulty? One of the things you notice, I think, when you work with a particular clientele, is that others, looking on, who don't know the client group personally, readily adopt positions that are either judgmental and rejecting or sentimental, infantilising and idealising.

Any fiction book or film where the characters are used primarily to teach us something arouses my instant suspicion. Once propaganda enters the scene of art, my hackles rise, whether it pads in on silken feet or crashes in, boots and all.

In the case of books and films about people with a disability, it seems to me that we are given simplified messages about members of this group. It is not so much a question of whether the stereotypes are negative or positive, but, rather, that the complexity and contradictions which are the hall-marks of people in real life have been stripped from these characters. Is that perhaps in order to ensure that they appear sufficiently different from us, the readers and viewers fortunate enough to be able to consider ourselves mainstream normal? Is it because the directors and actors are so preoccupied with presenting this kind of a person rather than this individual person?

Is it even a relevant factor that, with rare exceptions, such as "Dance me to my Song" and "House Gang", it is mainstream actors who are cast to cleverly ape the agreed hallmarks of the disability? What would happen if the roles were played by actors who genuinely lived with such a disability? "Dance me to my Song" is a film which, in my view, gained an added depth of impact and meaning from the very fact that the part of the woman with cerebral palsy was played by Heather Rose, a woman who herself suffers cerebral palsy. The writhing movements of her limbs were her own, rather than the clever result of much imitative rehearsing.

In this context, the short video, "No Less Perfect", which presents vignettes from the lives of a dozen or so young people with a learning disability, all constituents of the Community Living Program in Brisbane, Queensland, comes to mind. Surely, it is the unfeigned genuineness of the statement which is so moving when a young woman counters her wish to have a child with the detailed recollection of being told at the age of eight by "a doctor at Woodridge" that she shouldn't have children because "I wouldn't be able to look after one"; when another young woman who actually has a child ruefully recounts having "stuffed up once" by mistakenly treating a rash she noticed on her nephew's "little manhood" with 'Deep Heat'; when a quietly spoken man, asked why he left school when he did, responds simply, "Bullying. I couldn't take it any more"; and another having been

taunted on the train, ruminates briefly on whether he'll "just grab his throat, rip it out and smash him one up against the train," or just put the incident behind him and ignore it; or when a young woman recounts having explained in her careful way to those who teased her and threw food at her on the school bus, demanding that she and the other Special School kids help them with their homework, that the reason she couldn't was "cos we've got more learning difficulties than you have."

Such glimpses of the lives of these individuals, with their dilemmas and contradictory elements, make up a memorable brief documentary that shares none of the difficulties observed in films where the characters appear to be contrived to somehow represent such people in general, to serve as a vehicle for someone's views - maybe even our own - of the place of such people in the world.

But does this mean that only a documentary can get it right? With this question in mind, it is perhaps worth looking in some detail at a number of the better known commercial films where the central character has a learning difficulty.

"Of Mice and Men" has always struck me as a great title, ever since I devoured Steinbeck's novel of that name as a young teenager. The story, too, is captivating, and this has led to the making of several films based on the book.

George and Lenni are a pair of itinerant farm workers. The story opens with a chase as the two men flee on foot an angry mob on horseback. Lenni, with his great strength and bulk, and his liking for "soft things" is being pursued for having tried to touch a woman. George serves as his protector in this chase and in many other scenes.

Singing Lenni's praises to their next boss, George says "You just tell Lenni what to do and he'll do it," adding to the foreman later, "He ain't no cuckoo. He's dumb, but he ain't crazy". Slim, the foreman, sums up his own impression of Lenni, saying, "He's just like a big kid, ain't he?" to which George responds, "Yeah. Ain't no more harm in him than a kid, neither - except he's so strong." Slim observes in this conversation that he's "a nice fella" and counters George's "Ain't got sense enough to take care of hisself" with "Don't need no sense to be a nice fella." George's comment is that "He gets in trouble a lot on account of he's so dumb."

The theme of what danger might it hold for someone to be "dumb" in the colloquial sense and "strong as a bull" has already been raised. We have seen George order Lenni to throw away a dead mouse he pulls out of his pocket to stroke, telling Lenni that he can't have any more mice because he has been "petting them too hard". We have seen Lenni lift a loaded cart, to the wonderment of other workers. In the course of the story, we will realise that the fate of the pup one of the workers gives to Lenni is to be petted too hard, foreshadowing the fate of the bored and lonely woman (wife of the boss's son) who later

invites him to feel her soft hair. After this tragedy, George ruefully observes to Slim, "I shoulda knowed. I guess someplace in the back of my head I always did."

