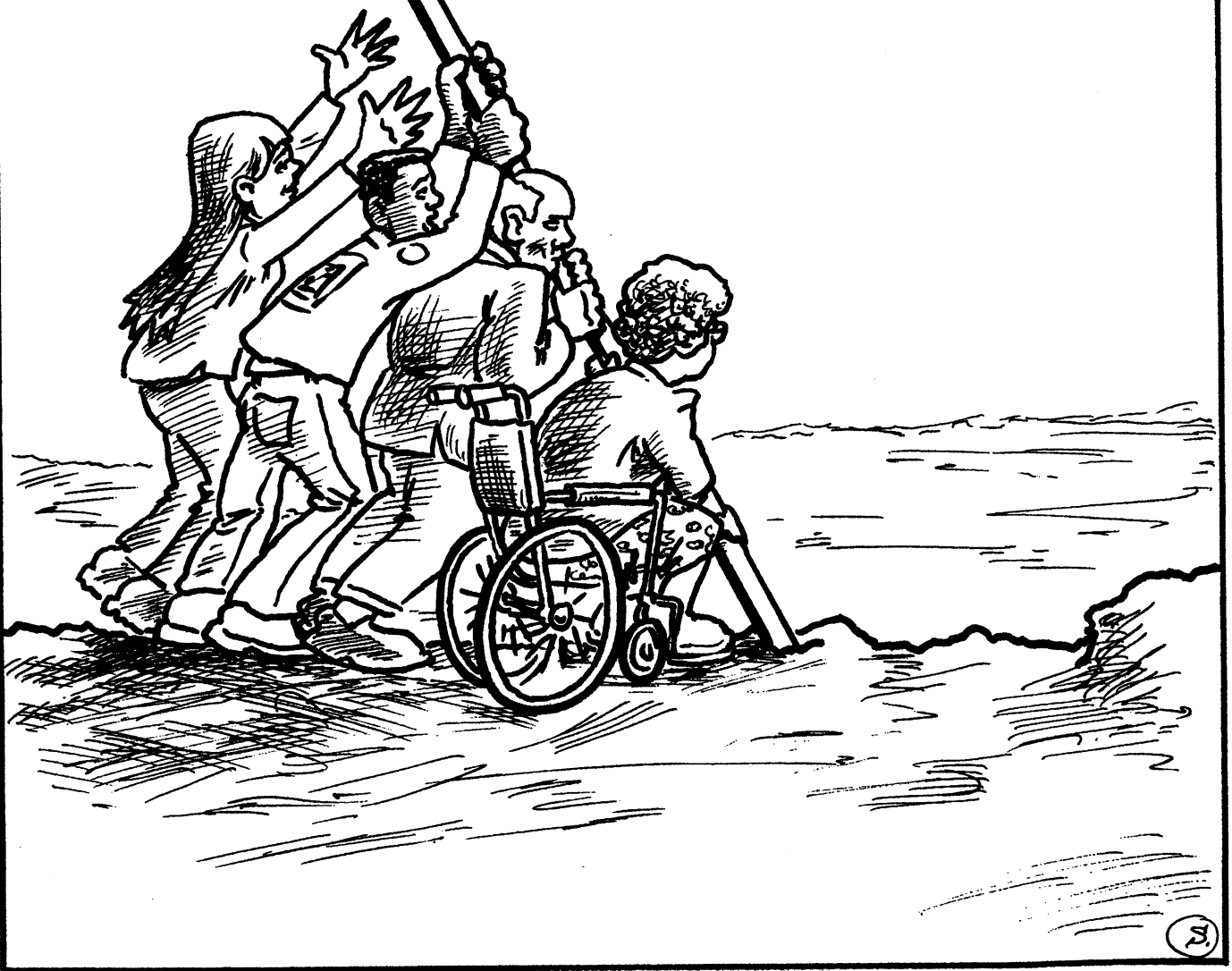


# IT'S OUR LIVES.

A SHORT THEORY OF  
KNOWLEDGE, DISTANCE  
AND EXPERIENCE.

PETER BERESFORD.



# IT'S OUR LIVES

**A Short Theory of Knowledge,  
Distance and Experience**

**Peter Beresford**

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**Citizen Press  
Tempo House  
15 Falcon Road  
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**Shaping Our Lives  
Unit 57 Eurolink Centre  
49 Effra Road  
London SW2 1BZ**

**Email: [information@shapingourlives.org.uk](mailto:information@shapingourlives.org.uk)**

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# A CAT CAN LOOK AT A KING.



←— DISTANCE IN FEET & INCHES- 3' 6" —→

←— DISTANCE IN UNDERSTANDING- 10,000 MILES —→

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# Summary

This small book is concerned with supporting people's empowerment by valuing their knowledge and experience. To do this it explores a new idea.

We are told this is a 'knowledge society' and that public policy and practice needs to be 'evidence-based'. But how do we actually *know* something and what is the best way of finding things out? For a long time it has been argued that key values for finding things out and producing knowledge are being 'neutral', 'objective' and 'distant'. But what about people who have first hand experience, for example, of being oppressed and discriminated against? If we go along with this approach, then their knowledge will be treated as less valid and less reliable. This can't be right.

