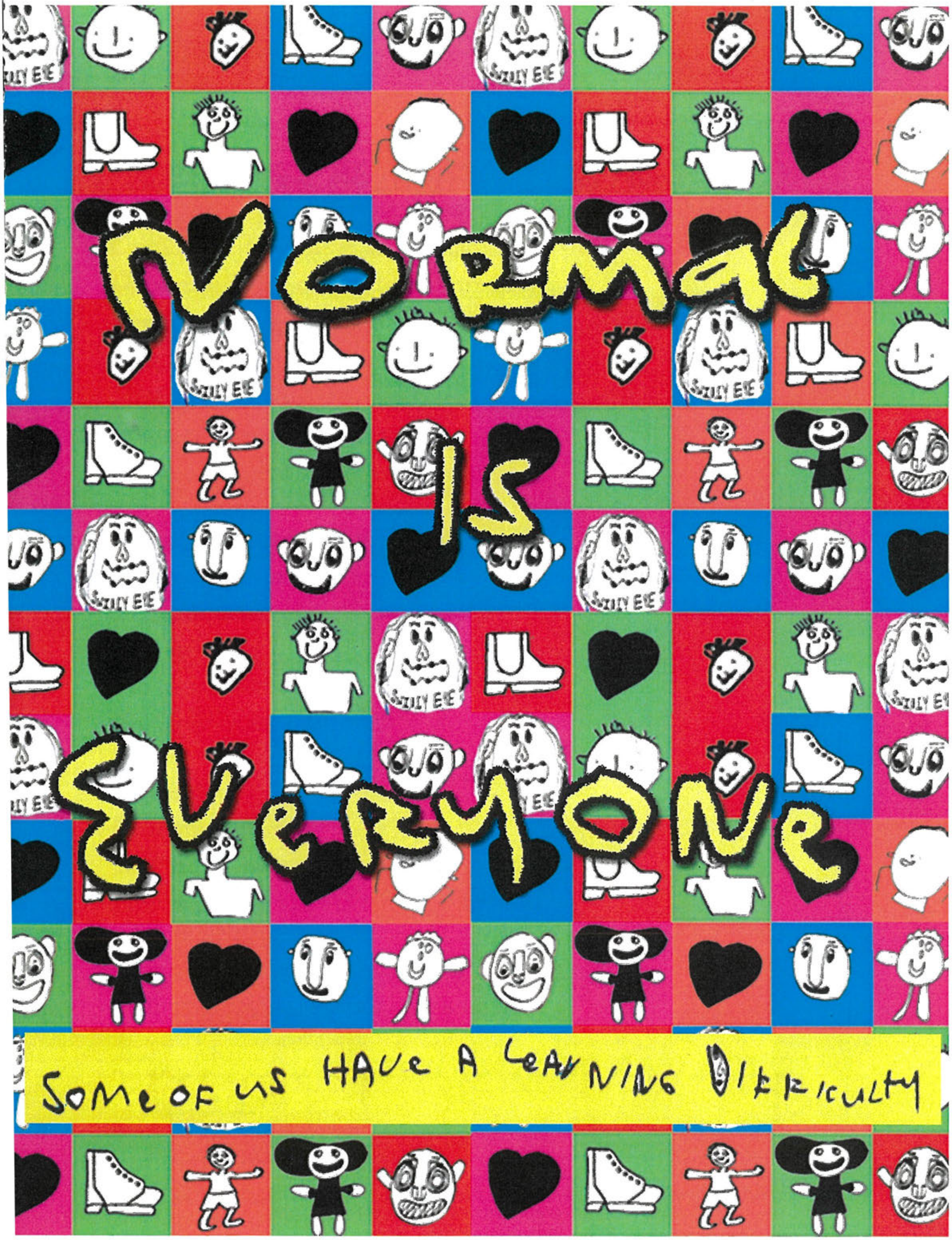

Working with People with a Learning Difficulty
A Manual in two parts - Second Edition

FEELING PROUD AND BEING PROUD

Confidence to achieve anything
Opportunity for others to understand
Understanding one another
Respect us, respect ourselves
As good as you !!
Goals can be achieved
Encouragement to have courage

Seeing the bad times through
To the good times
Relax and remember
Our strength
No less perfect
Going for good feelings

Never your fault
Or blame yourself
Be kind to yourself
Look for your friends for support
And help each other
Must be proud of yourself and other people
Everything we've done is good.

WE'RE COURAGEOUS, STRONG AND NOT TO BLAME!!

By Ian, Joseph, Katalin, Kylie, Lorelle, Paul, Shannon & Teresa – Standing Proud.

Acknowledgments

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First Edition 1998

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Helen Pavlin, Shari Walsh, John Hooper, Katalin, Shannon West, Helen Taschke, Joe Attal, Paul O'Dea, Ian Williamson, Teresa Campbell, Danny Thomas, Lorelle Smith, Natasha Shaw .

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Above all, we thank CLP constituents, to whose struggles and courage the Manual is testimony.

Morrie O'Connor, Jenny Fowkes
Community Living Program
5 Nundah St
Nundah Qld 4012.

About the Manual

We have prepared this second edition of the CLP MANUAL**, WORKING WITH PEOPLE WITH A LEARNING DIFFICULTY** to share knowledge and practice experience with colleagues. Because knowledge and practice deepen and change over time what we have written is, of course, incomplete. The Manual is not a static document - it is a collaborative and ongoing project. In this edition, we have attempted to include a greater level of the voices of people with a learning disability.

The Manual is in two Parts.

Part A – I might have a learning difficulty and I am not ever going to accept anyone calling me dumb – Definitions

This section presents material about the nature of learning difficulty and its consequences in daily life. The material has been gathered from recent research, enquiries, evaluations, and from constituents themselves.

Part B – I have a learning difficulty and I'm no different from you. I can be hurt and I can be happy – Dimensions of Practice

This section presents material drawn from the practice experience of CLP staff and of workers associated with CLP constituents. In recognising the difficulties and the achievements of the work, we suggest ways workers can engage with people with learning difficulties and support them to take charge of their lives.

At the end of Part A and Part B, there are References and Further Reading.

Please note that the term "people with a learning difficulty" is a preferred self-description of CLP constituents. For convenience in the Manual, we sometimes simply use "people".

About Community Living Program

Community Living Program (CLP) was established in 1987, initially under the auspice of the Commonwealth Rehabilitation Service. In 1989, a group of constituents, parents and others, previously known as Friends of CLP, incorporated as the Community Living Program Inc. and took on the formal auspice. In 1995 the organisational name became Community Living Association Inc. and C.L.P. became a service within C.L.A. Inc.

The Mission Statement of CLP is:

Community Living Program is a service which works developmentally with people with a learning / intellectual disability to enable them to achieve their maximum potential as members of society.

Community Living Program offers:

- an environmental context (or structures) in which people can take control of their own lives.

  Those environmental contexts include people's place of residence, self help groups, the wider community and participation in management of the organisation.

- a way of working which enables people to take control of their own lives (process)

  This includes building a working relationship, `unconditional positive regard', focusing on abilities and strengths, working at people's pace, utilising experiential learning processes, giving lots of positive feedback, enabling people to make decisions for themselves, enabling people to do things for themselves, enabling people to control resources.

- a holistic approach ie to work with the person in family, community and societal context. Some important areas of work may be around themes such as connectedness, physical and psychological well being, resources, personal meaning and meaningful use of time, and security and safety.

- CLP accepts the need for people to develop their competencies across a range of skill areas if they are to successfully become independent. Skill areas include:
  - practical skills (e.g. handling money, using phone etc.)
  - other person skills (e.g. making friends, negotiating)
  - self skills (e.g. delaying gratification, feeling good about self, handling frustration).

The main objective of CLP is:

To enable people with learning / intellectual disabilities to attain independent adult status, to take up valued roles and live independently in the community by assisting people with learning / intellectual disabilities to develop independent living skills and, as importantly, develop and exercise autonomy and decision making control over their lives.

Part A

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

Definitions

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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 poofters, 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.

******

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, infantalising 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 disenfrancisement 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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Part B
“I have a learning difficulty and I’m no different from you. I can be hurt and I can be happy”.

Dimensions of Practice:

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FIRST AND FOREMOST AN INDIVIDUAL

Somewhere in training I must have been taught about mental defect, but I obviously had no idea about what this disability meant to the person with it. I thought it was a sort of global state which reduced every level of the person and left an amenable vegetable with few feelings and no fantasy - a person one managed rather than related to. June showed me I was wrong. Far from managing her, at first she managed me. She was used to getting what she wanted and quickly became angry and frustrated if I thwarted her. Like any other person she began to do what I wanted to please me and she was acutely aware of any withdrawal of affection. She had strong feelings and a vivid, quite violent fantasy life which could sometimes take over. I often took June with me when I had to visit country police stations. I found I could not leave her in the car for fear she might wander, but if I locked her in she got angry and swore at passersby. Most of the time she sat like a lamb but sometimes when I was in the middle of a discussion with the station sergeant June‟s deep voice would boom out‟ “Are you going to bed with that man?” or “Quick shoot him, cut his legs off, hang him etc.”, much to the amusement of the constables and my discomfiture. So June taught me that she was first and foremost an individual, the classification “Mongol” told me little about her unique way of being in the world, and that some parts of her were as hard to know and others as easy to know as is the case with any person.

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BUILDING RELATIONSHIPS

For many people, life experiences have been of other people taking control and doing things for them. The implicit message is that they are not capable of understanding information, of making decisions and choices, or of following up decisions.

When workers assume a strength-based approach when having contact with person with a learning difficulty, the implicit message is quite the opposite. This approach bases itself in the belief that people have the expertise and ability to control the directions their life takes, while acknowledging that additional and ongoing support is often required for this expertise and ability to be realised.

The workers role involves the following:

a) assisting the person to understand their own sense of what is right, how their intuition works, what the best thing is for them, taking considerations of those around them.
The idea of wisdom is useful here. When people are challenged on what they think the wisest thing to do is, this concept sidesteps the negative ideas people associate with their intelligence and how smart they are. People seem to connect with the „wise person inside‟.

b) Offering people the option of being "in charge" of their lives and life directions – not entirely relying on others to make changes happen. People with learning / intellectual difficulty are serious in their desire not to be passive and powerless and keen to discuss what it would take for them to experience being in charge and responsible for various parts of their life even in seemingly micro details like knowing if the right change was received from a grocery store.

c) Resourcing the person
   I. with information or support to find out information.
   II. to assist their unique understanding of their situation
   III. with conversation to trace the potential consequences of direction a person is choosing and with challenges where risks are unsafe
   IV. in practical and material ways. This may mean worker at times „doing for‟ the person - though workers need to be vigilant about their motivation and the use it has for the person if the worker „does for‟ the person with intellectual / learning difficulty.
   V. to develop a plan

d) supporting the person‟s development of their own self-awareness "What do you think that says about you?‟

“What did you learn about yourself through all this?‟

e) being available for support when person is taking steps and may require a workers physical presence for encouragement. When people have the skills and abilities to handle a situation, gently challenge that this is an area the person doesn‟t need a workers physical presence for.

f) celebrate and congratulate people on achievements.

g) by informing people of the policy regarding confidentiality, grievance and privacy boundaries.

h) when working with a person with learning/intellectual difficulty whose family is a key support - approaching the work with the idea that the organisations support can complement the family‟s support offering strengths and resources to complement and supplement existing family strengths.

These same principles apply to one-off or short term work with a person with learning/intellectual difficulty - acceptance of the person, respect for their perceptions, hopes and commitment, and to support their ability to change their situation. For many people with a learning/intellectual difficulty, a relationship built on these principles is a new and powerful experience.

COMMUNICATING AND HAVING SATISFYING CONVERSATIONS

People with learning / intellectual difficulty try hard in many situations to be respectfully understood by others. Often, though, experiences of conversations are depowering to them. Communicating with satisfying results is an essential part of our human experience. Common are peoples stories about not being understood and not being able to understand in many settings – at the doctors, at Centrelink, at their workplace, with family, with door to door salespeople, at the bank, at the shops, chemist, cafes, with CLP workers, with forms and letters. A focus group for this section said they handled these situations by:

- Agreeing to something, even with little understanding about what was being agreed. Door to door salespeople gaining customers for mobile phone and other contracts are currently an increasing example of this.
- Telling the other person what the person with learning / intellectual difficulty guessed they wanted to hear. " When you try to listen to staff, you ask yourself What‟s this question all about? You really want them to explain it better".
- Pretending to understand
- Being vigilant about not hurting other persons feelings
- Being too scared and nervous to let on to the other person that they haven‟t understood
- Getting sick and giving up because it is too hard to try
- "Even if I totally disagree, I don‟t feel I can ever say it"

People with learning difficulty often prepare for conversations with others, but find it hard to carry out or to adapt to a direction of conversation they hadn‟t prepared for. "You go over it in your head, but you don‟t let others know because you‟re too scared" The result of unsatisfying conversation with others is often an extreme emotional reaction. People with learning difficulty feel like they are to blame and not smart enough to handle situations. As a result they get annoyed and frustrated with themselves. This type of experience over and over again contributes to the physical and emotional anxiety commonly seen among people with learning / intellectual difficulty – "I get a sore stomach".

What are the key elements to ensure good communication with anyone? When this question was put to a focus group of CLP constituents there was consensus that for people with learning / intellectual difficulty to be confident and not to be scared when talking to another, the onus is on the other person who needs to

a) focus on what is being said
b) want to hear what is being said

c) want to understand what person with learning / intellectual difficulty is saying
d) look at person with learning / intellectual difficulty

The barriers to satisfying communication for the person with learning/intellectual difficulty are when people mumble, don‟t make eye contact, talk too fast on complicated matters, when something requires action straight away, and when lots of questions are asked without the person knowing what the questions are about or why they are important. The “doctor asks lots of questions. I don‟t understand about depression, anxiety and medication”. Other barriers include information that is literacy dependant, when people talk to the support worker instead of person with learning / intellectual difficulty and treating me with uncertainty “when I say I have a learning difficulty or am on the Disability Support Pension”.

I feel upset when people seem too busy for me

I feel distressed when I don‟t get any support

I feel unimportant when people don‟t try to understand me and how I see things.

I feel hurt when people go too quick.

I wouldn‟t go back there when people use words I don‟t understand.

I get confused when people don‟t look at me and make eye contact.

Spork 1994

There are at least six ways to enhance communication with a person with a learning difficulty:

- **time and pace communication** at a rate comfortable for the person;
- **check understanding** so that everyone has the same understanding;
- **ask questions** in a way that encourages maximum participation in the conversation;
- **support a person to communicate with others if they are finding a conversation difficult;**
- **present information visually as well as verbally**;
- **use role play and video techniques** to prepare for situations which may involve difficulties.

Time and Pace Communication

Work with a person with a learning difficulty often requires a different pace than does similar work with a person without a disability. Often the pace is slower.

When people indicate that a conversation is difficult to understand workers can:

- plan longer meeting times or, if the person has difficulty concentrating for long periods, make shorter appointments and go over material repeatedly during a number of appointments;
- determine person‟s pace and adapt own pace accordingly;
- find a conversation pace that is appropriate (while people may find it difficult to follow quick speech, they may also find deliberately slow speech humiliating);
- be clear with person about time boundaries for meetings, and negotiate with person length of time for meeting and purpose of meeting;
- be patient and ensure people comprehend - people with a learning difficulty may appear to understand, even adopt a fast pace themselves, and so, in an effort to “pass”, mask their disability.

Check Understanding

Language is replete with jargon, slang and words which have multiple meanings. We have been socialised to use language this way, often as a type of „verbal shorthand‟. Because people with a learning difficulty find it difficult to sort through some of the meanings of words and phrases, it is vital to check understanding. In an attempt to minimise the impact of their difference, which they may feel to be stigmatising, people may use many techniques in conversation to mask their disability. These techniques include:

- saying they understand information;
- agreeing with worker‟s statements in an effort to please a worker;
- repeating a worker‟s words and appearing to restate conversation, but without understanding content and meaning.

To gauge understanding, workers can:

- ensure people genuinely mean „yes‟ or „no‟, and don‟t give what they guess to be the „right‟ answer. An awareness on the worker‟s part that people may do this enables the worker to identify in most instances if a person is giving an answer to please or to appear competent. A response on the workers part can be, “Is that what you really think?” or “Don‟t say what you think I want to hear. I want to know your ideas.”

- ask people to say in their own words what they have understood of a recent communication, for example:

  “What sort of things have we just talked about?”
  “Tell me in your own words what we have talked about ?”
  “When you go home tonight, and your mother/partner/friend asks you about our meeting, how will you tell them what we‟ve talked about?”

- check that people understand the broad purpose of the communication, for example:

  “Am I making sense ? ”
  “Why do you think we are talking about this?”
  “Why do you think I asked this question?”
  “How will this chat be useful?”