The issue of the potential for violence runs throughout the story. It was there when George finally gave the order "Get him!" to Lenni after the meanspirited son of the boss had been goading and taunting him. The man's hand is crushed, and no-one, not even George, can stop this process once Lenni has started. It is as if some inexorable force has been unleashed, and we are given views of the glazed eyes and distorted face of Lenni, the big kid with no sense who was dumb but not crazy. By the time we get to the climactic progression from stroking the softness of a woman's hair to crushing the life out of her, the reader and viewer may be struggling with the same realisation George faces after the event, that on some level, we "shoulda knowed", we "always did."

In many ways, this presentation of Lenni's life, with its considerable limitations and its few certainties is every bit as gripping as the vignettes of the documentary mentioned above. Being a more complete document, in fact an entire film based on a whole novel, its scope and its impact is of course far greater. And yet, on reflection, what do we think of the way Lenni's capacity for unrestrainable violence is presented? Haven't we perhaps been lured into the territory of the mythology about "these kind of people"?

Other films in which we are treated to the glazed eyes and crazed facial expression include "The Other Sister", where Carla's boyfriend Daniel, "the retard", gets drunk and runs amok at her sister's engagement party. The film-maker chooses to accompany this scene of out-of-control behaviour with the sweet strains of "Sleep in heavenly peace." Is this irony? In "Of Mice and Men", it is "Abide with me" that surges around the lone Lenni.

"Nell" tells the story of an adolescent girl discovered living alone in a primitive isolated cottage after the death of her reclusive mother and of the attempts of two people, a doctor and a psychologist, to reach into her world. The visiting doctor, notified of the death by the sheriff, finds the girl hidden away, sobbing, and is then attacked by her with primitive ferocity, Nell showing the same over-the-top strength that she later displays when she is institutionalised at the insistence of the psychologist for assessment.

This film presents Nell as embodying extremes of behaviour from the madness of the fighting beast to the grace of the innocent, dancing and swimming alone near her cottage, followed by the naive foolishness of the innocent being prevailed upon to undress in a pool-room into which she has strayed. Then there is the mystique of the mutually empathic and soothing responses displayed by Nell and the sheriff's wife, a woman who is portrayed as mentally ill. The sheriff, in attending to his decompensating wife in an earlier scene, had imparted some of his own facile philosophy to the doctor, explaining, "Everyone

who cares for some-one has an ulterior motive, even Mother Theresa." We have surely been moving through the territory of stereotypes here.

The romanticism of the film's approach to its subject reaches its peak in the court-room scene where Nell's future is to be decided. Having been withdrawn and autistic throughout the formal assessment period which precedes this hearing, Nell suddenly uses language to communicate for the first time with her two carer/researchers and the rest of the court-room. She delivers what is presented as her profound and heartfelt observation of the society into which she has been thrust, commenting on the fear shown by people generally, and the fact that they don't look into each other's eyes, concluding with an exhortation that there is no need to be afraid. Her special qualities of awareness have been hinted at earlier in the preceding scene, when the doctor and psychologist, brought together by their involvement with Nell, finally start a courtship by moving their hands over each other's faces in wonderment, exactly as Nell had done to them. The message seems to be that we have much to learn from an innocent such as Nell. No doubt we do, but it would be easier if it was presented in a less sentimental and self-indulgent form.

In the farcical scene at the end of Carla's sister's wedding, in a conversation conducted under garden sprinklers between Carla and her mother in their wedding attire, we learn that Carla, unlike her mother and the sister who is the bride that day, will include the lesbian partner of her other sister in the wedding she and Daniel are planning. And amidst the joyous screams and laughter of that wedding (fitted in as Carla says between another wedding and a funeral) we can see that the rigid, tense, opinionated mother we have observed throughout has suddenly been able to learn acceptance from Carla. Having earlier insisted to Carla that she "can do better" than marry Daniel, the mother on the wedding day not only takes Daniel to her heart, but her other daughter's lesbian partner as well. Carla will live happily ever after, and her mother has suddenly been enabled to abandon the judgmental views of a life-time.

Carla has asserted to her mother that she can't "do better" because she herself is not "better" and won't become better at tennis or anything else, no matter how long she waits. "But, " she continues, "I can do some things very well, I can love," and in response to her mother's anxious "Who will take care of you?" replies serenely, "We can take care of each other." Carla's clarity about herself here is reminiscent of several of the young people in "No Less Perfect". The very simplicity of her statements is telling, lacking as it does, the simplistic overlay so frequently superimposed. In this scene, Carla is not unlike Forest Gump in the movie of the same name who says, "You have to do the best you can with what God gave you."