This small book explores a different way of thinking about knowledge and doing research which seeks to value people's first hand experience and 'experiential knowledge' in order to support their empowerment. It offers a theory to do this. This theory states that:

**The greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted.**

This booklet looks at this idea in more detail. It explores how people try and find things out in their day-to-day lives and defines the terms on which the idea is based. It shows how research has often ignored people's experience and their own interpretations of it, although this is now beginning to change with a new emphasis on user involvement in research. It shows how the individual experience and knowledge each of us may have, can become collective knowledge which can really change things for the better.

The book also looks at what can distance people from their own experience and how this can be improved. It examines what distances people from others whose direct experience they interpret and how this gap can be reduced to improve the quality of knowledge that is produced more generally.

# Preface

This little book tries to explore a new idea. It is concerned with the relationship between knowledge and the first hand experience it may be based on. The book aims to offer a theory to help explain how we think about knowledge and the research people to do to find out more and increase knowledge.

Theories are often developed by people having an idea and trying to force other people and things to fit into it. The theory discussed in this book has grown the opposite way round. It has grown from seeing how things are for people, (especially people who face discrimination and have little power); how their knowledge and experience are treated (sometimes badly) and then trying to make sense of this and improve things.

This theory has grown out of trying to change things as well as thinking about them. For some time, I have spent much of my time, being involved in community and service user groups and organizations. These have been concerned with trying to make things better for ourselves and people like us. They have never been concerned only with thinking or writing about things just for the sake of it. They have also often been part of broader social movements which have generally prioritized people's own first hand experience and highlighted their capacity to offer their own accounts from their experience.

Some people may not agree with this theory or idea. It is at an early stage of development. The hope is that it can support people's empowerment. Its strengths and weaknesses need to be explored to see if and how it might be helpful. That's why the reader's thoughts and comments are valued.

This booklet is a first attempt to explore this idea. Comments from other people would be very helpful and are welcomed. If you would like to make a comment then please send it to:

[information@shapingourlives.org.uk](mailto:information@shapingourlives.org.uk) marked Knowledge and Experience or fax it to me at 020 7223 7116 or post to Tempo House, 15 Falcon Road London, SW11 2PJ

Peter Beresford

# Thanks

This is a small book, but I have many people to thank for helping me put it together. These include Kathy Boxall, Simon Kewer (who did the pictures and much more), Matt Coyte, Scott Fitzgerald, Suzy Croft and everyone at Shaping Our Lives. Most of all I want to say thank you to all the health and social care service users whose experience, efforts and understanding have led me to write this and inspired me to keep going.

# The author

Peter Beresford has a background of involvement as a service user, worker, researcher and campaigner in the field of citizen involvement. He has a particular interest in the involvement of people who use health and social care services. He is a long term user of statutory mental health services. He is Chair of Shaping Our Lives, the national user controlled organisation committed to increasing the say and involvement of health and social care service users. He is also Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University and Visiting Fellow of the School of Social Work and Psycho-social Studies at the University of East Anglia.

# Introduction

**Information is only the path...The goal is knowledge.**  
John le Carre, *Absolute Friends*

We are constantly told that this is an 'information age' and that we live in a 'knowledge society'. But how do we actually *know* something? For example, how do we know about the problems which people have in society, for instance, if they are poor, disabled, older, lone parents, have learning difficulties, or use mental health services?

For a long time there have been powerful views about this. Particular ways of trying to find out about such issues and problems have been developed. A big research industry has grown. There is a lot of talk about research being 'scientific'. It is as if it were like men in white coats examining insects or chemicals.

These ways of finding things out have often left out the people experiencing such issues and problems themselves. They have often given little value to what these people *themselves* think or have to say. Instead they have come up with their own ideas.

This book aims to challenge this way of doing things and look in a different way at what people themselves say who experience problems and discrimination in society. It seeks to look again at the value of their knowledge. This book aims to begin to develop a new theory which gives more, rather than less value to what people know who experience oppression.



# What is a theory?

**There's nothing so powerful in the world as an idea whose time has come**

A theory is when someone thinks they have found a way of explaining things. Examples of theories are that people don't fall off the world, because it is round, or if you drop a slice of bread and jam, it will always hit the floor on its jammy side (Sod's law). There are theories like the theory of relativity and theories about how human beings develop and behave.

Most theories aren't actually theories – they are *hypotheses* – that means that someone is offering the idea as an explanation, but they can't prove or disprove if it works. This is true here. But hypothesis is an even longer word than theory, so I will use the term theory here and hope that it is clear what is meant by it.

It can be as useful to refute a theory as to feel that it works. What it can do is help us to think carefully about something and perhaps begin to think about it in a different, more helpful way. In this way it can add to our understanding. That is the aim here.