- allow time for the person to answer, and understand how people use silences. Avoid the temptation to fill in silences with your own words.

- acknowledge that what the conversation is about is hard, if it is. Ask the person if they feel like trying hard for the rest of the conversation.

- if misunderstanding occurs, ask the person where in the conversation things became difficult to understand, for example:

  “What parts of what I said made sense?”
  “What parts of what I said were hard to understand?”

- speak in concrete terms, in language relevant and recognisable to the person. If a person is working out what to do in response to a situation happening for them a worker could support by guiding the person through the process with this sort of questioning:

  “Have you ever been in a situation like this before?”
  “What did you do?”
  “Has anyone in your family/any of your friends/anyone on TV been in a situation like this before?”
  “What was it like for them?”
  “Is it similar for you?”
  “What did they do?”
  “Is it different for you?”
  “What do you think about what they did?”
  “Would you do things the same or differently?”
  “How?”

- Offer opportunities for the person to ask questions, for example:

“Do you have any questions?”
“Is there other information you need?”
“Are there other things you want to ask about?”
“Is there anything else?”

Ask Questions

There are some simple guidelines here that can assist people understand questions:

- use open ended questions in preference to closed questions (eg “What happened then?”);
- use direct questions when obtaining information (eg “Did you do it?”);
- use sparingly loaded questions and statements that suggest your opinions. People are very aware of what others want them to think/feel/answer and will respond accordingly.
- be sensitive to difficulties with concept of time and connect questions to other events in the person‟s life; for example, instead of “How old were you when ....?”, try “What grade were you in at school?” or “Where were you living when ....?”
- point out any inconsistency in answers and seek clarification eg “I‟m a bit confused, you said before .... and then you said something different - can you help me understand exactly what happened/what you mean?”

Support A Person To Communicate With Others When They Are Finding A Conversation Difficult

Examples of difficult conversations may be communications with family, agencies, employers or services. Again, some basic guidelines can help:

- negotiate with person what role they want each worker to take during meeting;
- relate directly to person (not to their support worker).

Present Information Visually as well as Verbally

a. Verbally

When speaking with a person with a learning difficulty, the following guidelines are important to keep in mind:

- use clear, plain language;
- avoid abstract terms - use concrete examples and ground these examples in person‟s own experience;

- avoid complex sentences containing more than two ideas or concepts.

b. Visually

When working with a person with a learning difficulty, visual information can enhance the effectiveness of communication.

Constituents at CLP have said that “words are hard”, and that pictures plus words is the most effective form of visually depicting information and ideas.

Visual aids can be used when:

- i) conveying information;
- ii) outlining options for future plans;
- iii) processing a difficult situation and focusing on an issue (within a myriad of difficult issues);
- iv) debriefing and reviewing to consolidate and ascertain learning;
- v) planning to achieve stated goals; and
- vi) talking about feelings.

i) Conveying Information. Often, when we give information to people it is helpful to use pictures to illustrate what the information could mean for them, as in the following examples:

- When giving information about housing options, rough sketches or pictures and photos of different kinds of housing are useful.
- When giving information about contraception, pictures or actual items (as well as diagrams and descriptions of how to use them) make the information concrete.
- When giving information about the side effects of medication, diagrams are useful.
- When supporting people through court processes, drawings of court lay-out and court practices help demystify court processes.
- If a person is facing sentencing on a court process, descriptions aided by drawings could enable the person to understand more fully the potential change to their life.
- How to use ATM at banks
- When planning, putting steps on a calender assists to agree on and conceptualise time plan will take.

ii) Outlining options for future plans. Sifting through various options is part of how people plan. To ensure that each option is distinct, it helps to visually depict each option and its consequences (see Decision Making).

On many occasions at C.L.P., we have successfully used P.J.‟s story. P.J.‟s story, told through cartoons, is about a young person who lives at home with his/her parents and wants to explore independence. The story includes his/her contact with C.L.P. and C.L.P.‟s processes of sharing information with P.J. and his/her family, family meetings, individual meetings, and P.J.‟s thoughts and feelings along the way. The story ends with P.J. having enough information about C.L.P. and other types of independent living for P.J. to make a decision. How the story continues for the young person is left open: the young person may make a decision to move, to stay at home, or to delay making plans to move out. Depending on which option the young person chooses, the story then follows P.J.‟s decision and planning.

iii) Processing a difficult situation, and focusing on each issue within a myriad of issues. A difficult situation may be complex, with many different parts. To work through the situation with the person, it may be useful to split up the situation into its different parts: What happened? How did you feel? Why did you feel that way? What more do you want to do about it? What would you do differently if there was a next time? Each of these parts can be illustrated, using drawings, words, diagrams and pictures. Taking the parts one by one slows down the processing of difficulties and helps explore situations which are confusing or upsetting.

iv) Debriefing and reviewing to ascertain and consolidate learning. Another way of processing a situation is to explore what happened by using the binary concepts of „good‟ and „bad‟ and recording learning on the following chart.

a) What was good? Why?	**a) What was bad? Why?**
b)	b)
c)	c)
d)	d)

….chart can have as many lines as you need…

Through their saying what was „good‟ and „bad‟, it may become clear which parts of the person‟s experience were helpful, and which parts were unhelpful or difficult to understand. It also encourages the people to identify for themselves what worked, what would be useful to try again in different situations, and what things make situations unhelpful. These learning‟s can be applied across many new situations. To clarify what makes a situation unhelpful, people can look at “next time” and “doing differently”, and record their learning‟s, as below.

a) What would you do the same next time?	**a) What would you do differently next time?**
b)	b)
c)	c)
d)	d)

….chart can have as many lines as you need…

Naming the „same‟ and „different‟ encourages people to take some control by planning ways to respond in the future.

v) Planning to achieve stated goals. Drawing individual steps that people need to take towards goals has the benefit of breaking down a seemingly large task into achievable parts. At C.L.P. we use the Bridge Exercise for this purpose.

The Bridge Exercise enables people to understand the gap between where they are at the moment and where they want to be (their goal) in the future. Once people identify a gap between their current situation and their goal, we draw a bridge with many little steps, indicating jobs to do between now and then. People then brainstorm the jobs they need to do and write them on a card. We place the cards in chronological order. For example, the steps may include looking at housing options in the initial stages of work, picking up the key to new accommodation, connecting the phone at the point of moving, and so on. At the end of the exercise, the person has a stack of cards, each with a job that needs to be done before the goal is achieved, and can chose which ones he or she needs support to do.

vi) Talking about feelings. Discussing emotions can be difficult. People may have access to only a small number of words to describe how they feel, because nuances of feelings (eg „sad‟ or „upset‟) are abstract and difficult to name. It is hard to connect an internal experience of emotions with a word or words to communicate that feeling. Also, people sometimes are hesitant to name emotions, such as anger or sadness, because they don‟t feel they are able (or have the right) to seek redress for their problems. People are also hesitant to name distressing feelings because they may feel they are a nuisance and an annoyance to others.

Pictures of faces showing different feelings (as below) may help ground a discussion of feeling. The faces also give people a chance to identify and externalise feelings, and focus on a feeling and talk about what caused it, how it affects them, what they would like to do to change or diminish its effects on them, or what they might need to do to sustain it. They are particularly useful for some of the emotions people find difficult to name.

☺	☹	😐
OK	**LEFT OUT**	**FRUSTRATION**

The St Lukes Strength cards, bear cards and monster cards also allow individuals and groups to discuss emotions, their causes and effects.

Use Role Play Techniques

Role playing a new situation whether it be a phone call, a meeting or an interview can help people prepare before the event, what they want to say and what questions they may be asked. A role play creates as nearly as possible the environment of a new situation, and people can practise both what they want to say as well as possible responses to anticipated questions.

People can have a variety of reactions to role plays - from people having more confidence to people being more fearful - after they have enacted a role. When CLP constituents were asked about the usefulness of role play, the responses were that role plays are “really good, helpful and useful”. Good situations to role play included doing speeches, and talking to strangers in new situations. People acknowledge that role plays can be embarrassing to do, they are good because in real situations it is easy to “feel like a complete fool because your haven‟t rehearsed. Therefore it is vital that the worker and the person debrief thoroughly afterwards, to ensure than any negative emotions are resolved.

Video

CLP also uses video equipment as a method to support people to take charge of situations where they may feel they are being exploited.

Video Feed Forward is a technique where a video is developed through deliberate scripting, filming, casting and editing to show a person acting and behaving in ways they have not yet mastered. It is hoped that watching the video can assist in behaviour change. Situations where such video work has been useful has been with women handling situations with men in which they felt unsafe, people being assertive with employers, saying no to salespeople, handling difficult family situations in which conflict regularly arises, standing up to friends who put people down and feeling calm when learning how to drive. CLP has also used video in the form of creating “feeling good” videos. As one strategy in supporting people to develop an assurance and confidence in their own worth and abilities, video is created of the various facets of a persons life and their strengths are discussed by the person and others in their life. People have found the making and repeated watching of this video fun and a lot of work. It also appears that this is an effective technique alongside others when working with people when issues of their own worth and ability are a barrier to them taking charge of their lives and are affecting their own emotional and physical health.

SUPPORTING PEOPLE TO MAKE DECISIONS

Helping people make decisions has many parts: understanding that a decision needs to be made; gaining comprehensive information about different options; understanding the differences between options; exploring the possible consequences of each option; weighing up which option is most suitable. People with a learning difficulty may not be sure of where to start, and workers, in their concern and frustration, may feel tempted to take over the decision making process and tell the person what to do.

We have found that it is helpful if the worker and the person with a learning difficulty can take the following steps together:

- acknowledge and name clearly the decision to be made;
- explore all options, even those that a worker does not consider realistic. It is important that the person can consider the full range of options, both those the person suggests and those the worker may offer; so useful questions might include; "How do you think people do this?" or "What did your older brother/sister do when they were in this situation?"
- use visual aids to help sketch what each option means for the person‟s life, make sure all important information is obtained, consider and predict possible consequences, and identify steps involved in actioning each option;
- if possible, offer support for any actions involved in carrying out the decision;
- be available to talk about anything that occurs in following through the decision - reviewing, debriefing and consolidating learning are important.

Kyle wanted to move into his own place - but he was not sure where he could live or what it would be like.

At his workplace, Kyle‟s support worker gave Kyle information about an organisation where he could get support to work out what he wanted to do about moving out. Kyle rang up and made a time to talk about what he wanted to do.

When he went to the organisation, Kyle spoke of his confusion. He wanted to have his own place, but was worried about what it would mean for him. Kyle and his worker talked about what it would be like to have his own place. The worker gave examples of what it was like for other people, and Kyle spoke of his older sister‟s experiences of living in her own place. They also talked about alternatives to moving out, including staying at home and leaving things as they were, and becoming more independent while staying at home.

After Kyle had thoroughly explored each option, he decided he wanted to start learning how to become more independent at home and how to move out in six months time. So they talked about what Kyle would need to do. Kyle decided he wanted to talk to his parents and get support to budget and to learn how to cook.

When Kyle was ready, he spoke to the worker about housing options. He had worked out, with support, how much he wanted to spend on rent. The worker gave Kyle information about what options were available generally, and as well as those available in his price range and in the suburbs where he wanted to live. Kyle really liked a housing option outside the price range, so Kyle looked at his budget again to see if he could afford it. He decided he couldn‟t and, instead, chose three housing options in his preferred part of the city in his price range.

Kyle was anxious about contacting the housing organisations, so the worker supported him to work out what he wanted to say on the phone, and they practised the conversation together a few times. When Kyle received the application forms and needed support to fill them in, Kyle and the worker had two further meetings where Kyle filled in the forms. The worker helped Kyle understand some of the questions, and work out how to answer and how to spell some words.

If we take the view that people are able to make their own choices, we also need to acknowledge that they are „the experts‟ about their own situations and lives and that they have the right as well as the capacity to make their own life decisions. Supporting a person with a learning difficulty to make decisions can be time consuming but, when workers provide some structure and support, people can develop confidence in their ability to make decisions.

WORKING WITH PSYCHIATRIC DISABILITY

"The Human Rights of People with a Mental Illness Report" (1993) suggested that people with an intellectual disability are more likely than the general population to have a psychiatric disability. The authors of the Report raised a number of concerns about society"s response to people with an intellectual disability who have a mental illness. These included:

- lack of training and expertise amongst psychiatrists and mental health workers who work with people with intellectual disabilities;

- lack of services available, with people falling between services for the mentally ill and services for the intellectually disabled (both mental health and intellectual disability services can be reluctant to provide services).

Some psychiatrists believe that people with a learning difficulty are over-represented in mental health systems (Human Rights & Equal Opportunity Commission, 1993). Certainly, it is an area of confusion: the disadvantage people experience overlays all aspects of their lives, including their mental health, so that sometimes what are responses to disadvantage are confused with psychiatric disability, and sometimes what are mental health problems are seen as behavioural problems associated with a learning disability. In both cases, people can be inappropriately diagnosed and treated.

People with a learning difficulty find it difficult to appropriately access mental health services, due both to the lack of expertise of the mental health workers in working with this group and their tendency to try and divert them to intellectual disability or other systems, sometimes believing that they will not respond to treatment. It is important, therefore, to advocate for people with a learning difficulty when they come in contact with the mental health system, both in terms of their gaining admission and their gaining appropriate treatment. Wurth (1994) has noted that it is important for a psychiatrist to have a sound relationship with disability workers so that he or she can use accurate data in ongoing assessment and treatment.

> *In order to know clearly the effects of interventions, meticulous behaviour data are necessary, and obtaining these requires a close working relationship with staff. Commonly, little information is available from the patients themselves by self-report, and my*

> *observations are limited to the brief period that I spend with patients at intervals of two to four weeks* (Wurth, 1994*).*

In organisations where practice principles of self-determination and confidentiality are highly important, there are always tensions when workers see a need to move into an advocacy role. However, it is clear from practice experience that the nature of many mental health services demands such a role.

Einfeld and Tonge (1996, 108) contend that "any service that has a mission to provide care for those with „intellectual disabilities‟ needs to include the provision of mental health care within its perspective". Those who work with people with a learning difficulty need to have a working knowledge of current mental health issues and practices. Knowledge is important for three reasons:

- because of the prevalence of mental illness amongst people with a learning difficulty;

- because of the reluctance of many organisations who work with people with a learning difficulty to continue working with those who are found to have a mental illness, and

- because of the need to advocate for people within the mental health system, not to offer diagnosis, but to be conscious of what psychiatrists are doing as they go through their (often, trial and error) treatment routine.

Wurth (1994), O‟Connor and Coleman (1995), and The Human Rights of People with a Mental Illness Report (1993) all comment on the possible misuse of psychiatric medication. There are many people with a learning difficulty who are on medication but who have no idea why they are taking it.

Workers can:

- seek out doctors and psychiatrists who have an interest in the area of mental illness and learning difficulty, so that it is possible to refer people who want to check out their medication regime and support people to clarify the reasons for and schedules of their medication;

- encourage self-monitoring and self-referral, exploring with people how they can recognise the signs (danger signals) that their mental state is becoming disturbed and that it may be time to seek some help;

- recognise that bizarre behaviours may often be „logical‟ in context, especially in response to stress or post trauma, and support people to alert mental health professionals to their context;

- act quickly to advocate for people in mental health systems;
- be alert to how prone people with a learning difficulty are to anxiety and depression;
- ensure that those people who indicate that they need treatment get it (and appropriately), and those people who do not have a psychiatric disability do not get lost in mental health services;
- support people to understand what is happening emotionally for them, and their options (including, feeling safe);
- support people to persevere with ongoing therapy.
- be alert to the onset of stress, anxiety and depression
- Consider ways to develop preventative well being options and opportunities for people with a learning/intellectual difficulty.

PROMOTING MENTAL WELL BEING

In our view, people with learning / intellectual difficulties experience stress, anxiety and depression at higher levels than the general population. Furthermore, the stress that people with learning/intellectual difficulties experience is the worst and most dangerous sort of stress for physical and psychological health. It is chronic relentless stress.