The interchange in which Carla asserts that she and Daniel can take care of each other seems in keeping with the relationship we have seen unfold between Carla and Daniel, including their tentative forays

into the sexual arena, and their demonstrations of understanding and acceptance of each other's feelings.

Weddings provide a focal point for film-makers, particularly perhaps about people with a disability, as our society places so much emphasis on fairy-tale romance and the fantasy of a wedding being the key to happiness ever after.

Being married is promoted as "normal". In some films, such as "Tim" it is presented as the very thing which makes a troubling or anomalous situation normal. Mary, wrestling with guilt after her long kiss with the much younger and "simple" Tim, goes to see her mentor, a teacher at a school for the "mentally retarded" and renounces all further contact with Tim, only to be assured, "There is another way : Why don't you marry him?" This she does. Earlier we have heard Tim say to her "I like you like I like my mum and dad," and "I want you to hug me." After the wedding we see Tim and Mary in the marital bed, apparently both relaxed and fulfilled, converted into a regular Hollywood bride and groom.

Tim subsequently explains to his married sister who had feared that Mary's connection with Tim was exploitative, "I'm different. I'm married." The message seems to be one of having become "normal". This is the 24 year old who had led such a protected life he even had to ask Mary to answer his question, "What's dead, what's dying?" and who thereafter was able to explain to his father after his mother's death, "Mary told me about dying. It's just like saying goodbye and going away." Are we to assume Mary was able to offer an equally simplistic yet comprehensive explanation of what marriage involved, or just that the qualities of marriage are so magical that it all takes care of itself?

Forest Gump believes that "Life is like a box of chocolates. You never know what you're going to get", but throughout many years he keeps his connection with childhood friend Jenny, asking her finally after one of their elusive encounters, "Why don't you love me, Jenny? I'm not a smart man, but I know what love is." This is reminiscent of Carla's assertion, "I can do some things very well. I can love." While these are both simple statements, they are not simplistic like those in "Tim" and "Nell" for instance.

Forest Gump, like Tim, is a good-looking man. On this level, we are able to identify with each of them. Forest's, however, is a more subtle story, the symbol of the feather in the air drifting between what could be chance and what could be destiny, the context of Forest's life.

While we are to believe that Forest loves Jenny, he seems to remain respectfully puzzled and loyal, accepting of the fact that she keeps him at a distance as the years go by. Is he idealised in the film portrayal with his good looks and good manners, the altruism and fidelity that accompany his good fortune? The answer surely is yes. And what of Carla's Daniel, the child-man who volunteers, "Strange things are

happening to my body," and also tells Carla, "I love you more than band music and cookie-making" - dear little person that he apparently is!

There seems to be a tendency in a number of these films to swing between idealisation and demonisation of the main characters.

Are others like Lenni demonised? Is the rage of "the other sister's" tantrum-throwing Daniel larger than life? Does the distorted facial expression maintained by Leonardo di Caprio in "What's eating Gilbert Grape?" until the last happy ending scene serve the purpose of reminding us throughout that he is different from us, not "normal" until the handsome, smiling end?

And how come Carla, the other sister, who has always had the gauche stilted walk of someone portrayed as not "normal", is able to glide down the aisle on her wedding day? And Tim of the previously stiff-walking gait is suddenly capering on the beach, helping to free Mary of her inhibitions? We can only assume the same normalising magic we have seen elsewhere is at work on them all.

Are we encouraged to classify and categorise the key characters according to whether they manifest the brutish strength of the beast, once aroused, or the biddable charm of the innocent "big kid" while in tamed mode? Are we supposed to believe that these two extremes co-exist within the one person, emerging unpredictably as with Lenni and Nell?

Sometimes the support characters are presented in sanctified form, as, for example, the father of Tim, and the teacher whom Mary seeks out after watching a program on his school. Standing at the school-teacher's desk after their first meeting, these two literally have the following exchange:

"I'd like you to meet Tim"  
"I'd like to meet him too"  
"He'd like to meet you."

And I've already mentioned the teacher's solution to Mary's problem when they next meet.

Sometimes it may be the lead characters themselves into whom the idealised attributes are poured. Nell's capacity to see into the nature of society's limitations and then pronounce that there is no need for anyone to be afraid has already received comment. Then there is Carla's sense of justice, making her stick up for Daniel and his right to a place in the queue before she has even met him. Similarly, when she is duped into having half her face made up by an advertising gimmick, her embarrassment does not prevent her from delivering a fluent homily on the subject of justice and fairness.