# Talking about knowledge and research

**Some of us know what it is like to be learning disabled; others are university researchers who don't know what it is like...No disrespect to university people but they don't know what it's like to be learning disabled, they don't have the knowledge**

(Docherty and others, 2003)

Knowledge is one of those very big words that we may not often think about and which can be frightening. We may take it for granted But, if we are asked what it means, we may find it hard to answer. What is knowledge? What it is based on? How do we know something? What does it mean to know something? These are some of the big questions which human beings ask.

Because knowledge is an important idea, it is often talked about in complicated ways. People use long words like 'epistemology' and 'ontology' This can make it even more frightening and excluding. Words like this won't be used here! We may not want to be experts about an idea like knowledge, but it is helpful to feel we can understand it better and no longer need to be afraid of it.

Because it is important to 'know what you are doing', the importance of finding things out carefully and properly is often stressed. There is a lot of talk about doing this in ways which are 'rigorous', 'systematic' and 'scientific'. Much money is spent on finding things out and getting new knowledge. The National Health Service has a budget of £1/2 billion a year just for research and development. The government now says that all health, welfare and public policy should be 'evidence-based'. They mean by this that it should be based on *knowledge*.

Scientists have found out many new things in the last hundred years. They have made new discoveries, for example, about nuclear

physics, electronics, information technology, space travel, our bodies and microscopic or 'nano'-technology.

But many things that people think they know about they get wrong. So recently in Britain millions of animals were killed because they had foot and mouth disease. Since then it has been shown that this was not the right thing to do. For a long time, important scientists said there wasn't a problem of 'global warming' damaging the environment. Now it is recognised to be a real threat to us all.

## Seeing knowledge and 'finding out' as 'scientific'

There is also the question of whether you find things out about human beings and the societies they live in, in the same kind of way as you find out about the natural world of plants, chemicals and elements. For a long time there seems to have been a belief that you could do this. New areas of knowledge were developed like psychiatry, psychology, anthropology and sociology, to study human beings and the societies they lived in. These were called human and social *sciences*.

With their emphasis on 'science' and being 'scientific', these approaches to knowledge strengthened the idea that you could find out about people and how they live in the same way as you found out about other things. Their approach to research and the creation of knowledge was the same. They emphasised the importance of particular 'scientific' values. The most important of these values seem to be those of: neutrality, objectivity and distance.

**Neutrality** – this means not being biased about something, through being involved in any way - being detached and without any vested interest;

**Objective** – means not being influenced or affected by feelings or opinions -being able to consider something coolly, dispassionately, without being emotionally involved;

**Distance** – means not being close to the subject under consideration, being able to ‘see the big picture’ and not being affected by it.

All these values seem to be about the relationship of the person finding things out, or creating knowledge, to what they are trying to find out about. All emphasise that the person should be unaffected by, separated and *distant* from the subject of their attention – that is, what they are trying to find out about.

## The myth of neutrality

For some time now, more and more questions have been raised about whether this is really possible and whether anyone can actually be like this in relation to other human beings and the societies we live in. This is based on the view that social research - finding out and knowing about people’s lives and experiences - is not like researching things like rocks and plants. Rocks and plants are physical things. According to how we feel, we might think a particular rock is big or small, or beautiful or ugly, nice or nasty (especially if it falls on us, or we trip over it!) but there can’t be a lot of argument about what it is made of, where it is, or its dimensions and we can find out about all of these in straightforward ways. How we live and how people behave are different.

We come to human beings as other human beings, with attitudes and emotions. How we understand how people live and why they do what they do, is affected by our judgements and values. Is something important to know about? Should people behave like this? What is there about them that they behave as they do? Such questions are always affected by us being human too. We come to such understanding and knowledge through our senses and feelings – through what we have learnt and experienced - through our ‘subjectivity’ as other human beings.

There is another way in which human beings are different to rocks and plants. As human beings we all have feelings. We also have rights and responsibilities. So, for example, someone in the second world war, counting people going into cattle trucks on their way to extermination camps or doing 'scientific experiments' on them which killed them, might have been separated and distant from the subjects of their study. But what about the ethical issues raised by what they were doing? Such behaviour raises moral and ethical issues. What about the human and humanitarian values such activities ignore?

# Marginalising oppressed people

**They kinda demand you prove everything – prove you're alive – prove that you breathe – prove everything.**

**(Referring to the deniers of the Holocaust)**

Professor Raul Hilberg, (2000), commenting on the David Irving libel case.

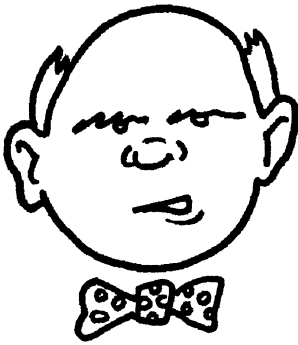
But there is another worry, which is equally important where values associated with research and the development of knowledge about people and how they live, prioritise being distant and separate from the subject under consideration. This has some disturbing implications. These are a particular concern for people who are the subject of such research or about whom knowledge is being sought.