For example

- Difficulty with literacy means stress over interpreting signs, letters, instructions, filling out forms etc.
- Difficulty with numeracy means stress over money, time, appointments, “Am I being ripped off?‟ etc.
- Poverty means stress over money, housing, food, transport, clothes, recreation etc
- Difficulty with comprehension means stress over not understanding, partially understanding, being expected to understand
- Difficulty with communication means stress over not being understood
- Feeling different from others means stress over self esteem
- Feeling vulnerable means stress over safety and security
- Wanting to fit in can mean stress over getting into situations you‟re not sure about
- People often experience stress over their interactions with others. A number of constituents at CLP named the origins of this stress as:
    - „being picked on‟
    - „being put down‟
    - „being sworn at‟
    - „being criticised‟
    - „something bad being said‟
    - „people don‟t want to be friends‟
    - „friends desert you‟
    - „being laughed at.‟

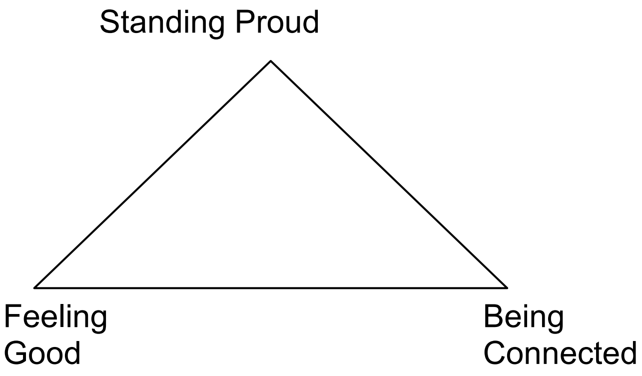
Chronic relentless stress because of feelings of lack of control over one‟s world creates further problems.

- Anxiety conditions
- Depression
- Sleep disorders
- Higher rates of stress related disease
- Addictions e.g. to fatty food as a way to relieve stress, to alcohol, tobacco, illicit drugs, spending splurges
- Higher blood pressure
- Behaviours that may bring other negative consequences e.g. anger, aggression

- Propensity to develop post traumatic stress disorder and other forms of mental illness. (in our view, people with learning/intellectual difficulties are vulnerable to post traumatic stress disorder if they experience trauma on top of a life of chronic stress and there is a high likelihood of experiencing trauma e.g. sexual assault).
- Poor physical fitness levels which further impacts on emotional health

When we have talked to constituents at CLP about responding to chronic relentless stress their suggested responses have been quite holistic:
„Don‟t take on negative stuff‟
„Believe in self‟
„Get out of the house‟
„See other people‟
„Do exercise‟
„Believe in dreams‟
„Try new things‟
„Set goals each morning and do‟
„Find other people‟
„Have friends over‟
„Spend time with family‟
„Budget and buy things so that they‟re yours‟
„Sleep/TV/video/cooking‟
„Positive self talk‟
„Not to take on blame‟
„Set small task – get it done, it takes your mind off‟
„Set goals – new things to do‟
„Don‟t stay with people who create bad feelings‟
„Think about what you have achieved‟
„Be kind go yourself‟
„Talk to someone‟
„Exercise‟
„Start something good‟
„Feeling good video‟

Therefore, we have developed a „Promoting Mental Well Being‟ response known as



The program includes a number of specific activities aimed at promoting mental well being within the overall work of CLP.

Feeling Good component is oriented towards exercise and physical activity as a stress management approach. Feeling Good focuses on exercise, physical activity and relaxation

Standing Proud component is directed as self esteem. It focuses on assisting people articulate learning disability pride. “If you don‟t have respect for a person with a learning disability, you‟ve got it wrong”. If focuses on supporting people not to self blame for exploitation done against them. It focuses on supporting people to develop strategies to deal with attempts at exploitation and it focuses on supporting people to feel positive about who they are.

Being Connected component recognises the need for social support and friendship. It focuses on developing social supports through bringing people together in the various Feeling Good and Standing Proud groups and it also is about trying to link people with other community activities.

The importance of these issues of stress, anxiety, depression have led to CLP endeavouring to act pro-actively in mental and physical well being.

Gretl’s Story

Sometimes it gets the best of me
Sometimes I have it under control.

I have felt very nervous and stressed for 2½ years now, but nervous since my childhood. I can remember my teachers trying to calm me down in school.

This has affected me in many different ways. I find it hard to sleep because of a bad dream I have. In my dream there is a bad ghost with a knife trying to kill me in bed. I get voices every day in my ears – they are a pain in the bum. They say bad things about me but I know they are not the truth. They talk lots of bullshit and tell lies. I tell them I don‟t believe them. The voices have been around for 2 or 3 weeks now. – I‟m learning how to get over them, to cope with them, to live with them. I wake up at 2.00 every morning and can‟t get back to sleep. In the morning I feel ratshit.

I feel tired and angry and I don‟t want to go out. But most of the time I go out to places – with my friends with my mum, to groups even though I‟m not 100%.

I talk to my worker at CLP about the awful feelings I have, or sometimes it might be different workers at CLP. I don‟t tell my parents because they think I am lying. I keep these feelings private from my friends.

The nervous and stress gives me headaches everyday. I get muscle pains and a sore back. My ears get blocked and I perspire. Sometimes, my heart beats fast and makes my breath fast. I get different types of stomach pain – sometimes I feel sick like vomiting, other times I feel pains like a knife in my stomach. I lose my appetite and don‟t eat a lot. I think this is caused because I don‟t get enough sleep because of the stress and nervousness.

I get angry on the shakes every day and I‟ve become very sick of them. I find it hard to carry cups and plates and I get upset and worried that they might get worse.

I have talked to many doctors with support from my CLP worker about the shakes and stressness and nervousness and it is confusing and upsetting and hard to understand. I have had lots of different tests that the doctor suggested to find out about the shakes. There are no answers at the moment. I find it hard to explain about the shakes to doctors.

The things I find most stressful are going out shopping, catching trains and buses, paying rent and bills, and food shopping especially on *pension day. Sometimes meeting my friends and going to groups is stressful but sometimes it is fun and o.k.*

Sometimes especially in groups, I get confused and my mind goes racing and it"s hard to concentrate and I find it hard to know what to say in groups. My mind goes blank and it"s hard to talk. My friends say to me "Are you all right?" and I say to them "I"m half left".

I"ve decided I don"t want to keep all this to myself because I get sick in my stomach if I do – I let other people know – I talk about these things mostly to my CLP worker, to my doctors. In between meetings or at night in my unit, I write letters explaining how I feel.

I"ve got all of this stuff happening in my life at the moment and it is taking a very long time to get over it. I say to myself it is all my fault, I"m hopeless, I"m useless. I get so frustrated with all the bad feelings. BUT I SAY TO MYSELF – I"M NOT HOPELESS AND IT IS NOT MY FAULT AND I"M NOT USELESS.

I do many things to make my life a good one and to help me live with it. I am a good netball player – I have joined a netball team as well as tried to start up my own team. I bought a bird – he talks to me and says hello. At night time when I go to bed he says good night to me and I say to him „you look adorable". I have some favourite movies – especially the Sound of Music and Titanic – I buy copies of my favourite movies for myself. I buy CD"s also of music that I like and play them a lot.

I also have a video called The Relax Video – I watch it on weekends. I have made a video called The Feeling Good video. It has me talking about good things about myself and what I do. I had a party for my 25th birthday. It was fun – it is on my video. I watch it every day.

I do a things to do list everyday.

I have 2 sets of cards that I have made. One set helps me to explain how I feel. The second set I carry with me. It reminds me I am strong / I am brave / I am a good sport / I am a good artist. When I go out I put it on my lap and read it quietly to myself. It takes my mind off the bad things.

I also used oils in an oil burner. I"ve also had a few massages and I bought stress balls and made a rice ball.

I go out with my mum every two weeks.

I have also taken care of myself by trying to find answers about what I am experiencing. I have gone to my GP, a psychiatrist, a neurophysician and had an MRI.

I am a member of the Talking About Schools group. We meet every two weeks and do presentations at schools and conferences. I"m also a member of Rebels With Attitude group. I go to a women"s exercise group and to Standing Proud.

I hope to get over all of these awful feelings. I"m learning all the time that I can get through the hard times and that time goes quickly. I have discovered that I am a very strong and brave person to get on better with things.

That is true.

The end.

Note: Gretl was the name chosen for the title of this piece by it"s author, after her favourite character in the Sound of Music.

SUPPORTING PEOPLE TO SPEAK OUT AND HAVE A SAY

People with learning difficulties experience many forms of discrimination. There are disability advocacy organisations who take up discrimination issues with and on behalf of people with learning disabilities. People can also choose with support, to „stick up for themselves‟ and to self-advocate.

As individuals, it is difficult for anyone to self-advocate on their own and, because self-advocacy requires skilled communication and some measure of self-esteem, it presents real difficulties for people with learning difficulties. As well, people with learning difficulties may not be able to name something that has happened to them as discrimination and/or may not believe that it is important. A crucial step towards self-advocacy is the shift from the belief that, “Its only me, so why bother? to the realisation that, “It‟s not fair!”, “Its not right!”.

For most of us, it is easier to advocate as a group rather than as an individual. In the case of people with learning difficulties, self-advocacy groups may form within services or outside services when people come together collectively to discuss similar issues, or when one person in a group shares an experience which resonates with others and leads to a collective group discussion of the issue.

While people gain a sense of collective power as a group, it is still difficult to know what to do, that is, what concrete actions people can take together, particularly on issues which are abstract, such as „rights‟, or on issues which stem from government policies, agency policies, or social attitudes. Many of the technologies of campaigning (setting up and running meetings, media work, keeping papers, etc.) take skills that people with learning difficulties find difficult. Further because people with learning difficulties have few opportunities for social get-togethers, there is usually a desire for an issues group to have a social agenda which can sometimes obscure the original purpose of the group.

Workers can:

- affirm that people‟s issues are important;
- help people name feelings (eg. sick in the stomach) that signal something‟s wrong;
- reinforce their right to act on those feelings;

- use appropriate films or other individual visual aids to prompt or expand discussions;
- encourage people to share similar issues;
- be alert to people‟s difficulties with abstract concepts;
- be alert to people‟s memory difficulties;
- share information and analysis;
- share information about available options;
- encourage groups to consider, collectively, a range of possible responses (from reaction to education, action, lobbying etc.);
- help people process what they want to do and how (eg. through role playing, telling a story, giving concrete examples);
- assist groups to find speakers;
- assist people plan activities, and listen and speak in a group;
- support people to exercise their right to vote;
- be clear about what support the agency / service can offer to people who want to act on an issue;
- assist people connect with advocacy groups.

Because workers need to give a lot of time and commitment to support people to speak out and have their say, it is helpful if the service has a policy position affirming that this kind of work is important.

Women Speaking Out!

Speakouts are a forum for people to come together to voice their opinions, listen to others, and participate in interesting and relevant workshops. Roving microphones and video and audio taping ensure that there is accurate documentation of what people say.

Some years ago, the Wild Women‟s Group in Brisbane were invited to participate in a young women‟s Speakout where a variety of young women‟s groups addressed issues which affected their lives. For the women involved, it was an opportunity to feel safe in speaking out and to be accepted by other women, including other women without disabilities. Their sense of security was enhanced by their attending the "Speakout" together as a group.

After some further involvement, the Wild Women‟s Group decided they wanted to have their own Speakouts, and supported by the W.W.I.L.D. - S.V.P. Service. W.W.I.L.D. - S.V.P. received funding from Brisbane City Council to hold two days of Speakouts. The women in the group helped to submit for funding and to plan the two days. They decided to have the first day for women with learning disabilities and the second day for all women.

At the Speakout, some women with learning difficulties who had never before attended such an event, seized the opportunity to have their say, speaking with a microphone and being recorded on audio/video tape. There was much excitement as the young women found the confidence to share an analysis of their lived experience with others (those with disabilities and those without disabilities), canvass issues, and canvass possible responses to issues. The Speakouts built on the group‟s growing awareness of the disadvantages and injustices they faced, and gave the young women the opportunity to have their say in a public, but „safe‟, forum.

Rebels With Attitude

The Rebels with Attitude group began in 1996 when a person called Daniel Thomas organised a workshop. He thought it would be a good idea to get people together who have a learning difficulty to talk about issues that affect people"s lives.

The group decided to continue to meet fortnightly. The group called themselves Rebels With Attitude. Rebels stood for people who speak out and live their lives the way they want to and Attitude was about having a positive attitude.

Rebels with Attitude is run by people with learning difficulties. The group is going strong at the present time with the support of CLP.

There are currently 10 members in the group who organise what the group does.

This includes:
- *writing funding submissions (the group has received a development grant),*
- *workshops on - speaking out*
  - *- being ripped off*
  - *- "What is Government?"*
- *organise speakers (e.g. a police liaison officer talked about crime and safety*
- *linking up with other disability organisations that speak out about people"s rights like QDN (Queenslanders with a Disability Network)*
- *there is a subcommittee of the group who make decisions about money management and issues that come up for the group.*

The group has been running for 4½ years. During that time, we have purchased a computer with funds from a Gaming Machine Grant that we received last year. We also received a Community Development Grant from Brisbane City Council which we spend on membership gathering activities like a bus trip.

Rebels conducted two workshops called People with Disabilities Speak up for Themselves. Three members of the group were asked to prepare speeches and talk about what it is like to have a disability. The group was also responsible for making flyers and we also helped set up the venue and recorded the two workshops on video. We have copies of our workshop report available.

At the workshop we talked about:
- *What it is like to have a disability*
- *How we are treated by people in the community*
- *Why do you think people in the community treat you this way*
- *What don"t people in the community understand about disability*

We also talked about how people with a disability in the community can stand up and fight for their rights and what we could do about speaking out to the community.

The workshop has lead on to other groups starting up. In the workshops, people got into two groups and made clay sculptures of what they would like to see in their ideal community.

Talking About Schools

The "Talking About Schools" group started in 1997. The group initially started after a number of individual constituents spontaneously spoke to their workers from C.L.P. about being bullied at school.

The "Talking About Schools" group currently consists of eight members and two workers from C.L.P. who assist us to facilitate our meetings.

When we first met together there were separate girls and guys groups. This was to respect the privacy and sensitivity of the stories being told.

We worked in our groups with storytellers who helped us to feel comfortable about telling our stories. On the day that the women's group came together we "came to school" complete with a tuckshop, and the men's group played a storytelling snakes and ladders game called "What a Life".

Our stories were taped and we had help to do this from community artists Sally and Darryl who helped us remember our bullying experiences by giving us some subject words and situations to help us tell our individual stories.

After this we began to meet together as a joined group and from the taped stories we developed a booklet called " Talking About Schools" which divides our stories into 4 sections. These sections include :-
1. *What was school like*
2. *What happened when we were picked on*
3. *Being picked on by teachers*
4. *What we did*
5. *What other people did*
6. *What should be done to make things better.*

We then came back together again to produce illustrations for the booklet. We then sent the stories and illustrations to the printer to be put together.

In March 1999 we held a public launch to officially release the booklet. These books are available at a cost of $5.00.

The aim of the "Talking About Schools" group is to raise awareness about people with learning difficulties experiences of bullying. Our central theme is that we believe all students need to be treated equally and with respect.

Our focus at the moment is delivering presentations to various high schools. Our presentation consists of a brief history of the group, a video that the group has made showing examples of physical and verbal bullying and sharing of our stories. We conduct an interview with each other in which we talk about the effects of bullying. We finish by talking about the future plans we have as a group.

The presentation goes for about 30 minutes.

We have presented to three schools and to the Beyond Bullying Association"s conference last year.

I have enjoyed being part of this group as it has allowed me the opportunity to express my thoughts and feelings about being bullied. I strongly believe that bullying is wrong. The group has encouraged me to speak out about it and in doing so maybe I am able to help other students and schools with similar experiences.

“No Less Perfect” Video

C.L.P. was given a grant from the Brisbane City Council to make a video depicting our lives in a variety of different aspects.

We met on a weekly basis with the assistance of two community artists and workers from CLP and WWILD Service. The workshops comprised of us using different media to express our ideas. These included collage, drawing, using a video camera, speaking and storytelling.

This video is in an interview format. We chose our settings for our personal interview about our lives. 11 Constituents were involved with making the 20 minute video. The idea to make the “No Less Perfect” Video came from the Rebels with Attitude group workshop in 1998.

The “No Less Perfect” Video group consisted of us talking about the way we are treated and also about how we would like to be treated by society as a whole. We feel that we deserve to be treated with respect and that people with a disability shouldn"t be treated differently.

The video showed our experiences of parenting, schools, flatting, family, work, learning to drive, hostels, difference and hopes and dreams. Basically we shared our life for a brief period of time at a personal level. We explored to a certain extent the idea of reconstructing normal by discussing that their is a societal norm out there and if you don"t fit that so called „norm" you are viewed by people and thought of as being different and therefore treated differently.

The launch of the video was well received and approximately 35 copies have been sold and more have been distributed to organisations throughout Australia.

The response has been overwhelming with comments and feedback coming back from a range of people.

The making of the video was designed to get a powerful message across to a broad range of people in the community whether they be other people with a disability or people without a disability. Saying that we may be different but we still have many abilities which we can use effectively in our lives.

Standing Proud

In 1999 we had 3 Standing Proud workshops. This year we have planned a series of five workshops. About 10 people have been involved in the workshops this year.

We have these workshops in conjunction with a gentle exercise class that runs twice a week.

In Standing Proud we have talked about how we want people to understand us. Last year we designed a mural with some of our ideas.

The ideas that are most important to me are these two.

I have a learning difficulty which means I have had to have a lot of courage and strength to get by day by day.