Lenni, having grown up in the racist society of the time, is still portrayed as untainted by the stereotyping attitudes around him, leading him to ask Crooks, the abused black rouseabout, "Why ain't

you wanted?" He then ponders the answer, "Because I'm black," from one who also experiences the rejection he knows as one of society's outcasts. While it is a moment of self-communion, it has for me the same flavour of falsity as when we are expected to believe Tim has gone through life totally oblivious of the fact of death. Not that Lenni's fellow feeling for Crooks, another outcast, is out of place, but that he would need to ask the question.

Inevitably, some of the person's individuality recedes from our awareness as the vehicle lumbers in for the purpose of raising our consciousness of certain social issues such as the oppression, isolation and rejection experienced by many members of minority groups. With this intrusion, some of the grip of authenticity is lost.

So, if the problems of this genre include oversimplifying and preaching, stereotyping, demonising and idealising, just exactly what function do such films serve for their makers and viewers?

Could it be that people with a learning disability readily become a focus for the fantasies of others? Thus: let's have them weirdly grotesque/let's have them intuitively and profoundly insightful; let's have them clumsy and gauche/ let's have them unbelievably graceful when unobserved; let's have them sexually rapacious/let's have them unable to distinguish between the stirrings of sexual desire, the hug of a parent and the fun of making cookies. Let's be humble: let's have them marry like normal people, let's have them teach us in our intelligent ignorance what they in their dumb sensitive wisdom understand. Let's feel restored as we close the book, come out of the cinema or rewind the video.

After such a cynical-sounding summing up, the reader is surely entitled to ask, well, just what did you want from these films?

Actually, I believe what is missing is exactly what was being addressed years ago when terminology was clarified so that one avoided the depersonalising nature of the old term, "disabled person", or worse, "the disabled" and acknowledged the richness of an individual life by rather choosing to use the term, "person with a disability."

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## AS PEOPLE IN STRUGGLE

When ex-Prime Minister Fraser told us that “life wasn’t meant to be easy”, he was saying that for all of us life has significant points of struggle. Most of us struggle to grow from a dependent child to an interdependent adult, to establish identity, to develop competence, to establish a career, to develop relationships, to gain material security, to deal with fears, to face illness, to face ageing, to deal with sorrow and pain. While these struggles are common human experiences, they vary in intensity from individual to individual, and from group to group. For a person who is black, or migrant, or poor, the struggles will be the same as and different to those of people who are white, Australian born or wealthy.

Smith (1969) referred to a ‘competent self’ as having the following characteristics: feelings of self-respect and self-esteem, a belief that the self is causally important, a general sense of efficacy or potency, an attitude of hope and optimism, and a behavioural orientation characterised by activity and initiative.

For many people with a learning difficulty, these characteristics of a competent self are hard won. Throughout their lives people with a learning difficulty are told both directly and indirectly that they are failures. The messages come from over-protective others, from peers or from people in large systems, such as the education system. It is little wonder that many people with a learning difficulty have to battle feelings of low self-esteem, lack of confidence, and lack of potency.

- *I was used to feeling a real jerk (Brown et al, 1990:68).*
- *[I] felt helpless and dumb (Ray, 1991:174).*
- *It did not feel too good to be told that you are not going to be as good as everybody else (Spork, 1994:12).*
- *I have a disability. I can’t accept it. I can’t deal with it (Spork, 1994:12).*
- *I feel that I’m worth nothing and can’t think (Spork, 1994:12).*
- *And so it’s, yeh, y’know, it’s not always easy to cope with (Spork, 1994:13)..*

For people with learning difficulties, the struggle to be your own person and make your own decisions - the struggle to be potent, to feel hope and optimism - is difficult. Compounding the struggle is the social disadvantage people experience. Poverty, unemployment, illiteracy, homelessness, being victims of crime (particularly fraud, assault and sexual assault) are additional burdens to bear, which is why people with learning difficulties are over-represented in the mental health system.

Between the micro level of low self-esteem and the macro level of social disadvantage, there is also the mezzanine level of negotiating the everyday. People with a learning difficulty struggle everyday to understand what is going on around them, to understand what people are saying, to make themselves understood and, above all, to not appear different. However, people can and do triumph over their difficulties, even if only partially.

- *I learned to think differently about myself and my situation.*
- *I was starting to feel better about myself.*
- *I'm a bit more positive about life ....feel better about myself and more confident.*
- *[I have] the ability to look after myself and take responsibility for my actions.*

*(Brown et al, 1990:75-77)*

- *[I] feel good inside.*
- *[I'm] happy most days.*

*(Ray, 1991:175)*

For workers, not only is it important to be aware of the complex struggles that people face, but also to believe, with them, that they can prevail.