If you have direct experience of problems like disability, hardship and poverty; if you have experience of oppression and discrimination, when such research values are accepted, what you say will always be seen as having *less* value – less *credibility*. Because you will be seen as 'close to the problem' – it directly affects you – you cannot claim that you are 'neutral', 'objective' and 'distant' from it. So on top of the discrimination and oppression you may already experience, you face an additional problem. You are likely to be seen as a *less* reliable source of knowledge. We can see how this worked for a long time against women and children who were subjected to sexual and violent attacks. In male dominated societies, these were not placed high on public or political agendas. The knowledge and experience of women and children who were subjected to such attacks, were not listened to or valued. It is only in recent years in western societies that issues like child sexual abuse, domestic violence and rape, have begun to be acknowledged publicly and formally as serious problems.

What this means effectively is that if you have experience of discrimination and oppression you can expect routinely to face further discrimination and be further marginalised by being seen as having

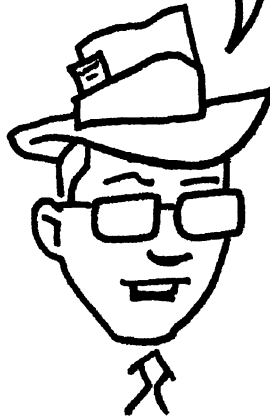
## WE ALL KNOW ABOUT POVERTY.

I'VE DONE A  
LOT OF RESEARCH  
ON POVERTY.



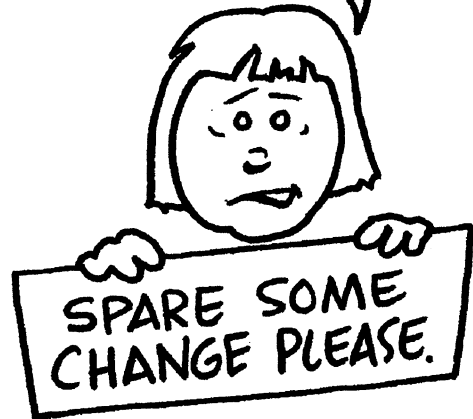
I AM AN  
EXPERT.

I'VE WRITTEN  
A LOT ABOUT  
THE POOR.



I AM A  
JOURNALIST.

I KNOW  
TOO MUCH  
ABOUT  
POVERTY!



I'M POOR.

less credibility and being a less reliable source of knowledge. This fundamentally and additionally invalidates people who are already heavily disadvantaged.

This problem is magnified for many users of health and social care services because their identity is devalued and they are treated as though their knowledge is suspect. Thus people with learning difficulties have often been seen as lacking the intellectual ability to provide reliable information; mental health service users as irrational and children as immature. Such discrimination has undoubtedly contributed to the many instances of abuse and neglect experienced by these groups in state 'care' and the frequent failure for them to be listened to and these problems to be dealt with quickly and effectively.

It should be said that it is not only in the context of research that disempowered people can see their knowledge and experience demeaned and devalued. The same often happens in legal and quasi-legal settings where they might be seeking to have wrongs redressed. Here too, they can expect less weight to be attached to their version of events than to that of more powerful people and interests.

## **Privileging others**

It is not only that the knowledge of people who experience oppression is likely to be given less credibility where values of neutrality, objectivity and distance predominate in research. Such values privilege those who don't have such experience – because they can claim to be 'objective'. In this sense, their ignorance is seen to make them better 'knowers' or sources of knowledge.

Perhaps it is because of this, that most of the 'experts' who have become important writing about social issues like poverty, disability and unemployment, don't have such experience themselves. Being close to something through having direct experience of it has frequently been seen as a form of 'bias'. But there are other ways in



which people may be 'biased' which have been talked about less often.

In welfare and social care, for example, the bias of researchers and commentators who have been socialised into the values and culture of the service system is rarely discussed – except by service users! So 'bias' may be worth thinking about – but in a different way.

## **Knowledge and power**

Knowledge is inseparable from power. It is the victor's version of a war that becomes history. It is generally the powerful who define what is true. There is much truth in the saying 'Knowledge is power'.

Gaining new knowledge can help empower people. But the knowledge of those with least power tends to be granted the least authority. All knowledge is not equal. Some knowledges, deliberately or otherwise, are subjugated. This is perpetuated by powerful structures and values about what counts as knowledge.

Traditional approaches to the production of knowledge have reinforced the powerlessness of people with little power. Such approaches have been based on and embodied inequalities of power. In extreme societies, like, for example, Nazi Germany, only some knowledge is acceptable. Some groups are not permitted to study or to teach. Some books are burnt. Some art is outlawed. Where knowledge is seen to challenge dominant beliefs, it is forbidden. The Nazi's 'People's radio' only broadcast state programmes.

## **The problem with old assumptions**

The problem with traditional approaches to research, with their emphasis on being 'scientific' and treating people as objects, is that they have coloured our attitudes towards knowledge and finding things out more generally. There is still a strong tendency for other forms of knowledge, or ways of finding things out, to be seen as inferior. Thus 'randomised control trials' (RCTs) in medical research are often seen as 'the gold standard' for research. It is not just that

such dominant approaches to finding things out are seen as having particular strengths. Their weaknesses tend to be overlooked and less value is attached to other forms of knowledge.