And

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

As a group we have written a poem called " Feeling Proud and Being Proud" about courage and strength. This poem is at the start of this publication.

This year we have developed our ideas further. We worked with an artist and designed 3 posters.

Other things that we have talked about have been :-

- *how we want to be treated.*
- *how we feel about ourselves . In the group we've felt safe enough to share our personal stories and feelings and we've been able to encourage each other.*

Some of the stories we have shared have been about being used and being ripped off.

We spent one workshop recently focusing on this issue. We played a storytelling game called "What a Life". This game is a giant snakes and ladders game where there are story cards about situations on lots of the squares. The cards prompts the players to remember and tell our stories about the situations written on the cards.

At the end of this workshop we summarised our ideas and created another mural. One of the posters we designed was about being ripped off. Its message says :-

If you pick on me because you think I'll take it you're a bully and you've got it wrong. We're not going to take it. We look after ourselves. We're not going to let you take advantage of us being a bit slower.

Personally I've found that the groups have been interesting and a lot of our different ideas have been shared. I feel stronger in how I'm able to stick up for myself and I hope we have many more.

Note: The Rebels With Attitude, Talking About Schools, Not Less Perfect Video and Standing Proud case studies were prepared by two CLP constituents – Paul O'Dea and Lorelle Smith for a presentation at C.I.D.A. Conference 2000.

TALKING ABOUT SCHOOLS

Valerie: The teachers said to my parents „Your daughter can‟t cope with the lessons‟ and they transferred me to special class. I didn‟t want to go to special class and they said, „You have to, if you stay in normal class with the slow ones like you.‟

Daniel: I didn‟t think there were any good days at school.

These themes are common as people talk about their schooling experiences. As people continue talking about their school memories, inevitably stories about being picked on, being bullied and being left out emerge.

Steve: I got thrown in a wheelie bin … these two bullies picked me up and put me in this wheelie bin and they were teasing me, and I cried and cried and cried and cried.

Valerie: I just cried when high school students picked on me. I started at special school in 1990, and they picked on me. I cried then. The primary school students, too, picked on me.

Lorelle: Sport – I always used to come last, hey, it made me feel awful…

Valerie: And the high school students call me „spastic, stupid, dumb‟, because I went to special school.

I didn‟t want to go back
I didn‟t want to tell anyone
I felt awful
Bad – I felt terrified
I got teased – called stupid
I was terrified

People believe that the experience of bullying and exclusion while at school had a significant impact on how they learnt and that their education quality was severely compromised.

In the classroom, people remember being so distracted by the fear of being bullied and picked on that they couldn‟t listen to the teacher properly. People said that during classtime, their focus was on the memory and anticipation of bullying and vigilance about subtle bullying and intimidation that happened during class time. Consequently, people now feel that they „didn‟t learn properly‟ and „missed out on learning‟.

Socially, people felt the effects. Isolation was a common experience and difficulty in making friends was an inevitable consequence. People spoke of being so stressed and uncomfortable that they just wanted to be by themselves at lunchtime – the key opportunity both for forming and maintaining friendships, as well as for being targeted for bullying.

People‟s memories are of going home at the end of the day and being fearful, of not wanting to go back to school and of having little interest in learning.

Family, school and peer responses varied. People spoke of their parents immediate intervention with the school as being a supportive response. People saw "that things did get better when parents became involved, however this did sometimes result in the student moving schools rather than the issue being resolved" (CLP, 1998). Often the school‟s response was experienced by people as ineffective.

Sandy: … the teacher moved me right beside his desk because he was keeping an eye on me. If anyone else was bad they had to come and sit next to me, which was kind of a bit of an insult.

Steve: I couldn‟t see the teachers…they made it worse.

The Talking About Schools group is a group of people with intellectual/learning difficulties who have worked together since 1997. The group is committed to addressing these high levels of bullying that is experienced in schools by people with intellectual/learning difficulty. The Talking About Schools group have undertaken a range of activities to promote their message that students with a disability are often treated unequally. This inequality manifests in bullying.

The Talking About Schools group have spoken about the impact of school bullying into their adult lives. People have spoken about the length of time it takes to „get over it‟. Members of the Talking About Schools group are in their 20‟s and 30‟s and it has struck the workers who resource the group that although people have healed somewhat, the memories are strong and vivid.

Since finishing school, people speak of realising how much learning they have missed out on. Some have made efforts to "catch up" through TAFE and other adult education opportunities.

People too speak of sadness about the difficulty they have forming trusting friendships and of not having friendships from school that last into their adult lives.

As well as regret, a lovely strength, wisdom and expertise is very present among people as they speak of these stories. This group states "when looking back, we have a strong sense of what‟s wrong".

Gathering together has contributed to the development of participants personal power and self-awareness through collective process. Participants have said that being able to share their pain and wisdom with others has aided in identifying current experiences of bullying and exploitation. Associated with understanding and identifying exploitation is hopefully a reducing tolerance for putting up with these relationships and the development of strategies to ensure safety and well-being.

The Talking About Schools group regularly delivers presentations to local schools and at relevant conferences and other speaking out opportunities. Core elements of the Talking About Schools groups message are

i. the reality of people with intellectual/learning difficulty experience of bullying and social exclusion at school,
ii. that these shouldn‟t be tolerated within a school community and
iii. a gentle and diplomatic challenge to students and teachers about how inclusive their school communities are and how useful their bullying protocols and policies are.

The Talking About Schools group offer the following opinions and advice:

1. People with intellectual/learning difficulty should always be included and treated equally
2. Students with intellectual/learning difficulty need to learn the same stuff as any other student.
3. Students with intellectual/learning difficulty can get their work done
4. Disability isn‟t something to be made fun of – stop, think, listen before you act.

Note:- Thanks to the Talking About Schools group who gave time to assist in the preparation of this section.

WORKING WITH ISSUES OF SEXUALITY AND INTIMACY

People often speak of wanting to form intimate relationships with others. They say, “How do I get a girlfriend?” or “I want to find a boyfriend”.

Many are confused and mystified by relationships, and they want to know:

- **How do people find a partner?**
- **What about sex?**
- **How do I know if a relationship is ok or not ok?**
- **What about children?**

How do people find a partner?

Fegan, Rauch & McCarthy (1993) tell the story of David‟s and Narelle‟s relationship.

Both Narelle and David had had protected and isolated childhoods. Neither had many friends and, when they finished school they worked at a sheltered workshop. It was at the workshop that they met - “we were attracted to each other right from the start”. There was opposition to their engagement from their families - similar opposition to that which they had experienced earlier when each left their family homes to live independently. They had initial plans to have a child, but have since decided not to. Their main supports are Narelle‟s mother, work colleagues and a county nurse. (Summarised from, Fegan, Ranch & McCarthy, 1993).

Llewellyn (1994) tells Jane‟s and David‟s story.

Jane and David met at a workshop where they both worked. They had been friends for a couple of years and had made plans to marry in a year or so when Jane became pregnant. People opposed Jane having the baby, but Jane decided to go through with the pregnancy. Jane‟s mother supported her decision. When Tom was born Jane, David and Tom lived with Jane‟s mother until Tom was three and a half. They now live independently and have developed skills in independent living and parenting. Their relationship is strained, and they continue to rely heavily on Jane‟s mother who is happy to provide this support. Her philosophy is that “slow learners” like Jane and David should be “given a chance” and that, with family support and encouragement, they will succeed (Summarised from, Llewellyn 1994).

These couples‟ relationships represent to many people what they would like for themselves: to be a partner in an established relationship. Many people, though, live isolated lives, and their relationships with others are exploitative and non-mutual. The way to form a relationship with another is unclear, mystifying and full of risks. And, for these reasons, some see parenting as an unreasonable goal. Yet, as in the above stories, there are some simple principles we can enact when we are supporting people with a learning disability who want to form relationships with others.

- *People with learning difficulties have the same desire for close relationships with others as do people without learning difficulties*

  Myths abound about people with learning difficulties being asexual „eternal children‟, never reaching adulthood, and not being able to parent. These myths fly in the face of the reality - people with learning disability desire the same intimacy as their same aged peers who do not have a disability.

- *Relationships develop within a social environment.*

Many people with a learning difficulty do not keep in touch with friends when they leave school, and the period immediately following school is often a time when they do not have much social contact with others. It is during this time that the desire for friendships and close relationships is felt keenly, and frustration ensues whey they do not have the social environment to meet this need.

People need to be in regular contact with others for relationships to grow. For the couples in the above stories, the regular contacts were in their workplace. Other people may have contacts in local community activities, social groups, task and issue specific groups, in committees and local community organisations, or any setting where people come together for generally similar reasons.

Some practical approaches workers can take when working with people with a learning difficulty who are seeking to develop relationships with others are to:

- support individuals to link with local community groups and activities;
- support individuals to arrange parties with friends;
- encourage people to come together socially for an organised event (eg AGM, Christmas). At these events, people will often meet up with others they have known from school, or other gatherings. Workers can support and encourage people to swap phone numbers if they want to stay in touch;
- identify tasks/issues that people might want, as a group, to work on together;
- explore who have been the important people at school or past work settings and offer people support to reconnect.

- *Individuals develop relationships more freely if others in their environment support their developing independence through age appropriate developmental stages*

It is difficult for a relationship to develop if individuals are protected and controlled to the extent that decisions and choices about relationships are taken out of their hands. Workers can support people to normalise their desire to have a relationship, regardless of what others say. Support can also be offered to the person to challenge significant others to let go and enable the individual to explore relationships.

- *Established relationships are strained if significant others oppose decisions a couple makes.*

If significant others disagree with practices a couple adopts in everyday life, tensions can arise. Again, this situation often arises from the assumption that people with a learning difficulty need to be told what to do because they cannot make important decisions. If a couple has established their own way of doing things and these ways are not harmful, then their autonomy and their right to learn from consequences and their choices should be respected.

- *A couples" relationship is less strained if there is support when new, confusing or difficult issues arise.*

A couple may need support from someone they trust - family, community members or a local support service.

What about sex?

Many women say they do not understand „the rules" of relationships; for example, they may meet someone and have sex and assume they now have a boyfriend and may get married, even though they don"t know their name, or if they will see them again. Sex and intimacy in a shared relationship are abstract concepts, very difficult to understand when one"s own life experience has very often been one of abuse, exploitation, disadvantage and loss of self esteem.

McCarthy (1993) has documented common sexual experiences of women with learning difficulties, these include:

- most do not have ways of expressing their sexuality that are autonomous from men"s;
- those women who say they enjoy sex as much as men usually reveal, on further questioning, that they like having a boyfriend and that
- the kind of sexual activity women experience centres on their male partner"s pleasure;
- women with a learning disability experience little or no physical pleasure from sex and there is a lack of awareness of the clitoris and of women"s orgasms.

McCarthy"s research suggests is that there is a high level of confusion and misinformation about sex among people with learning disabilities.

Some principles that workers can keep in mind when working with people on sexuality issues are:.

- People need clear, thorough and easy to understand sex education, including: how bodies react during sex and why; safe sex; mutuality of sex; the variety of sexual relationships and sexual options and an understanding of the emotions attached to sexual expression.

- People need to explore, for themselves, the role of sex in the broad context of their relationship. People need the space to consider if they want sex or not. If they do want sex, they need to think about what is important to them in sex, and what is unacceptable. Putting boundaries around what is and isn"t acceptable sex in their relationships enables people to make informed and prepared choices in situations where it might be difficult to make a decision. A person may want support from a worker to work out how to communicate boundaries to others.
- If a worker becomes aware that a relationship is exploitative, the worker needs to name and challenge the exploitation with the person involved. If a worker becomes aware of illegality in a relationship (eg rape), the worker needs to inform the person involved of the illegality.

- People may not have had opportunities to talk about relationships and sex with peers, and so may need support from a worker to normalise their experiences of sex. Workers can facilitate same sex groups to discuss sexuality and related issues; peer education, especially where people can share experiences of relationships and sex, helps normalise sexuality and support people in their varying experiences.

- Workers can support couples considering a sexual relationship to seek professional sex education. Discussion about sexuality may be embarrassing, or, if there has been abuse, shameful, so people may need clear boundaries to work through sexuality issues and feel safe. Boundaries include confidentiality, respect, and permission and opportunity to stop discussions if things get too „tough" or „scary". In a trusting working relationship people can benefit from discussing their sexuality, obtaining reliable information, redefining their beliefs and exploring their sexuality in a healthy way.

David Thompson (1994) has researched the experiences and sexual relationships of men with learning disabilities. Thompson found that men"s sexual experiences with other men were more common than their sexual experiences with women.

However, in discussions men talked easily about their sexual experiences with women, and were more open to talking about sexually abusing women and children than talking about their sexual experiences with other men.

Thompson suggested possible reasons for men"s hesitancy to discuss their sexual experiences with other men were:

- social taboo against men having sex with men;
- negativity of the experience (often painful, forced, humiliating and not for pleasure);
- perception abuse occurred because of their own lack of strength, reflecting poorly on their masculinity;
- reluctance to identify as homosexual, and non-identification with being gay.

Thompson also observed that men"s" sexual experiences with other men were controlled by the man perceived as more powerful, who might or might not have a learning disability. A man with a learning difficulty might, therefore, take either role, depending on his partner.

How do I know if a relationship is OK or not OK?

Because Karen regularly travels on trains, she recognises by sight railway workers and regular passersby at her local station.

One day, on her way home, a railway worker asked Karen to go into his office. He started touching her. The touching did not lead to intercourse.

As he was the sole worker at the station at the time, he needed to sell tickets when customers arrived. Two or three times he asked Karen to wait in the office until he came back. Karen stayed because she was scared, because she thought the door was locked and because she didn‟t know how to leave.

Karen later spoke to the police about what had happened. The police, over the phone, told her there was nothing they could do - that her consent had been implied because she had stayed there and not screamed. The police offered to go to the station and talk to the person involved. Karen has not heard if this happened.

When talking about the incident with her worker, Karen said she “just froze”. From the start she had felt very uncomfortable, but couldn‟t make a decision about what to do because her confusion and anxiety had been so great.

People experience exploitation in many forms and in alarmingly high numbers. The literature documents people‟s experiences as victims of crime, as victims of financial exploitation, (eg William's, 1995) and as victims and survivors of sexual exploitation and assault (eg Sobsey, 1994). Often, though, people with learning difficulties do not consider themselves to have been exploited - some name what happened as „unfair‟ but, for most, it is „just considered a part of life‟.

Exploitation occurs when someone in a position of perceived power takes advantage of someone less powerful, for their own gain or gratification. Often the victim is not in a position to be able to say “no”, or stand up for themselves. Or, simply, they do not understand they are being exploited. People with a learning difficulty depend on honesty and fairness from others in common everyday situations. When people are not honest and fair, people with learning difficulties feel confused, become vulnerable and, at times, are open to exploitation.

Common themes of people‟s experiences of exploitation are:

- difficulty in listening to and acting on their feelings of fright and discomfort in the situation, in other words, translating a feeling (eg sick in the stomach) to action (eg leaving a situation or saying something);

- difficulty in making a decision on the spot about whether something is right for them or not;

- difficulty in being assertive.

Other issues include:

- People often have difficulty gaining redress through the legal system. In some situations, people with a learning disability are seen to be giving “implied consent”, that is, they have not been able to say „no‟ and so have sometimes inadvertently consented to a situation.

- Past relationships may have been abusive, which may predispose a person to expect, for example, that non-mutual/satisfying sex is part of intimacy, and the price to pay for having a partner.

- Sometimes security of housing tenure may depend on a person‟s compliance with exploitative behaviour.

In a recent workshop at CLP, local service providers and academics considered the exploitation experienced by people with a learning difficulty. The group considered possible service responses to exploitation in general, (not solely to sexual exploitation). Suggested responses and practice principles included:

- work on the issue in the context of a relationship where a degree of trust has developed - this will be important if worker needs to challenge person‟s view of an exploitative relationship;

- name incidents as exploitation, in terms of “If that happened to me, I would feel/think ......”;

- challenge people‟s understanding of perpetrators as „friends‟, and name the negative elements of the relationship for what they are eg assault;

- talk with the person about their own personal signals of fear, discomfort and unease (for example, some people talk about feeling sick in the stomach in unsafe situations); support people to trust their feelings as important physical signals of an anxiety-provoking and possibly unsafe situation and to act on them, instead of dismissing them;

- support may also include a practical plan of what actions people can take when feeling anxious or unsafe;

- provide information about legal redress options;

- support person‟s right to decide what to do (give information, support decision making, challenge anything unrealistic, illegal or inconsistent);

- develop agency/service policy for situations where both perpetrator and victim are in contact with the service, for example:
    - separate workers for perpetrator and victim;
    - service position on reporting a known crime;
    - wether and under what conditions service continues to be offered to perpetrator.