## **AS PEOPLE WHO ARE STRANGERS IN THEIR OWN LAND**

The Gulliver Exercise offers us a way of experiencing what it is like to be a person with a learning difficulty. Community Living Program developed Gulliver as a way of working with a variety of groups to help them get inside the experience of people with learning difficulties, people who are very much strangers in their own land.

As an educational tool, Gulliver has been a success, despite reservations about portraying people with learning difficulties as victims and underemphasising their capacities. People who do the exercise say that it reminds them of living in other cultures where English is not the spoken language. They identify strongly with the experience of Gulliver, because it gives them increased insight into what things might be like for a person with learning difficulties.

The Gulliver Exercise is very simple. Ask people to relax and close their eyes. Talk about the original Gulliver. Ask them to imagine themselves as a present day Gulliver. Read out the exercise slowly. Debrief the exercise by asking: How did you feel as Gulliver? What things did you find difficult to do? What disadvantage did you experience?

## **GULLIVER EXERCISE**

**I invite you to take a voyage of imagination.**

**Imagine yourself as a modern day Gulliver.**

**You are thrown out of your own culture into a different culture, to live with a different race of people.**

**Physically you are like these people, but you are not quite up to their beauty images: you are not as agile or well coordinated as they are.**

**You speak their language, English, but it has developed differently: it is more complicated; they use very big words, and they speak very fast. Most times you have difficulty understanding 50% - 70% of what they say. You feel exasperated, anxious, angry, stupid at not knowing what is going on. Lots of times, you pretend to know.**

**Their written communication is even more difficult: they have developed a new written communication that you find very difficult. You understand only 20% to 40% of it. You cannot understand their newspapers, pamphlets, forms etc.**

**They have also developed a different money system. It's very complicated. You hope that if you give them some of their money, they will give you things of proper value, but you have no way of knowing that they do.**

**Their times, dates etc are also very different. It is difficult to learn, and sometimes you still get muddled.**

**You find it difficult to get around. They live in a huge city. They ride personal transporters that cost a lot to buy and are difficult to get a licence for. There are a few public transport systems that are simple to use, but only a few.**

**You can't get a job in their work places. This means you are poor - you have poor housing, clothes and food, and you are also bored.**

**People often get exasperated with you. They get angry at you and they end up doing things for you.**

**It feels really good when some of these people seem to want to be friends with you. You are ready to give your money to them, and go along with things they want to do.**

**One of these friends forces themselves on you sexually. You are confused about whether this is affection, and the way they do things in this place. If it isn't, you don't know whom you could complain to or how.**

**It is very stressful living in this society - not understanding what is going on, trying to do the right thing, trying not to appear stupid, not understanding the messages.**

**Sometimes it's too hard: you allow yourself to be childish and irrational, and sometimes you feel like you are going mad.**

**(O'Connor, 1994)**

## **PEOPLE WITH INTELLECTUAL / LEARNING DIFFICULTY JOIN AND RAISE THEIR VOICE TO RECONSTRUCT NORMAL. NORMAL IS EVERYONE**

What you have read so far paints a picture of the complex myriad of dimensions that together create an alarming potential for disenfranchisement in the lives of people with intellectual/learning difficulties.

When people speak of the manifestations of disenfranchisement, they speak of difficulties in reading and understanding, of being put down, of being bullied and ripped off, of being ill, anxious, shy, of not feeling equal or good enough, of feeling bored, broke and lonely.

When people gather and share their stories of being called stupid and dumb, of being physically, sexually or emotionally exploited, of not understanding information, not 'getting' what others mean, of being excluded paradoxically an energy of hope and possibility develops as people sense they are not alone, that they are ok, not to blame and have a common desire to challenge and change those things that inhibit the actualisation of their real selves.

*You can't express yourself like an individual because there is a norm out there that you've got to go by the norm. I just can't understand that. (Lorelle, No Less Perfect video; CLP)*

*When we talk with each other, we are "able to share our pain and wisdom with others. It is nice to do this with friends who have a common goal" (Talking About Schools Group, Disability Access week nomination, 2000).*

*We're sharing these ideas with you because we've seen many people ripped off and we want to make things better for those who get ripped off, ourselves included (Standing Proud, 2000. Stop, Think, Listen mural).*

*I have a learning difficulty which means I have had to have a lot of courage and strength to get by day by day. (Standing Proud, 1999. Walk in my life for a day mural)*

As these voices gather and speak out together, they do so with pain and confusion, at times frustration and a portion of anger but mostly with spirit, strength and hope that acceptance will ensue as their voice labours, prevails and triumphs.

*Normal is everyone  
Some of us have a learning difficulty.*

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