## Devaluing first hand experience

When someone talks from experience – because something has happened to them and they know about it ‘first hand’ - it is sometimes dismissed. For example:

- *Well, they would say that.*
- *That's all they know.*
- *That's only what happened to them.*
- *They can't see the 'big picture'.*

What they say is often described as ‘anecdotal’, ‘unsupported assertion’, ‘apocryphal’ or ‘just their stories’ – however important or interesting it may be, or how often it is repeated.

Knowledge based on experience, or as it is sometimes called, ‘experiential knowledge’ then comes to be seen as second best – of value only when it can be corroborated by other kinds of knowledge or methods of finding things out which are conventionally valued more. This can result in a situation where something is only seen as true when researchers tell us it is. This devalues people who have had negative and oppressive experiences. It can also in turn devalue research, which people then see as merely saying back to them what they already know. To make matters worse, the issues that matter to people who have little power, may seem unimportant to the more powerful people who generally shape research agendas. So research may not be done, leaving them on their own, without research findings to back up what they know from experience.

THE  
THINKER.



I AM DISABLED,  
THEREFORE I KNOW.

# A different way of thinking

**What we are seeing today are people saying, I've been there, seen it, done it, got the tee shirt and another generation shouldn't be there.**

Former Maze prisoner, on the closure of the Maze Prison, Northern Ireland, Channel Four News, 26 July 2000.

Some people, particularly those facing discrimination and oppression, have become increasingly concerned about such traditional ways of thinking about research and the production of knowledge. This has begun to happen as they have learnt more about how researchers actually do research and have shared their thoughts and ideas with other people who have been on the receiving end of policy, services and research.

They aren't saying that research can't be helpful and important, or that only people who have had direct experience of something, have anything useful to say about it. It doesn't mean either that we don't need to try to find things out in the most careful and systematic ways possible. But it does leave many people questioning the old assumption that knowing about something from your own experience means you are in a weaker position to comment on it than if you don't have that experience, because you aren't 'neutral', 'objective' and 'distanced' from it.

There is now a lot of talk about 'involving service users' in research and 'knowledge production', as if it is the right thing to do. But there is also a lot of opposition to such involvement, as though it reduces the quality of research and means that it is less 'rigorous' and 'scientific'. Sometimes the offer of involvement seems to have less to do with feeling that it will improve the quality of research, than with just doing what's expected or required. This has come to be called a 'tick-box' approach and it is common.

## A different approach

In this discussion I want to begin to explore a different idea. This is the idea that the knowledge that people develop, based on their own experience, may not only not be inferior (to other knowledge), but it can have positive strengths and values which other research and knowledge may lack.

To begin to consider this, let's look at how we usually try to find things out and acquire knowledge. What do we do in our everyday lives?

### How do we find things out in the real world?

A health warning is needed here. It's not necessarily enough to use our 'commonsense'. 'Commonsense' can be a dangerous thing. 'Commonsense' approaches may not be the right ones. They can encourage us to accept the obvious; reinforce attitudes and assumptions based on nothing more than prejudice. But it is still worth trying to connect our understanding of big ideas like 'knowledge' and finding things out, with what we do in our day-to-day life. When we want to know something in our ordinary lives, what do we tend to do? Say we are thinking of going somewhere for a holiday, buying something, sorting out a problem that has befallen us. How do we try and find out and get reliable information, based on knowledge that can be trusted? This is what people said when I asked them:

- Depends on what it is – ask someone who knew something about it;
- Ask someone who has done it, been there, got one;
- Read a rough guide by someone who has a lot of experience of the subject;
- Look at websites by people who share that identity, or have that problem or condition

We particularly seem to value information from someone we know and feel we can trust, based on first hand experience. We go by 'recommendation', 'word of mouth' and 'personal commendation'.

There are many sayings in our society which reflect this approach to developing knowledge and finding things out. They highlight belief in the importance of first hand experience as a basis for knowledge. For example:

- *Straight from the horse's mouth*
- *Don't try and teach your grandmother how to suck eggs*
- *You don't know how it is for someone until you have stood in their shoes*
- *Who knows better where the shoe pinches than the person wearing it?*
- *You don't know about someone's life until you have walked down the same road as them*
- *Set a thief to catch a thief*
- *Done it, been there, got the tee shirt*
- *Poacher turned gamekeeper*
- *You've got to have been there...(to know)*

Although this is an important tradition in many cultures, it is one which we have frequently been discouraged from taking seriously in the context of research and knowledge formation. The assumption seems to be that it may be good enough to live by, but not for when we put 'finding out' on a more formal footing. Perhaps it is time to reclaim this idea; renew our interest in this tradition and explore it more carefully – before throwing any babies out with the bathwater. The point is not to take it on trust or just accept it as a good idea, but to think it through more carefully. It really is time to test out received messages that it is necessarily inferior and unhelpful.