- encourage person to engage in group work; same sex groups where participants explore good and bad relationships have proven beneficial as people explore the issue and learn from peer experiences in short term, educative groups. Participants have stated the benefits of groups where other members also have a learning disability as opposed to groups when other participants do not have a learning disability and the context and pace are not suited to their needs.

What About Children?

Mark and Elizabeth have two children, Samantha and Anthony. When Elizabeth was pregnant with Samantha, their first child, they went to a residential mother and baby unit to learn about caring for their child - a positive experience. They also received and continue to receive support from Elizabeth‟s family, and also from their wide circle of friends and acquaintances. Mark works, and Elizabeth continues part-time work with Samantha and Anthony in child care a few days a week. Mark and Elizabeth strongly express their desire to show others that, even though they are people with intellectual disabilities, they too can bring up children and, to this end, they endeavour to be as independent as possible (Summarised from Llewellyn, 1994).

Mark‟s and Elizabeth‟s story challenges many of the prevalent stereotypes about people‟s inability to parent if they have a learning difficulty.

Mark and Elizabeth enjoy their role as parents, they capably and responsibly carry out this role and have the right combination of support for their needs.

Tymchuk and Andron (1990) list the sentiments that have been expressed about people with learning difficulties ability to parent, these include;

- people with a mental retardation have more children than other parents;
- children of parents with mental retardation will be born mentally retarded;
- those not born mental retardation will be at high risk of developmental delay and physical health impairment;
- parents with mental retardation will abuse their children;
- parents with mental retardation will purposefully neglect their children;
- parents with mental retardation will provide inadequate child care;
- parents with mental retardation will interact with their children in a way that is punitive, non-reinforcing, restricting and non-stimulating;
- parents with mental retardation are unable to learn, apply and maintain adequate parenting knowledge and skills (Tymchuk 1990).

Parenting, for anyone, can be a time of overwhelming stress and tiredness. People with a learning difficulty need extra time and space to understand new things, so they are often easy to identify as having problems with parenting and come to the attention of child protection agencies in high numbers, as reported Tymchuk and Andron (1990), and McConnell, Llewellyn and Bye (1997).

Tymchuk (1990) qualifies each of these points in turn. His research found that people with mental retardation actually have fewer children and have them later in life than others do. The chance of people with mental retardation having a child born with a biological condition that is associated with what society defines as mental retardation is the same as those of any other parent. Where abuse does occur it is usually as a result of another person in the life of the mother with mental retardation (Tymchuk,1990).

Tymchuk found that with supportive intervention the risk of developing cognitive developmental delay and physical and health impairment is lessened, as is the risk of neglect. With support, parents with mental retardation provide adequate child care and changes can be made to interactions which may appear non-reinforcing, restrictive and non-stimulating. He also found that parents with mental retardation are able to learn, apply and maintain adequate parenting knowledge and skills when interventions are matched to parental learning characteristics. This included the use of illustrated materials, well trained staff and interventions that are initially intensive and then periodic for a long term (Tymchuk, 1990)

McConnell, Llewellyn and Bye (1997) sought parents views about what they needed most support to enhance their parenting abilities. The areas that parents nominated were:

- understanding child development
- social and community skills

- vocational skills
- knowing what services are available and how to use them
- meeting people and making friends.

These comments indicate ways workers can effectively support parents who have a learning difficulty.

- People with a learning difficulty need individualised support to learn the practical elements of child care. Mark‟s and Elizabeth‟s early intensive contact with a residential mother and baby unit was a positive and important, and they learned skills such as feeding and nutrition, bathing and hygiene, toilet training, safety and nurturing.

- Support is effective if it is ongoing and responsive to the developmental needs of the child and family. A trusting relationship between the family and support worker is vital.

- Information at any stage needs to be appropriate for people with a learning disability (see Communication - verbal and visual). Parent Effectiveness courses often rely on high levels of literacy, and topics are covered at a pace that people with a learning difficulty find hard to keep up with.

- As in all relationships, connections with family, neighbours, community members and relevant community services (eg, child care centres, playgroups, hospitals, mailing lists for community centre activities, specialist support services for people with a learning disability) are essential for people to feel connect to others, and for them to be able to call on assistance in times of need.

WORKING WITH HOMELESSNESS

That there are significant numbers of people with a learning difficulty who are also homeless is now widely documented (Human Rights And Equal Opportunity Commission, 1989, O‟Connor & Carter, 1992; Paterson and Hunter, 1993; Coleman, 1994; Hill & Price-Kelly, 1995; Lindsay, 1993; Spencer and Ray, 1992). The Human Rights & Equal Opportunity Commission Report, (1989) refers to people who are homeless and who have an intellectual disability as „particularly vulnerable‟. Certainly, they face many of the same issues as other people with a learning disability, but with added complexities.

People who are homeless and have a learning difficulty are „particularly vulnerable‟ and face complex life situations because:

- relationships may be abusive and exploitative
- support around issues may be sporadic or non-existent
- they may have experienced significant family breakdown and, in turn, a limited sense of belonging
- „difference‟ from peers may mean exclusion from the homeless networks on the streets
- learning difficulty may go unrecognised and limit helpful responses to the person‟s needs
- adaptive skills and coping strategies learnt as a result of homelessness may mean that people don‟t „fit‟ within service systems for people with learning difficulty
- service systems for homeless people lack understanding of learning difficulty.

Workers at the At Risk Resource and Outreach Service (ARROS) in Brisbane worked with young people who are homeless and have an intellectual disability. The ARROS model of service had been a result of the YAR<>MID research in Brisbane (Coleman, 1994). The service had two workers, one in a direct support role and the other in a resourcing role. The experience of workers at ARROS was that, in order to respond to people who are homeless and have a learning difficulty, it is essential to develop and maintain a strong working relationship. There are three key elements of relationship building: pace, time and space.

Pace
The rate of progress or speed
at which relationships are built.

RELATIONSHIP BUILDING

Time
The length of time that is
allowed to build relationships

Place
The environment where the
relationship building occurs.

Workers can:

- **Pace** work with people to show proactive interest in building a relationship; initiate the first contact; follow up with offers of other meeting times; inform people of the nature of the support that workers can offer and how often; initiate conversation around issues of concern; allow the person to set the pace of the meeting times; engage with people‟s achievements to signify progress.

- **Time** the relationship building to occur as an ongoing part of the work, acknowledging that there is always something new to understand about the person. Continued contact over time helps to build trust, demonstrates a genuine interest in issues and needs, and allows the person to use the working relationship according to their needs.

- **Place** the relationship building in the context of the person‟s life by being flexible about where to meet; join in activities that the person enjoys; take an interest in the environment in which they live; become aware of the environments in which people feel comfortable and uncomfortable; negotiate barriers of lack of money and transport.

It is sometimes difficult to know whether it is homelessness or learning difficulty which is the more significant factor contributing to a person‟s disadvantage. The Human Rights and Equal Opportunity Commission Report acknowledged that people with learning difficulty are, potentially, chronically homeless:

> *"They are the young people who for whatever reasons are unable to move on to independent living situations; the reasons may include age, intellectual disability, emotional disturbance, poor education, inadequate living skills and extreme poverty" (HREOC, 1989;44).*

What is clear is that these people at risk of chronic homelessness experience high levels of disadvantage which translates into complexity of need, and people may have multiple issues and needs.

Furthermore, the immediate needs expressed by people may be inconsistent with the worker‟s perception of their needs. The following are examples of what has been uppermost in the minds of some people when they have spoken with At Risk Resource and Outreach Service workers:

> *People talk down to me and make me feel dumb.*
>
> *When I stay in here [in a shelter] it reminds me that my family don‟t want me.*
>
> *I can‟t stay in here [the city] there are too many weirdos and the cops are always on your back.*
>
> *I wonder if I will ever find a boyfriend - having a baby is important to me.*

Often, workers feel compelled to address the obvious material disadvantages young people face - shelter, food, money. These basics may, at times, not be the expressed needs of the person.

Late one afternoon a phone call came through. "Can you find me a shelter place for tonight?". The worker went to meet the young person. On the journey to a shelter, the young person talked about feeling sad, about how they were worried about not having a gift for Father‟s Day, about needing a bed but not being happy about staying in a shelter because it was a reminder of family separation. On arrival at the shelter, the young person asked about Father‟s Day and if it would be all right to stay away for the night. The shelter worker explained the rules of the shelter and said „we‟ll see‟. The young person left the accommodation the next day.

Both workers and people find it difficult to respond to the broad structural inequalities that contribute to social disadvantage. Responding to the multiplicity of needs experienced by people who are homeless and have a learning difficulty is limited by available resources. However, there is one resource that is limited only by our capacity to join with people, that is, a relationship. While people may well have developed skills to cope with homelessness and learning difficulty, what they are often missing is a relationship that encourages self-expression and that is characterised by regard, respect and understanding.

A full report of the At Risk Resource and Outreach Service pilot project can be obtained from the Community Living Association.

WORKING WITH COURTS AND LEGAL ISSUES

Definitions

It is useful to make a distinction between legal, clinical and "self" definitions of learning difficulty.

The Queensland Criminal Law Code (July 1997) uses the term "intellectually impaired person". Specifically, s229F states:

> "A person is an „intellectually impaired person‟ if the person has a disability -
> a) that is attributable to an intellectual, psychiatric, cognitive or neurological impairment or a combination of these; and
> b) that results in -
>   i) a substantial reduction of the person‟s capacity for communication, social interaction and learning; and
>   ii) the person needing support.

From a clinical perspective, "intellectual disability" is a broad and frequently misunderstood label. Intellectual disability involves some degree of impairment of mental functioning, with the degree of disability ranging from borderline to profound intellectual impairment. An individual may have an intellectual disability alone, or may also have other disabilities. People with an intellectual disability do not necessarily have a physical disability, or a particular physical appearance (Villmanta Legal Service, 1993:6).

"Self" definitions are valuable because they provide an insight into the impact of intellectual disability on the individual, and enable non-disabled people to gain an appreciation of the experience of living with an intellectual disability.

> *"…..Sometimes you can‟t even see the disability inside you. You can‟t tell."*
>
> *"…..the public don‟t understand. Some people with intellectual disability, it could be the way they look or they might have some sort of behaviour problem and the public just make fun of it."*
>
> (Spork, 1994:11-12)

Difficulties

When people with a learning / intellectual difficulty come into contact with courts and the legal system, they may have difficulties with memory, concentration, literacy, comprehension, abstract concepts, and suggestibility (for example, desire to please). These difficulties, noted in detail in other sections of this Manual, can create problems in the following areas.

> Judge"s Clarification. When a judge communicates with an aggrieved person, he or she may ask questions to clarify whether or not the person understands a question or an implication. Given the tendency of intellectually disabled people to agree with authority figures and to mask misunderstanding, they may indicate that they *do* understand a question whereas, in fact, they do not. It is helpful if judges can request the witness to state in their own words their understanding of what they are being asked.
>
> Cross-examination can be extremely stressful, anxiety-provoking, and confusing. People may require frequent rest intervals to aid concentration and a support person to help them clarify questions and statements.
>
> Written Statements. Police officers and prosecutors need to word statements in as detailed a way as possible to build a strong case for the prosecution. There are, however, inherent problems when the person has an intellectual disability and written statements are not based on their words. As a result, the person may contradict themselves in the courtroom because they are not familiar with the contents of the written statements.
>
> Special Witness Provisions. While S.21A of the Queensland Criminal Law Code defines a special witness as any person who is likely to suffer trauma or likely to be disadvantaged as a witness, there tends to be an under-utilisation of special witness provisions for people with intellectual disabilities.
>
> Oaths. The common law requires that a person taking an oath understands its nature and implications. Court officers need to check that a person with an intellectual disability understands the oath and can swear it without fear or anxiety. People with an intellectual disability may misconstrue their involvement as a witness to mean that the court case is, in essence, a competition between themselves and the alleged offender. They may believe that if the alleged offender is found innocent of the charges, they will be found "guilty" and sent to prison.

Direct service staff who work with people with a learning difficulty may need to support a person who is a victim or a perpetrator of a crime, or who is involved in some way (for example, as a witness) in a legal or court proceedings. It is our experience that a worker needs to take an active role in supporting the person within the legal system, and such support needs to occur within their employing organisation‟s policy context.

Practical Responses - Victims And Witnesses

1: The Incident and Its Aftermath

When a person discusses an alleged crime with a worker, the worker needs to support the person to name what has occurred.
The worker should be aware of issues of safety and emotional support for the person. For example, the person may need to move to a different physical location. The worker should diary the words the person uses to describe the incident, along with the time between the event‟s occurrence and the time when the person first discusses the event with the worker. The worker needs to inform the person that they (the worker) may be called as witness, and there may be confidentiality issues.

Workers may judge it useful to support the person to seek advice from a lawyer or a specialist agency. Relevant agencies may include a Sexual Assault Service, an Advocacy Service, or a Community Legal Service. Where the person has sustained injuries and has not sought medical intervention, the worker should support the person to seek it, explaining the role and responsibilities of the Government Medical Officer, and the official report the Officer will make.

Workers need to discuss and clarify the options of reporting or not reporting the event to the police and explain the likely course of events associated with each option.

Workers can offer to accompany the person to the police. At the police station, it is often necessary to advocate that the person has (where possible) access to audio and/or visual recordings of statements, as written statements may create difficulties in court. Where audio and/or visual recording of statements is not possible, it can be helpful for people to get an audio reading of their written statement.

If a person wants the worker to accompany him/her to the police interview, the worker should help the person to prepare for the police interview, and clarify whether the person wants the worker to help get information across to the police or simply be present.

At the police interview, workers need to be alert and ready to support the person in relation to:

- the person‟s fears and anxieties;
- any police attempts to minimise the complaints;
- attempts to talk past the person or treat them as a child;

- inappropriate use of closed questions;
- mis-communication between the person and the police; and
- use of appropriate techniques for taking statements (ie. use of video or audio recording).
- getting a record (audio or video) if possible, of the statement.

The worker should, with the person‟s permission and if necessary:

- check for understanding;
- call time for breaks;
- ask the officer to direct questions to the person;
- ensure that the person has adequate time to remember events;
- advocate for the use of video or audio statements;
- ensure that the person has adequate assistance to check the statement; and
- inform the person that they may obtain a taped copy of the interview.

After the complaint has been lodged with the police, the worker needs to discuss with the person what may happen next, for example, court procedures, possible timelines, dates to remember, and the need not to contact the alleged offender.

2: The Committal Hearing (Magistrate‟s Court)

As early as possible, workers need to support the person to contact the Department of Public Prosecutions or the Police Prosecutor to:

- set up an interview to assess whether the matter can proceed to court:
- inform the prosecutor of the person‟s special needs (eg. communication, memory, or other issues);
- approach the magistrate regarding special witness provisions (eg. video, screens, witness support);
- establish whether the support worker should prepare a court report, or be prepared to be called as a witness.

The worker may support the person to make pre-trial visits to the court to see what it looks like and how it functions, and may need to advocate for the person to have pre-hearing access to the Prosecutor, the person‟s special needs.

Mentions: You may hear the term Mention in relation to the Magistrate‟s Court. Mention is relevant to the alleged offender. It is their first court appearance, where the police bail and committal date are set. A complainant/victim is not required to be at Mentions.

3: The Trial (District or Supreme Court)

Between the committal and the trial, the worker needs to prepare the person, as for the committal hearing, and discuss with the person the possibility of:

- the worker accompanying the person to the trial;
- the person gaining access to special witness provisions (for example, closed circuit television for evidence and cross examination, screens in court, or giving video recorded evidence). It is important to discuss the use of special witness provisions with the person"s solicitor well before the court date, as it is virtually impossible to get these things arranged on the day of the court hearing;
- discussing with the solicitor any other supports and interventions that could help the person, eg. some means of alerting the solicitor to the fact that the person is becoming tired or confused;
- supporting the person, as requested and agreed;
- going to the courts well before the person"s trial, sitting in on other similar cases, and observing in particular the cross-examination process.

After the trial, people need time and space to fully debrief what has transpired. The worker should give information about and support the person to obtain access to victim"s compensation if they wish. (Refer to Victim Support Service booklet on Compensation).

4: Victim Support Service Involvement

People can, if they need, contact the Victims" Support Service, and obtain the name of the VSS Clerk. The worker should raise with the VSS Clerk and Legal Officer the needs of the person, as the prosecutor is likely to begin work with the case, at the earliest, in the final weeks before the trial.

The worker can support the person to write formal requests to the VSS for special witness provisions, so it can be recorded with the DPP.

Practical Responses - Alleged Offenders

Workers need to inform people if, in the understanding of the worker, an activity they have undertaken is illegal, and caution them about sharing information about illegal activities, because the worker may be required to give evidence in court, that is, there may be confidentiality issues.

Workers don‟t condone illegal activities, but assist people to understand the impact of and take responsibility for their actions, and provide them with information about their rights.