# What's the big idea?

**We read fine things, but never feel them to the full until we have gone the same steps as the author.**

John Keats

The idea here is a simple one. You may have thought about something like it yourself sometimes. It starts from the sense that devaluing the knowledge and views of people who know things from first hand experience and who have suffered hardship, discrimination, oppression and wrong, cannot be right, cannot be helpful.

It challenges the conventional view that distance is a good thing for finding out and creating knowledge. It is based on the idea that having direct experience of something is likely (often, if not always) to be helpful in making sense of it. It follows from the belief that knowledge may well be *strengthened* by being closely based on direct experience rather than *weakened* by it, as we have long been taught to believe. To put it simply, the idea is that the closer the link between direct experience and knowledge the more reliable that knowledge is likely to be. The idea could be summed up like this:

**The greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted.**

Or put another way:

**The reliability and accuracy of knowledge and the distance there is between the direct experience and the interpretation of that experience upon which such knowledge is based, are likely to be in inverse proportion to each other.**

## Scoff if you want!

This is a very different way of thinking about knowing things to what many of us have been taught. Some people may feel that this whole idea is silly and meaningless. What's the point? They may well be right. But the aim here is try and help us think through things to which traditionally not enough attention has been paid. Critics may say that this hypothesis rests on terms and ideas that are based on values. But in a way that is the point. Part of the aim here is to take on the *subjective* nature of what we are talking about - our experience as human beings - to make sense of it, rather than to deny it. Feminist and some other progressive researchers have been arguing along these lines now for some time. Hopefully, at the least, readers may find this discussion helpful, by thinking of it as a *metaphor* – a way of thinking things through and perhaps making more sense of them. But there may be much more to it.

## Getting back to basics

**If you haven't been poor, you've no idea what life is like**

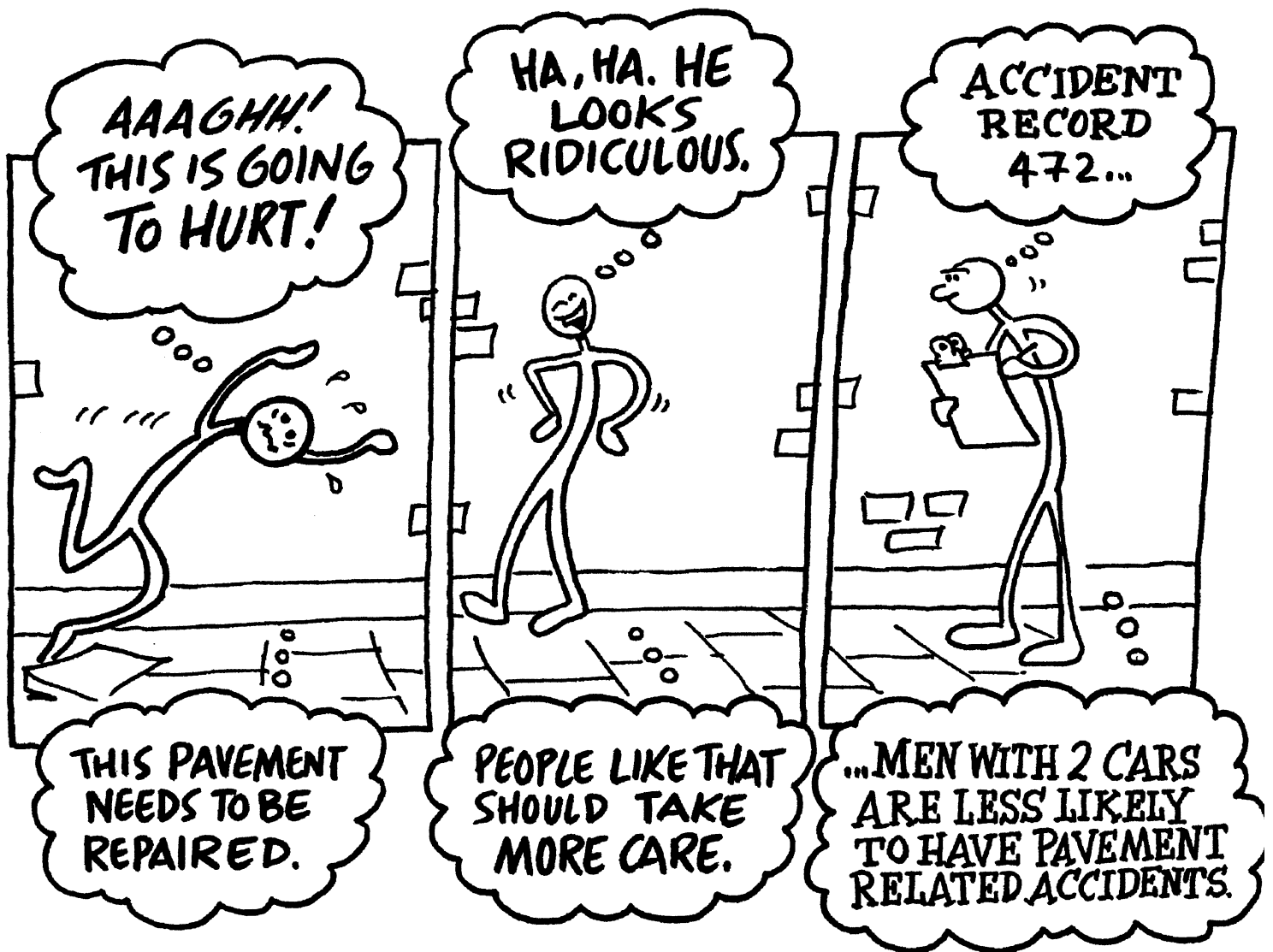
Dick Van Dyke, interview with Andrew Duncan, Radio Times, (1999) September 4-10, pp16-22, p20

It may be helpful at this point to think again, from the start, about how we know about things. So how do we know something? It may be by seeing it, reading about it, hearing about it. We may hear it on the news, or watch it on TV. It may be something somebody is very keen to tell us. We may try and find out about it by asking other people, going to the library, looking on the internet. It may be something our parents told us or our teachers teach us. There are many such sources of knowledge.

Or something can happen to us. We break a leg, have a baby, have a car crash, win the lottery, grow old, or are admitted to a psychiatric hospital. We experience it *first hand* - for ourselves. Then we *know* about it from our own direct experience. We know about it *for ourselves*.



# IT DEPENDS WHERE YOU'RE STANDING



This is different. It means we aren't seeing it through other people's eyes or ideas. We are not hearing about it second hand and forming views and judgements about what people who experience it say, or what we think of them or what others say about them. We are not relying on what an institution or organisation tells us.

### **Having a baby**

**It was and wasn't like I expected. The ante-natal classes prepared me well. But I never realised it would feel like having giant period pains. You can't really know what it's going to be like. After, I was utterly drained. Didn't feel anything about anything. Being in labour is like nothing you've ever experienced.**

Only when we experience something for ourselves, does our knowledge about it connect directly with first hand experience. Then alone can it be based on our own interpretations and understandings of that experience. In all other cases when our knowledge is not based on direct experience, for good or bad, it is based on someone else's interpretation(s).

When it happens to you, is when knowledge is potentially closest to direct experience. This is because the person who is trying to make sense of, interpret and understand the experience, is also the person to whom it happens. In such cases, our knowledge can be based on our own understanding of our own experience. So what we know is based on our interpretation of our experience. Experience, interpretation, knowledge are all located in the same place. This makes possible (but doesn't necessarily mean that there will be – (this is a point we will return to) the minimal distance that there can be between them.

The picture can be very different when these elements; direct experience, interpretation and resulting knowledge, are separate and distanced from each other. Take an example from social care research. Such examples are not uncommon. A group of people with learning difficulties go to a local council day centre. They don't like it very much. Some of them have shared these feelings at a group they go to. They feel that some of the staff at the centre are bossy. They

don't treat them as equals. There isn't much to do. They do the same things over and over again. Transport is unreliable and slow. All they do like is the chance to meet each other outside of home.

A research project wants to explore the views of service users about local provision. The researchers ask them what they think of the centre; how long have they been going, what do they do there, what do they like about it. The researchers get a generally positive response. The research findings highlight this. They are reported in the local paper, saying how happy service users are with the centre. There is a picture of the service users smiling.

What service users don't say, is that they have been careful *not* to say anything negative about the centre because they are frightened the council will close it as part of the spending cuts it is making. In their view, something is better than nothing. Thus service users' experience is negative, but the picture that becomes public knowledge is positive – because the researchers do not 'know' what it is really like to use the centre or what service users really feel about it. They have tried to find things out in a certain way, they have placed their own interpretations on the data – and the service users certainly aren't telling them.

## Defining our terms

At this point it may be helpful to try and be clearer about some of the terms that are being used here, beginning with: *experience*, *distance* and *interpretation*.

### Distance

The word distance is not just used here to mean how far something actually is physically from something else – in feet and inches or centimetres, metres and kilometres.

It is not just about what is called 'objective' distance; that is how far point A may be from point B on a map. It is also about *subjective* distance. That is to say how far away something *feels* to someone;

how far away it is from their actual experience or understanding. This may also mean how close or far away they are in understanding from the people or group who do have such experience. It does not mean that such distance cannot be reduced. Nor does it mean that we can't learn about such experience, even if distanced from it. But we will find out about it in different ways. We will learn from different sources.

If we have experienced something, then our understanding of it will be informed by that experience. There is a direct link between the experience and our understanding, or interpretation of it. Our knowledge of it is based, at least partly, on our experience of it and closer to it because of that.

There are many things that may distance us from experience which we don't have ourselves. Later we will look at what might increase or decrease this distance.

## Experience

Experience is that which happens to us. Direct experience, first hand experience, personal experience or 'lived experience', are all terms used to mean where knowledge follows from what has happened to us. This is 'learning from experience'. There is also now talk, in the fields of health and social care, of people who are 'experts in their own experience'. This means that their knowledge and expertise is seen to follow from direct experience which they have, (for example as service users) rather than solely from academic learning or professional training. It is also valued as such.