If a person discloses to a worker that they have committed a serious crime, there are issues about whether the worker has a duty of care to the community to report the crime. Workers need to clarify or refer to their organisational policy and procedures in this area.

It is important not to give the people false hope, for example, by implying that because they have come to the worker and reported what they have done, the worker will be able to get them off.

Workers need to ask the person‟s permission to seek advice, and/or support a person to seek advice, where the worker either needs expert advice or feels that the person does not understand the gravity of the situation. It helps, too, to discuss options, and the consequences and likely courses of events associated with each option: for example, naming others involved, "taking the rap for others", running away, not turning up at court, pleading guilty or not guilty.

If people decide to speak to the police in the company of a worker, workers can offer to participate in a recorded interview with the police, as a third party support person. The Police Procedures Manual states that a person with a "recognised" intellectual disability can have a support person. As in work with people who have been victims or witnesses of crime, workers may need to support alleged offenders through court proceedings, explaining legal processes and helping ensure that they have a fair hearing.

Arnie‟s story tells of one mans experience of the court process

"Like a Dirt Stain on a T-Shirt I Just Want to Wash Out": Arnie's Story

Arnie

Arnie is a 26 year old Brisbane man who describes himself as someone "who has trouble reading and writing", that is, he has what is commonly called a mild intellectual disability. 'Arnie' is not, of course, his real name, but his chosen pseudonym for this story - the Schwarzenegger connection reflects both his recovery from the events in the following story and his off-beat sense of humour.

I first met Arnie at Community Living Program (CLP) in 1993. He had then been associated with CLP for four years, during which time CLP workers had been able to assist him develop the personal and social skills required to live independently in the community - which he had done successfully, and with considerable pride, since 1992. Having received support from CLP for such an extended period of time, the agency was an important part of his life: he was an active member of the CLP management committee, and he was also a member of a men's group, along with some of his close friends and other men with learning difficulties.

To know Arnie is to know his desire to acquire the best that the television/stereo/video world can offer. In 1996, he was particularly proud of the 68cm television he was renting from Rentlo. Despite the huge financial burden of repaying such items, they were his number one priority and, although he constantly stressed and worried about his repayments, he was always up to date, sometimes at the cost of food and other necessities. Arnie tended to worry a great deal about many things, often things that hadn't happened but might happen. He was very conscious of his personal security, and very diligent about locking his unit and his bike.

The Robbery - September 1996

In the second week of September 1996, Arnie attended a BBQ for staff and constituents at CLP. He wisecracked his way through the afternoon, and was in good spirits. After the BBQ was over, he rode back to his public housing unit, planning to watch a few videos he had hired. As usual, he locked his bike at the stairwell and, entering his unit, locked the screen door behind him, but not the wooden inside door because it was still daylight and a bit warm.

Soon after, his next door neighbour, Alec, knocked on Arnie's door and invited him across the way for coffee. He had seen Alec occasionally, and said hello to him as he went past, but he didn't know him well. He was, in fact, a bit wary of Alec, and he initially declined the invitation. But Alec kept knocking and asking, so Arnie, feeling intimidated and wanting to appease his neighbour, eventually agreed.

Arnie recalls that the unit was almost devoid of furniture, and the electricity didn't appear to be on. Alec handed him a cup of 'coffee', and encouraged him to drink it. Arnie was reluctant because the drink didn't look or smell like coffee, but Alec insisted and stood over Arnie who was sitting in the one lounge chair. Afraid, Arnie complied. He said that the drink tasted awful, but Alec insisted he drink all of it.

He remembers feeling sick and sleepy, and falling onto the floor. He remembers Alec taking his wallet and keys from his pockets. He wanted to resist and put up a fight, but felt he couldn't even move his arms. At this point, he must have passed out.

His next recollection is of waking up on the floor of his flat and discovering all his things missing. His TV, stereo, CD‟s, video, wallet and keys, money box, even his kettle were gone. Greatly distressed, he ran upstairs to a neighbour whom he knew and liked, and yelled through her door that he'd been robbed. Frightened by his distress, she wouldn't open the door to him. He then ran downstairs and into the car park, screaming and crying, which drew some other neighbours to him. They found it difficult to understand Arnie partly because of his extreme distress and partly because he kept losing his balance and falling over, but they called the police. With the assistance of the neighbours, the police officers made out a report.

Before the police arrived, Arnie called CLP from a neighbour's flat and told a worker, Lisa, what had happened. Lisa said she'd be there as soon as possible. When she arrived at his unit, Arnie was still very distressed and having great difficulty maintaining his balance. He wanted to go straight to the bank to cancel his stolen passbook and get a new one. Together they did this, with Arnie fluctuating between being highly emotional and falling asleep, probably because of the after-effects of the drug.

The next day, with Lisa's support, Arnie rang the police to say that he now remembered more about the night and wanted to speak to them again. He also wanted reassurance that they were doing something about the robbery. He was still very upset and confused, and the police found it difficult to understand him, particularly as his recall of events was at times inconsistent. However, the officers took a second report.

In the first few days after the robbery, Arnie received a lot of support from his neighbours who took him under their wing and organised food parcels and kitchen things, even a haircut. Their efforts were well-intentioned, but the implicit message that they were telling Arnie what to do and where to go increased his distress and his sense of loss of his previous lifestyle. A week after the robbery, he was beginning to say that the "old Arnie" had gone. He was very afraid of Alec being next door, and arranged to sleep in an upstairs neighbour's flat. He started saying that he needed a "new head", that Alec had taken everything, and that he had lost everything. Many of his skills seemed to desert him: in his distress, he couldn't ride his bike or even make a cup of coffee. More and more he just sat and stared blankly, or he had anxiety attacks where he cried so hard he couldn't speak. We saw him slipping further and further into depression and anxiety.

Hospitalisation

At CLP we were concerned, especially when Arnie started to threaten to hurt or kill himself, that we talked with him about spending some time in hospital. Two weeks after the robbery, Arnie was admitted to the mental health unit of Royal Brisbane Hospital.

Arnie spent three months in RBH. Initially, he became more and more anxious - he even became incontinent and lost bowel control. It is impossible to underestimate the effect of the robbery on Arnie who, in two weeks, had gone from living an independent lifestyle to being a patient on a locked ward. Through taking away Arnie's possessions, Alec had ripped away not only Arnie's sense of self but also his sense of personal security. He lived in a constant state of fear and became suicidal. At one stage he stopped eating, and hospital staff had to feed him themselves. The staff in the unit did a tremendous job with Arnie. The registrar worked with us to understand his history, believing that his behaviours had nothing to do with his intellectual disability and everything to do with a breakdown and subsequent "psychotic depression". Without the hospital staff's ongoing care and treatment, I am convinced Arnie would not have recovered.

While in hospital, Arnie was consulted by a detective who took an official statement, based on his initial report of the incident. A CLP worker was present to support Arnie to do this.

After a month in hospital, Arnie recovered sufficiently, in the Registrar's opinion, for the hospital to discharge him. This lasted only a few days. Alec was still next door and Arnie didn't have his things back. In Arnie's eyes, nothing was as it should be. We approached the Department of Housing to see if they could move the alleged offender, but this was not possible because he hadn't been convicted of the offence, and there were no suitable units elsewhere for Arnie.

When Arnie returned to hospital, we gave him support to spend time at his unit during the day, to make contact with his friends, and to visit his usual haunts. At times, these contacts seemed to further heighten his sense of loss. He couldn't have a conversation with us or his friends, often walking away mid sentence. He began to wander the streets, aimlessly and dangerously: either he had lost his awareness of road safety, or he didn't care. I have painful memories of this period: for example, one time I went with Arnie to visit his friends at a community organisation he knew, and saw him walk away from them, lie down on the ground, and cover himself with a pile of garden soil; another time, he tried to get out of my car while we were travelling at 60km/hr. The work was draining and beyond the capacity of one worker to sustain, so Lisa and I alternated the days we spent with Arnie. Prior to the robbery, Arnie had required only 5 hours of support a week; we were now spending 5-6 hours every day supporting him outside the hospital.

A large positive of this time, however, was the amazing support Arnie got from the men's group, who showed their deep concern and understanding for what he had been through. He might wander right into the middle of their cricket game, but there was always someone to lead him gently out of the way and talk with him. They were saddened and shocked by Arnie's condition and, when he began talking of what had happened and how he felt like his life was over, they told him that that was "silly", that they had all been through hard times, and that he just "had to hang in there". It was a credit to them and their friendships that they didn't give up on what was a very difficult situation.

Getting ready for legal proceedings

We had, from the start, talked with Arnie about what was likely to happen with the statement he made to the police and, possibly, further legal proceedings. He needed to be informed, but he found it difficult to understand. He was convinced, probably from his TV viewing, that the Court would be "me against Alec" and that the loser would go to jail. He was terrified that "the Judge won't believe me, I'll go to jail and Alec will have won". He could not be dissuaded from this view and, from his perspective, it was a fairly accurate assessment at the time: he had lost his possessions and unit and was institutionalised, while Alec was still living it up in his unit. Arnie was being "punished", therefore Alec had won.

He was gradually recovering from his anxiety and depression. His mother in Central Queensland, who had been informed of his hospitalisation, offered him a chance to live with her for a while. Arnie accepted, and was discharged and on the train north just before Christmas. This was an important point in his recovery, as it enabled him to get totally away from Brisbane and the unit. Arnie and his Mum returned to Brisbane to get the rest of his gear in January, and he ended his tenancy with Qld Housing. We saw him briefly in January, and as were relieved as he was to see that he was obviously recovering from his breakdown. We reminded him that he was welcome to contact us any time, whether he was in Rockhampton or in Brisbane

In retrospect, we should, at this stage, have been proactive and contacted the police and the Department of Public Prosecutions (DPP) to get some sense of when the Committal Hearing was to be held. We could then have had some phone contact with Arnie prior to the Hearing, and helped clarify his understanding of what was to happen. Unfortunately, we only knew of the Committal date when the police contacted Lisa to tell her that she was being called as a witness the next day at the Hearing, and the first contact we had with Arnie was when he and his mother arrived at the Magistrate's Court.

Attending the Committal Hearing - February 1997

Arnie was much more "together" than when he had left Brisbane, but he was feeling, understandably, very anxious about the court process and especially anxious about Alec being in the courtroom with him. He still held to his view of a "combative" legal system, where he and Alec were pitted against each other: if Alec wasn't committed to trial, then Alec would have won, and Arnie would have lost - he would be in trouble and go to jail. Lisa and I, the police detective and eventually even the police prosecutor tried to dissuade him from such a fear provoking interpretation, but were unable to change his view. As the day went on, his fears and anxiety were only heightened.

It was now over five months since the robbery. Holding a chronological sense of events and time-frames was hard for Arnie who has difficulties with concepts of time and with recall. The police statement he had given after the robbery to the police would have been a helpful prompt, but there were two problems: one, it was taken in a written format not as an audio or audio-visual recording; two, it was written in the language of the police officers, for example, "...he *rummaged* thorough my pants pockets".

Having to make do with this, Arnie and I read through the document a number of times - which not only refreshed his memory of events but also dredged up some painful feelings. These feelings, coupled with his anxiety about the Court process, led him to becoming very distressed.

Lisa and I explained, as best we could from our own limited knowledge, what would happen. When we met with the Police Prosecutor, we found that he had not been informed of Arnie's intellectual disability, and was a bit taken aback. However, he explained to Arnie that he would ask him questions about what happened on the night of the robbery, and that the Defence lawyer would also ask him questions. This further agitated Arnie, who repeated his fear that no one would believe him, that he'd go to jail, that "Alec is going to win". The Police Prosecutor attempted to calm Arnie, reassuring him that he would be believed and that he merely needed to answer the questions.

We asked whether Arnie could have a screen between himself and the accused. We had discussed this with Arnie earlier, after he had unfortunately run into Alec in the lift, which really freaked him out. The Prosecutor agreed to arrange with the Magistrate for a screen to be in place, as well as for me, at Arnie's request, to sit beside him for support while he gave evidence. (Under the Special Witness Provisions, a screen and support person are two of the options that a Magistrate or Judge can offer a witness with an intellectual disability.) Arnie's mother sat where he could see her in the gallery.

Arnie was called as a witness, and he and I went into the court room, both of us with trepidation. Thanks to the efforts of the Prosecutor, I was allowed to sit beside the witness box. The Magistrate immediately sought to satisfy himself as to Arnie's understanding of the Oath and the need to tell the truth. Unfortunately, the words he chose - "Mr. [Smith], do you understand that if you lie you could go to jail?"- undid all the work we had done to reassure Arnie that he had nothing to fear from the Court process. He turned to me and reached for my hand, with tears in his eyes.

He was able to answer the Prosecutor's questions fairly calmly, but became confused about the chronology of events. When the Prosecutor sought to clarify details, Arnie began crying: "He is going to win, you don't believe me". The Prosecutor asked permission to "speak words of comfort" to Arnie, as I wasn't allowed to speak to him, and Arnie quickly calmed down and was able to continue.

Throughout the questioning, Arnie looked at me when he answered questions, perhaps because I was a familiar face. I tried to help him relax by smiling and nodding back at him. The Magistrate stepped in and asked me not to do this, as it could be misconstrued later as 'leading'. He spoke quite harshly, which made Arnie worry about my getting into trouble. Later he told me he had thought I might have to go to jail.

The Prosecutor then asked questions about what had happened when Arnie was inside Alec's unit. This had been the scariest part of the incident for Arnie, and his remembered fear, in addition to his difficulties with time frames and memory, resulted in him contradicting an earlier answer. When the Prosecutor asked the question again, Arnie "lost it". He jumped to his feet yelling, "Nobody believes me, just forget it, let him go, he's going to be laughing at me, he took everything and he's going to win".

After this outburst, Arnie was inconsolable. The Magistrate called a break, and Alec was removed from the court. Arnie and I went to the loo so that he could wash his face and get a drink, which helped him to calm down. I told him that he was trying hard and doing well, and that he was being believed, but that the Prosecutor needed to ask questions to get the story about what happened. I reminded him that the Defence would also ask questions - that was their job.

After we returned to Court, the Prosecutor said that he thought it would be best to leave his questions there. The Defence lawyer asked a number of questions, very quietly and gently. Arnie was relaxed, but he also contradicted himself a few times. Eventually, Arnie was excused - a relief for both of us.

We spent some time talking in the witness room with his Mum, and with Lisa after she returned from giving evidence. Arnie was still upset, but relieved it was over. We congratulated him on getting through the cross-examination, and Arnie was able to say that it wasn't as bad as he had thought it was going to be. He thought the Judge had heard him and was on his side, even though "he scared me at the start". He and his Mum needed to leave to catch a plane, but we made sure that he understood that the Judge had two choices: to refer the matter to trial at District Court, in which case Arnie would have to give evidence again, or to dismiss the case. He found it very distressing that it might be dismissed and, even though the cross examination had been hard, he was keen to go to Court again. The police officer who was driving Arnie and his Mum to the airport assured them both that he would contact them to let them know the outcome. At CLP the next day, we heard that the Judge had ruled that the case proceed to trial.

Getting life back on track

Four months later, in June 1997, Arnie returned to Brisbane, having become "bored" with Central Queensland, and wanting to "get his life back". He arranged with two friends to spend two weeks with each of them until he found a place of his own - illustrating both the depth of his friendships and his recovery from the breakdown.

He contacted CLP soon after his arrival, eager to announce his return. It didn't take long for him to turn the conversation to Alec, wanting to make sure he got "what is coming to him". Over the next six months, nearly all my work with Arnie was focussed on his dealing with the robbery and preparing for the trial.

Emotionally, he was still devastated by the robbery, even though many things fell into place for him on his return to Brisbane; for example, through a Housing Group, he got a two bedroom flat, twice as big as his old flat, at a very affordable rent. He fluctuated between celebrating these new and, in some ways, better beginnings and blaming Alec for having to make the changes. When he had difficulties budgeting his money, which had always been a problem for him, it was Alec's fault. If he had trouble with literacy, that was because of Alec and the robbery. From his perspective, Alec had taken away his life. He was so bitter about the robbery that he found it almost impossible to see that, through guts and tenacity and support from his friends, he had re-established his life. Perhaps, in some ways, staying angry, reliving the pain and blaming himself was a refuge from his day to day struggles.

If Arnie was to not get stuck, going over and over the robbery and what it had done to his life, he needed to find ways to express his feelings about Alec, the incident, and himself. I found that supporting him to reflect on his life, before and after the crime as well as the journey between, was a useful way for him to make sense of what had happened. It was painful, but it helped him realise that his life didn't only revolve around being a victim of crime. It meant acknowledging that what had happened was a horribly traumatic experience and expressing all his anger, self-blame and fears, but moving towards an understanding that his life was more than just the robbery. It was never about encouraging him not to express his anger and fear when it arose, but supporting him to find ways not to let it defeat him, or let it rule his life.

One technique that Arnie found useful was for us to set up a 'ritual' for him to express all the fear and anger he wanted to direct at Alec. It also helped him deal with his frustration that he would not get an opportunity, as he had originally hoped, to confront him in Court. He had realised that, in the very controlled Court environment, the victim's only input is through their evidence.

The desire to have your say and to vent your spleen is very natural. Arnie and I created a ritual, borrowed and adapted from a Gestalt approach for our purpose. Arnie is artistic, and a great story teller. He often speaks in metaphors, even though his literacy skills are limited. He dictated a statement to me, "How I feel about Alec", with the subtitle, YOU PIG. In it he said what he'd like to say to Alec and how he felt about what had happened. He threw in a few vengeful phrases in very colourful language - my favourite was, "YOU ARE LIKE A DIRT STAIN ON A T-SHIRT I JUST WANT TO WASH OUT".

Arnie wanted to type up his statement so, over a period of two weeks, he typed directly from the copy I had written. It was very time consuming for both of us, but his commitment and passion for it was incredible. He then practised reading it until he had virtually memorised it. He took great pride in his document: it was one step towards getting back at Alec, showing himself and others he didn't have to be afraid any more.

Next, he drew a very unflattering picture of Alec's head. We put this head on an upright fan, dressed up in clothes, and surrounded the effigy of Alec with chairs, to represent police officers -Arnie‟s touch to make him feel that Alec was being punished. He sat behind a table, facing him like a judge, and read his "YOU PIG" statement with great enthusiasm. It was a powerful moment. We then took the effigy apart, and walked away, symbolising Arnie being able to walk away from Alec and the power he had in his life. Arnie was very excited by what we had done, and he even decided to burn the drawing. It was contrived and a bit abstract, but Arnie, who thinks in metaphors, found it satisfying.

Preparing for the trial

We were also supporting Arnie to prepare himself for the up-coming District Court Trial. There were a number of key areas of work:

* developing Arnie's understanding of the Court process and his role in it as a witness

* working with the Victim Support Service and getting information on time-frames, victim impact statements, criminal compensation etc.

* visiting an empty courtroom, and watching similar trials

* pre-trial meeting with the prosecutor

* revisiting Arnie's statement.

Even after his experience of the Committal Hearing, Arnie still saw the legal system as an arena of combat where the winner goes free and the loser cops all and goes to jail. Over time, we worked to develop his understanding of the Court process, knowing that he would not be able to give evidence if he was terrified. In his anxiety and fear of the judicial process, the crucial concept that he found difficult to grasp was that he was only a witness - and that witnesses don't go to jail just because a person is not found guilty. What eventually helped allay Arnie' fears was a video produced by the Victim Support Service, "Violent Crimes - The Legal Process", which explains Court processes from the point of view of a victim of a violent crime. In the video, the presenter explains "that if they find the accused not guilty, it isn't that they didn't believe you or that they thought you a liar, but that they didn't have enough evidence to convict". I'm sure I had previously tried explaining this same point to Arnie many times and in a number of different ways, but seeing it on the video seemed to make it concrete and credible.

The Victim Support Service (VSS), and particularly the VSS worker, played a key role in helping Arnie prepare for the trial. I contacted them, with Arnie's permission, to seek their support and to let them, and therefore the DPP system, know that Arnie had an intellectual disability and that their preparations needed to take that into account. The worker kept Arnie and me up to date about what was happening in the pre-trial processes and about the possible dates for the trial. This input was crucial for Arnie: he felt he now knew someone in the system, and that gave him a sense of having some control over what was happening. When he was anxious, he often got confused about the legal process, and at those times, with my support, he was able to call the VSS worker to clarify what was worrying him, to find out information, and to be reassured that the legal system was working towards Alec's conviction. As a worker, it was very helpful to have someone from whom I could find out information about legal processes, an area with which I was unfamiliar. I could then be very clear with Arnie about the process and clarify questions that he had, as well as be clear about possible outcomes, so that he could prepare himself for what he might feel if Alec was found not guilty.

The VSS told Arnie that he could prepare a Victim Impact Statement which the Prosecutor would present to the Judge if Alec was found guilty. Developing the Victim Impact Statement was an opportunity for Arnie to record what effect the robbery had had on him. After we talked it through, Arnie dictated to me his reflections on the impacts of the robbery and drugging. He was able to make sense of what had been a very tumultuous time in his life and, most importantly, realise that he had moved on, that he "had got his life back". He also felt heartened that the Judge and the Court were interested in knowing what he had been through.

The Victim Support Service was also able to support Arnie to visit an empty District Court room. It was important for him to get a sense of where everyone sits in the courtroom, especially where he and Alec would sit. When he discussed the upcoming trial, he had a picture in his mind of where it would all be happening, and it helped him be less fearful.

There are a number of public galleries above District Court rooms in Brisbane where you can watch trials in progress, and Arnie watched a number of trials. He was nervous the first time but, as he got used to being in a Court, he became quite fascinated with the trials. This was useful preparation for him, getting concrete information about how a Court works, and especially seeing people being cross-examined as he would be.

I asked the VSS worker to try an organise a pre-trial meeting with the prosecutor, and this occurred a few days before the trial. The meeting helped Arnie to become slightly familiar and comfortable with the Prosecutor. He asked the Prosecutor if there would be a screen in front of the perpetrator, and if I could sit beside him in Court. He was reassured on both counts. The Prosecutor used the meeting as an opportunity to get to know Arnie and how he would question him in Court.

When they practised the questioning process, Arnie greatly embellished his story and contradicted himself a number of times. Because this could have seriously damaged the way Arnie's evidence was perceived in Court, the Prosecutor continued to question him about certain details. Arnie thought that the Prosecutor thought he was lying, and he got very upset - which was helpful in many ways, because the Prosecutor was able to explain that it was his job to help Arnie tell his side of the story, that he needed to ask questions to do this, that Arnie would be believed, and that he didn't have to be afraid because nothing would happen to him in Court. It also alerted the Prosecutor to Arnie's communication style and his emotional fragility.

In hindsight, it would have been useful before meeting with the Prosecutor, to have helped Arnie revisit the original police statement - it had, after all, been over 17 months since he'd given his statement to the police. However, after the practice with the Prosecutor, Arnie and I sat down and re-read his police statement a number of times. Without passing judgment, I pointed out to him the places where what he had said to the Prosecutor contradicted what he'd said earlier. In his statement, for example, he said he went into the neighbour's flat after being invited in for a coffee, but he told the Prosecutor the guy had physically grabbed him and dragged him in. He saw the difference and admitted he'd tried to make his answers stronger. In fact, the guy hadn't dragged him in, but he hadn't been able to say no because he was scared. Seventeen months after the event, he still was blaming himself and, by altering his story to stress that he had no physical opportunity to get away, he didn't have to admit to himself and others that he did what he was told because he was scared.

Again we talked about who was to blame and who was on trial: "Did you do anything wrong? Whose fault was the robbery?" Arnie knew in his heart that no one would blame him, but he had never actually admitted to me why he embellished the story. We'd been building up to this moment for six months, but it was only two days before the trial that Arnie could admit the truth of what had happened to himself, and to me. It was a watershed, because he now realised that, if he wanted

Alec to be convicted, he just needed to tell his story, let the Prosecutor do his job, and try not to worry about what others thought.

The Trial - Day 1 (February, 1998)
We arranged that the investigating officer would pick up Arnie, Lisa and myself in his car. For Arnie, this meant going to Court with allies who believed and supported him. On the way, the officer stopped and bought Arnie and himself a Coke - this chuffed Arnie enormously: "The police are on my side".

When Arnie found out that the trial was to be held in a Court room we had visited, along a corridor we had walked many times, he relaxed visibly. Knowing that we would have a long wait, I had encouraged Arnie to bring his drawing materials to occupy himself. As we sat waiting for the trial to start, Arnie chatted to people and showed them his artwork. Many times that morning, we stressed to him that all he had to do was answer the questions, and his part in the trial would be over.

When he was called to the stand, he saw the screen in front of Alec, and saw that I was to sit beside him, as the Prosecutor had promised to arrange. He could also see the VSS worker in the gallery. The Judge, who had been informed by the Prosecutor of Arnie's difficulties, took the step of reassuring him that he would be believed and that it was the job of the Prosecution and Defence lawyers to ask Arnie questions. The Judge's reassurance helped Arnie relax again.

He was calm and responded clearly to open-ended questions from the Prosecutor, who had obviously learned a lot from the meeting two days earlier. The Prosecutor was blunt, but this helped keep Arnie on track. He was so relaxed that he asked the Judge if they would get him, and me as well, a drink of water! Because he was calm, he gave very clear answers, just telling his story as it had happened. He didn't need to embellish the story to give people an insight into how horrible it had been for him.

When it was the turn of the Defence lawyer, he asked Arnie some loaded and leading questions which, for the most part, Arnie didn't fall for. When the Defence asserted, however, that Arnie used to talk to Alec frequently and had asked if he could go to Alec's place that night - the accused's version of events - Arnie rose to his feet, slammed his fist on the witness box, and shouted, "He's a liar! I had good stuff and he took it!" The Judge asked Arnie to have a drink and calm down, but the Defence decided he didn't have any further questions.

When Arnie left the stand, we congratulated him on his evidence and conduct in the Court room. He was justifiably pleased with himself. We went to Macca's to celebrate that his part in the trial was over, and we toasted him. I reiterated that, no matter what the verdict, Arnie could leave Alec and the robbery behind him now and get on with his life. If the verdict was 'not guilty', people would have believed Arnie's story, but thought there wasn't enough evidence. I said that Arnie had gone all the way, shown Alec that he was no pushover, and for seventeen months had kept Alec worried about going to jail. Arnie agreed, but was honest enough to say that he'd be really mad if Alec was not found guilty.

He wanted to watch the rest of the trial from the gallery. He saw the police evidence - including some of Arnie's things they'd found in Alec's cupboard - and he got to see Alec on the stand and his story being challenged. They also played a video interview with Alec, that didn't reflect well on him. We had to keep reminding Arnie that he couldn't speak from the gallery - he was all for debating what Alec was saying - but he dealt with it well, getting upset only a few times.

When the trial was held over to the next day, Arnie was firm that he wanted to go back to watch the conclusion. The police officer gave us a lift back to CLP, and we talked about what Arnie could do that night to relax. The police officer thanked Arnie for giving evidence, and said that it was all over now - no need to worry any more.

The Trial - Day 2
When the Prosecutor summed up, he emphasised Arnie's disability, but he also stressed how awful the robbery and the aftermath had been for him. The jury retired, and the VSS worker and I reassured Arnie again that, no matter what the verdict, the trial was now over and he could get on with his life.

The jury returned - with a guilty verdict on all charges. Arnie did a restrained fist pump, and went on a hugging spree. It was a huge affirmation for Arnie that twelve complete strangers from the community had believed his story and thought what had happened to him was wrong. He had great satisfaction seeing his Victim Impact Statement handed to the Judge, and the Judge reading it. Alec was sentenced to jail, and the Prosecutor informed the Judge that Arnie would be applying for criminal compensation. To say that Arnie was happy with the outcome is an understatement.

Arnie thanked the Prosecutor and the assisting solicitor, and we returned to CLP on the train. At CLP, we got in some champagne, called together some of Arnie's friends, and celebrated the verdict. Arnie thanked everyone for their support.

It is now more than nine months since the trial, and over two years since the robbery. Arnie is in the process of applying for Criminal Compensation through Legal Aid. He still has occasional nightmares about what happened to him, but he is very involved with a local community organisation, where he spends most working days maintaining their garden and chooks, and doing his drawings. A month ago, he had an exhibition of his drawings (three hundred of them!), and sold quite a few. He is a member of the CLP committee of management again, and the proud owner of a very impressive stereo system, television and VCR. He has washed the dirt stain out of his T-shirt.

Note:- Arnie"s story was written by John Hooper for inclusion in "VOICES – People with Intellectual Disability and the Criminal Justice System". VOICES was a publication of the Victims of Crime Project jointly sponsored by Alina, Community Living Association and WWILD. Funded by Department of Justice, Queensland, 1998.

WORKING WITH FAMILIES

While parents have their own individual needs and aspirations, as valid as those of other family members, a primary task of parents is to nurture and protect their children. When a child has a learning difficulty, parents provide extra support, negotiating for services and advocating for their child from an early age.

As children grow to young adulthood and engage in the normal tasks of adolescence, they begin to separate their identity from those of their parents, wanting more independence and privacy and their own sexual identity. For all parents, there are tensions between encouraging independence and continuing to protect their child.

Parents of a young person with a learning difficulty may, however, see the developmental tasks of adolescence, such as acting out and withdrawing from the family, as part of the young person"s disability rather than as a normal part of adolescence. Alternatively, if parents don"t believe that their adolescent son or daughter can move towards independence, they may see their own lives subsumed by an ever-dependent child. While still at school, the structures and the resources of that system are available to give parents support. On leaving school, both the person with a learning difficulty and their parents can feel unsupported and isolated.

Practice Principles

At C.L.P., we have separate workers for a young person with a disability and for their family. A youth worker supports the person with a learning disability and the Family Worker supports the parents.

Family work at CLP has three key principles:

a) acknowledging the parent as an individual in the family

b) addressing the parent"s feelings of isolation.

c) normalising the experience of having a child who is growing to adolescence and young adulthood

Acknowledging the parent as a separate person within the family

As the parents of a person with a learning difficulty, mother and fathers have their own stories to tell, and their experiences need to be validated. While the issues and concerns that parents raise are usually related to their son or daughter, they are often issues that affect their own lives as well – their relationships, their work or their health. Often parents feel stuck in their own lives when they see their son or daughter not moving on.

Developing a relationship with the parents is important, and actively reaching out to them is the best way to begin. We phone parents to check how they are seeing things, and we arrange to meet them when and wherever it is comfortable and suitable for them.

Addressing feelings of isolation

Parents who have a family member with a learning difficulty often talk about feeling isolated and unsupported. One parent may take on the primary caring role, but both parents can feel isolated from their partner and extended family members, particularly when they have to make decisions about their son or daughter with a learning disability. Parents can also feel distanced from friends who do not have disabled children, believing they can‟t understand or offer support. Then, too, once a child leaves school, parents can become even more isolated than before, without information about services and without supports, and with less contact with other parents. The family worker‟s task is to acknowledge and offer the opportunity to talk about the feelings of isolation, to offer contact with other parents, and to give information about services available in the community.

Normalising adolescence

Adolescents need to develop a sense of their own identity, separateness and sexuality. The relationships between adolescents and their parents are challenging for both, and very different to childhood relationships. Parents often find the behaviour of adolescents difficult and hard to understand.

Because parents of a child with a disability have had to focus on the child‟s extra support needs, they can assume that the issues presented by adolescence are part of the disability, rather than a part of a normal developmental stage - especially if the child with a learning disability is the oldest child in the family, and it is the parent‟s first experience of adolescence.

The family workers task is to give parents information about adolescence, to support them and to suggest ways of living with their adolescent.

When Steven first contacted CLP he was a young man of 20, living at home with his parents. After leaving Special School at 17, Steven had been working with a supported employment agency. A number of short-term jobs had come his way, for example, working as a trolley boy and as a kitchen hand in a fast food outlet. He had also been referred to a number of TAFE courses and, while enjoying these, Steven was frustrated that none had led to a job. With nothing to fill his time meaningfully, Steven spent his days in shopping malls or at home watching TV. He quickly spent his Disability Support Pension payment and usually had no money left within a few days. He told Paul, the youth worker, that he was fighting a lot with his parents. He wanted to move out into his own place, but his parents kept telling him that he wouldn"t be able to manage. He was keen for the family worker, Robyn, to contact his mother.

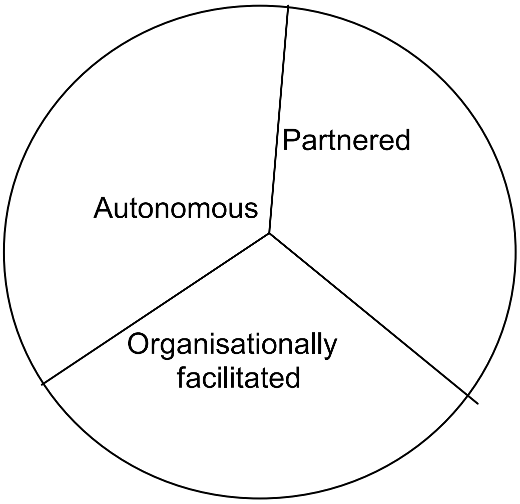
Robyn arranged to meet Jan, Steven"s mother. Robyn was able to encourage Jan to tell her about the situation, as she saw it with Steven. Jan was worried that he had nothing to do with his time and that he was always asking her for money. Steven would get very angry with her when she refused to give him extra money. She felt that the only way to control the situation was to keep his bankbooks and give him a daily allowance. Steven"s reaction to that was to get even angrier and threaten to leave. Jan"s husband, Eric, accused her of mollycoddling Steven: his way of handling it was to tell Steven to take more responsibility. Jan said Steven had become much more difficult to live with in the last few years. She felt that Eric left everything up to her and that the rest of her family really had no interest in what was happening.

After talking to Paul, Steven decided that he would like to get together with his parents, and with Paul and Robyn to talk about his plans to move out and to use support from CLP to do this. Steven arranged the meeting for one evening at his family"s home and, with support from Paul, made a list of the things that he wanted to talk to his parents about. During the meeting, Steven was able to give Jan and Eric a lot of information about his plans, and the work that he was doing with CLP. He asked Robyn to answer some of the questions that they asked about how CLP supported people when they were living independently. Jan and Eric talked a lot about how worried they were about how Steven would manage his money, about him being lonely and how they felt he would not be safe living by himself. At the end of the meeting, both Steven and his parents were feeling that they had begun to work out their differences. They were keen to continue contact with CLP and have further meetings.

WORKING WITH GROUPS

Community Living Program has worked with many groups of constituents. These groups have embraced considerable variety, some have had a social focus, others have been task or feelings focused, some have been highly procedural and others informal, some have been autonomous and others facilitated, some have been co-operative and some conflictual, some hard work for all and some fun.

The development of groups has come at the direct or indirect request of constituents or out of the planning of workers. There have been things done well and there have been mistakes.



While there are many dimensions that can be used to consider groups e.g
Short term/long term
Task/support
Formal/informal
It is the dimension of ownership that has been where most of our learning has occurred.

The earliest groups at CLP were organisationally facilitated and were set up around constituents being introduced to CLP, getting used to CLP space, meeting CLP staff, getting used to social situations. Such groups have continued to be important at CLP. There are presently facilitated groups involved in:

Literacy (in conjunction with local neighbourhood centre)
Physical and psychological well being
Prevention of exploitation
Communication and social interaction.

The next group development at CLP was the development of autonomous groups. Specific amongst these was a housing co-operative, later to become a non-profit company run by the tenants and a political advocacy group. Supporting these groups threw up many issues that had not been foreseen and that we as supporters were unprepared for. Some of these issues included tensions between individual and group needs; for example, one member may want meetings to be held at their place (maybe to feel self important or to gain companionship), but this may be a very difficult venue for other group members. Or someone might say to the treasurer, “You are my friend, so you will let me skip paying (rent etc) this week”. Because the treasurer wants that person as a friend, he or she may find it difficult to say „no‟ to the individual on behalf of the group.

Another issue is the performance of „tasks‟ that an autonomous group will have to do. People with a learning difficulty may not find it easy to complete some groups tasks, due to comprehension difficulties, literacy, numeracy difficulties, memory difficulties and issues of self-confidence. Some examples of difficult tasks are: formal meeting procedures (including chairing and taking minutes), letter writing and interpreting correspondence, maintaining records (ie minutes and financial negotiations with others) and carrying through decisions.

A third issue for autonomous groups is leadership. Because people with a learning difficulty often experience abuse, it is not surprising that they sometimes expect that leadership roles mean that they will be able to „boss others around‟. It is our experience that addressing these issues in autonomous groups has been difficult and at times painful. Groups have had to educate themselves as issues arose and have had to have considerable support in developing more formal processes and procedures to deal with issues. It is also clear to us that more extensive support and training to groups earlier, the adoption of formal systems early on, and a clearer expectation of what our role was would have been of help.

Partnered groups arose partly as a response to these difficulties in situations where there seemed to be constituent energy around an issue which CLP though was important. One example of this is the „Talking about Schools groups‟, many constituents at CLP have stories that they tell about school, most of these stories are about bullying and bad experiences they had at school. Workers at CLP brought people together to talk about their experiences to suggest they be documented and shared with schools etc. Constituents responded with great enthusiasm. They provided the content, speak at events, plan what next, share tasks of approaching groups etc with workers. The workers support constituents in doing tasks or provide support by doing tasks and facilitate the group meetings.

Constituents of CLP have evaluated groups positively and CLP is committed to continue working with groups. We feel that in many ways our learning is still rudimentary, however, we believe that being aware of dimensions such as:

- autonomy
- organisational facilitation
- partnership
- task focus
- emotional support

is crucial to the organisations approach in working with groups.

UNDERTAKING RESEARCH

There are always logistical and ethical considerations in research with any group of people. Some of these considerations are technical, for example, those relating to validity and reliability. Some issues are linked to ethics and values, such as confidentiality and anonymity for people who take part in research as participants. While this section will touch on some of these broad issues, it will focus specifically on issues that have proved to be relevant to research with people with learning difficulties.

Most of the information here is based on what we have learned from the YAR< >MID Project, research designed to look at the life experiences and needs of young homeless people with an intellectual disability, who generously shared their lives and their time with use during the project:

In planning research with people with learning difficulties, it is important to think about whether the research design will limit or expand the ability of the researcher to enter into the world of learning disability and to understand that world. As in the YAR< >MID Project, some prefer a research design which is qualitative, as this allows for the possibility of a meeting of minds and also allows for issues that the researcher (as an interested outsider) may never have considered to be part of the research agenda. Qualitative research, carefully thought through, gives a richness of data that is not achievable through quantitative research. It allows participants to identify issues and to have their say in their own way. It provides a process of interaction between researcher and participants such that both can check information and further explore issues raised. Most significantly, qualitative research (or research using qualitative methods) is a way for the voices of participants to live in - and often to enliven! - the research report. These voices give strength and reality to the research findings.

Once a decision has been made regarding the design of the research, attention needs to be given to planning and implementing the research strategy. Identifying participants for research (the sample) involves a mix of logistical (such as, “How do I locate the people I need to talk to?”) and ethical (such as, “How do I identify and approach people?”) issues.

In the case of people with learning difficulties, of identifying participants can be difficult. Many people who have disabilities are reluctant to identify themselves as having a disability, often because of previous negative experiences related to disclosing their disability . Others have never been diagnosed as having a disability, and simply identify themselves as being different or having problems with things others find easy. If the research design relies on service providers to link the researcher with participants, it is of prime importance that these workers are able to identify learning difficulties. This is not always the case.

Ethical issues are also of importance and need to be thought through carefully when the target of the research is any group of people who are marginalised/socially disadvantaged. In these cases, the mere fact that a person has been approached to participate in research identifies them as different, and leaves them open to further discrimination. This can be the case even if the research is perceived by the researcher or the people approached as having the potential to benefit the group. Nobody likes to be singled out or labelled, yet the process of research often does precisely that.

There are strategies to overcome or lessen these negative impacts, requiring awareness and sensitivity on the part of the researcher. The researcher can, for example, send letters to workers in a range of youth services, telling them the researcher is interested in contacting young people with intellectual disability who are, say, homeless. Sometimes the response to this contact can be a resounding silence, which contradicts experience. Re-contacting workers and asking them about young people who show a range of characteristic behaviours will help in fact, responses will flood in. Workers may also raise, and want to be able to discuss, the impact of young people being approached to take part in a research project, and how this can be done in a way that respects the privacy of participants.

Once contact with the proposed “participants” is established, ethical issues need to be presented and worked through. One of the basic issues that should be resolved before any data is collected is that of consent. The standard must always be *informed* consent, and this standard raises particular issues when the subject group are people with learning disabilities. The first responsibility of the researcher is to ensure that information about the project, and what participation will mean, is explained in a way that makes sense to participants, a particularly testing task when the term „learning difficulty‟ covers a wide range of specific disabilities, and when the level of disability and its effect on functioning can vary widely.

There are two essentials in gaining informed consent: informed consent must mean that the participant know both what steps will be involved in the research for them personally, and what the aims and potential benefits of the research are.

The researcher must be acutely attentive to each individual and use initial contact time to assess each individual - as opposed to making assumptions about individuals based on labels, such as „intellectual disability‟. Sensitivity needs to be coupled with the ability to be flexible and persistent (not to be confused with pushy!) and to present the researcher needs to present information in a variety of creative ways. Clear verbal explanations work for some people with learning disabilities: for others, drawings are more effective.

Further, the researcher must allow whatever time is needed for the participant to absorb and process the information at their own pace. This may mean leaving a break between the time of initial contact and initial data collection. In this time the participant may think through the issues, or they may want to talk with a friend or worker about the implications of their participation. It may mean that the researcher has to be prepared to answer what appears to be the same question a number of times. It may involve going back more than once to discuss the project. Time must be granted graciously and without making the informant feel that the researcher is impatiently tapping their fingers while waiting for a reply.

While some people are adept at resisting pressure from outside, others are not so clear about their boundaries. People with learning disabilities (in common with people from other marginalised groups) are often cited as having a strong desire to gain approval by complying with the wishes of others. They are also vulnerable to agreeing to suggestions and ideas, the implications of which they do not always see clearly. While there are people with learning difficulties who are assertive about their own needs and able to resist suggestions from others, there are many who are not.

Researchers need to err on the side of caution. Where there is any doubt about consent, further work should be done, or the particular informant should be excluded. (This, of course, raises other issues, since it gives the researcher power to include or exclude people solely on the researcher‟s own assessment.)

At the interview stage, the chosen research design will have a significant impact on the type of information that can be gathered. In a qualitative project, there is scope to allow the interview to take the form of people telling their own stories. The story telling can be guided by the researcher around a series of themes. There is also room for the researcher to enter into a dialogue with the informant. In this way it is possible to circumvent some of the difficulties attributed to false compliance which can make the data generated in survey style interviews unreliable. However, even in such a situation, the amount of time allocated for this part of the research will also have a significant impact on the quality of information gained.

Most people enjoy the opportunity to talk about their own experiences. People with learning disabilities are no different. Their stories, though, often make significant demands on the researcher‟s memory, concentration and ability to order material into some structure. People with learning disabilities often need encouragement and time to do justice to their own knowledge. This may mean that interviews need to be conducted over a number of sessions, and it certainly means that the researcher should be willing to work to the participant‟s timetable - rather than expecting the reverse.

Research shows that people with learning difficulties are often exploited and abused by a range of people. The experience of reviewing these life events can be painful, and researchers need to be alert to participants‟ feelings. The appropriate stance for a researcher is non-judgemental, with acknowledgment of the sensitivities of others. Further, the researcher needs to have a strategy to respond to participants‟ feelings: for example, allowing time in the process for de-briefing or limited follow up, and ensuring that the interviewee has support from others in the time immediately following the interview/s.

Because of the quality of contact with people in this type of research, it is inevitable that relationships form between researcher and informant. All researchers have the responsibility to ensure that there is clarity about the type of contact that can be established and maintained. Many people who are marginalised, including people with learning disabilities, are often not welcome in mainstream community. Their lives can be lonely and boring. The researcher displays a high level of interest in the informant, and receives information that may be private. Researchers place themselves in the role of confidante, and may also share parts of their own lives. As Johns (1995) writes, relationships can and do develop over the course of the research project, and these relationships must be negotiated with openness and honesty.

Ideally, in all types of research, there should be a process of feeding back information to the participants. In qualitative research, this is crucial because the researcher holds information that belongs to the informant. Wherever possible, the information should be taken back for checking with the informant. The informant should also be shown how this information will be used, with particular attention to direct quotes and their context. In some projects, this is not always possible, as when young people are highly mobile and cannot be recontacted. If there are doubts about any material the researcher thinks is sensitive or identifying, and the informant cannot be recontacted, it is better not to use the material. There are also choices to be made about the way in which the research findings are presented. If researchers want to present the findings in a journal, they will need to be familiar with the style and requirements of the particular journal. If they are presenting a report, then there is more scope for creative presentation. When a quantity of rich data has been collected, the data can be presented in the form of life stories or direct quotes in the report. Art work and photographs (taken by the researcher or the participant) can also be included. The report should also include a specific acknowledgment of the contribution of participants

Distribution of the report will help to determine whether there are any tangible outcomes. In the case of reports on issues relating to learning difficulties, the tendency is to distribute through disability networks. This is understandable, but leaves out the many mainstream organisations who work with and support people with learning difficulties. The distribution process should also include relevant government departments and politicians . Finally, whenever possible, a copy (or at least an extract) of the report should be given to the participants. This is a way of saying „thank you", and it is also a tangible reminder to the participant of the contribution they have made.

At the end of a project, energy is often low and it is easy to leave out this last step. However, where possible, the researcher needs to give a copy of the finished report to each participant, showing them (and often being asked to mark) the sections which contain their words. Quite a few will be genuinely excited to be " in a book", and the researcher can demonstrate in a concrete way that their information has been valuable.

Research which is properly thought out and executed has the power to help us understand the strengths and needs of the people we study. However, how useful the research is to participants often depends on attention to detail and attention to each individual. Researchers have the ability to bring new understanding to the wider community, and should leave each participant with a sense of their having made a valuable contribution to that new understanding.

WORKERS' FEARS & ANXIETIES

Workers can experience a range of feelings when they begin work with people with learning difficulties.

"I thought (people with a learning difficulty) were different but I wasn"t quite sure what the difference was."

"I didn"t have any idea of how the difference would affect how I should work with people."

"I was afraid of not being able to connect."

"I was afraid of doing the wrong thing … of making things worse."

"I was afraid of not having [the necessary] skills… and of not doing the right thing."

"I wanted to „see the real person" and talk „with the person about the difference" but had doubts that I would be able to."
(Berlin & Fowkes 1994).

A common experience in the early stages of work with people with learning difficulty is an initial sense of difference and uncertainty as to how to handle the difference.

Workers Can:

- gain an overall understanding of how having a learning difficulty impacts on a person's development, socialisation and life experience;
- ascertain, by listening to the person, what have been the major stresses of having a learning difficulty (for example, poverty because they cannot get a job, being exploited, vulnerability, wanting to please others, low self esteem);
- develop relationships of acceptance and trust;
- take time to listen and understand, and convey this respect to the person;
- ask the person directly if information is clear or needs to be put another way;

- accept that the process of working with someone with a learning difficulty is different to working with someone without a learning difficulty, because of the need to regularly clarify understanding;

- work from the premise that we give the same information to people with a learning difficulty as we give to people who do not have a learning difficulty, but the way we give the information may differ (see Communication);

- work from the premise that people with a learning difficulty can make their own decisions and choices, that the responsibility for planning and actioning plans is theirs, and that our job is to support them to take up this responsibility;

- check with the person regularly how the work is going for them. Is it similar or different to what they thought it would be like? Is it helpful or unhelpful for them? What is good/ bad about the work? negotiate together what path to take in any further work.

Working from these principles helps to combat anxiety and free up workers who feel stuck and unsure.

Working with people who have a learning difficulty is both similar and different to work with people who do not have a disability, though there are far more similarities than differences.

- all people have a similar repertoire of emotions, and respond, in part emotionally to most situations;

- all people have the ability to think through and understand their issues;

- we can learn from everyone, including people with learning disabilities;

- the elements of relationship building are much the same - establishing trust, building rapport, etc.

However, when we work with people with learning difficulties, we

- we need to be more aware of the language we use;

- we need to be more aware of making assumptions, and remember to check them out;

- we need to move at a an altered thorough pace;

- we need to make abstract concepts concrete, and meaningful;

- we need to be open and honest about any difficulties we have communicating;

- we may need to work harder to make ourselves understood. Sometimes a worker needs to try a variety of strategies when information is not clearly presented, asking a person how they prefer information to be presented will help to clarify the situation. Some people work best by talking things through, others by writing or drawing. People often have their own ways of remembering and recording information. As the working relationship develops preferences and learning styles will become evident..

WHEN WORKERS DON'T KNOW WHAT TO DO …

There are times and situations when, despite our experience and knowledge, it is difficult to know what to do. As workers, many of us can find it especially difficult to join with people when they are, for example:

- aggressive and threatening towards workers or others;
- self-abusing (drugs or alcohol) / self-harming / suicidal;
- exploitative of others;
- non-responsive to all approaches and suggestions;
- „stuck‟ and unable to move forward;
- confused / lost / not making sense;
- making difficult demands on workers;
- not telling the truth;
- engaging in illegal activities.

Of course, the difficulties lie as much with the worker as with the person exhibiting any of the above behaviours. Because all behaviours have meaning and purpose, it is helpful to work with the person to name the behaviour that is occurring, and to explore what lies behind the behaviour that the worker finds challenging - bearing in mind that there are added communication difficulties for people with learning difficulties, and so workers need to be careful not to make guesses which can turn out to be very wrong.

Workers can:

- share the difficulty with the person ("I don‟t understand what‟s happening.")
- change their way of working and experiment with other ways;
- talk in confidence with other workers / mentors / supervisors;
- develop strategies within the organisation to address similar difficulties in the future.

When all else fails, we need to remember that “some days some things sometimes work” - and keep on listening and learning !

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