First hand experience may be intentional or otherwise. It may be an event or circumstance – someone survived a plane crash or grew up on a farm. Or it may be something to do with *who* we are – our identity, for example, being a woman, a lesbian, gay, bisexual or trans-sexual, or disabled. So experience is about *being* as well as happening. There are quick and enduring experiences. There are rare and extraordinary experiences as well as commonplace ones. What is a commonplace experience for one person, may be an extraordinary one for other. Experiences can change. People also

sometimes talk about particular experiences 'changing them'; of 'life-changing experiences'.

Later we will be looking at what might bring us closer and further away from our own experience.

## Interpretation

This is the element in this discussion which has perhaps tended most to be overlooked and taken for granted. All experience; everything that happens to us, all that goes on in a society (and that society itself), is subject to interpretation. The interpretation of experience is an essential part of the process of constructing knowledge.

There has been a tendency in research and knowledge production, particularly in traditional research approaches, to take the interpretation of 'data' and findings' for granted – almost as though there is only one way of interpreting them 'accurately'. But in all research (even natural science research to some degree) issues of interpretation are important. They are especially important in social science, social research and the knowledge that comes out of them, where the focus of attention and resulting knowledge is about the behaviours, activities, intentions and perceptions of human beings.

All experience, as has been said, is subject to interpretation, whether it is our own or other people's experience; our own or other people's interpretations. Interpretations of other people's experiences can be seen as *secondary* interpretations; that is to say, they are one step (or person) removed from the experience itself. When something happens to us, we generally go through a complex, interactive process of experience and interpretation within ourselves. It happens. We experience it. We seek to understand it, make sense of it and give it meaning. Such interpretation may be both a conscious and unconscious process we go through. It may be instantaneous or something that continues for a long time. It need not be fixed – it may change, as will be discussed later.

There is no one way of interpreting experience – including our own - although people sometimes have to be very determined to place

positive interpretations on what might seem very negative experiences (thus comfort phrases like 'could have been worse', 'mustn't grumble', 'there are thousands worse off than me', and so on)

There is still a tendency to gloss over the issues raised by interpreting first hand experience from outside. Some researchers now offer findings about what they call 'lived experience', without considering the implications of the fact that they as outsiders have come to be interpreting it. But they, like all external interpreters, are one step removed from experience which they do not share. This has implications for how they present it. Later we will look more closely at the distance between experience and interpretation and how it may be increased and reduced.

## **Additional exclusions**

As has already been mentioned, there is also a tendency for the capacity of some specific groups to understand and interpret their own experience (and indeed anything else) to be questioned and seen as restricted or defective. Such attitudes have particularly tended to be held about people with learning difficulties and mental health service users/survivors. They have also been associated with disabled people too, reflected in 'Does (s)he take sugar?' attitudes. People are seen as lacking the intellectual ability or rationality to make sense of things – to make sense of their experience - even though, given the opportunity, they are almost invariably able to signal their views and feelings. There is also a tendency to assume that communicating differently, for example, using non-verbal communication, signing or pictures, means that people are also less able to understand. These attitudes and assumptions reflect deep-seated prejudices and discriminations.

# Research and direct experience

At least three stages can be identified historically in the relationship between social research and people on the receiving end of the policies and social problems it has studied, informed, described and analysed. These stages can be summed up in terms of people being:

- **Ignored**
- **Surveyed**
- **Involved**

## **Ignored**

The poverty research of the nineteenth and early twentieth century, some of the earliest and most influential social research, was interested in poverty and the poor, but not what they had to say about poverty. Poverty researchers defined what poverty was, checked on the resources available to people and how they used them and then offered their own explanations for why particular people were poor. Researchers were not primarily interested in the views and experience of people with experience of poverty themselves. Here then, there was not a question of researchers interpreting research participants' experience. This was ignored. They simply offering their own interpretations. Significantly, these were strongly presented as 'scientific'.

## **Surveyed**

This second stage is the one most closely associated with social research and related information gathering exercises, like market research and political opinion polls. It is still probably the strongest and most valued approach to social research. It's what people think of first when social research is mentioned. Here people's views and experiences are sought. They are seen as a valid and helpful data source to be collated and analysed as the basis for producing quantitative (and sometimes qualitative) research findings. But such

analysis and interpretation are undertaken by external researchers. The interpretations of research participants (or other poor people) are not generally sought. Having experience and first hand knowledge of poverty is not seen as a necessary or relevant qualification for undertaking such research and analysis. Few (if any researchers) have identified as having such experience.

## **Involved**

In recent years, there has been an increasing emphasis on the need for 'service user' and 'public' involvement in research. Government has argued the importance of this. Statutory and non-statutory research funders have required evidence of such involvement for research bids to be accepted. So far, however, such user involvement has not generally included involvement in the analysis of data, either by research participants or by people with similar experience. Involvement is generally still tightly constrained. It certainly does not necessarily mean that who analyses data or the location of analysis changes, although it can make this possible.

User involvement in research can take place in all aspects and stages of research, from who identifies the research focus and questions, through research process, to dissemination and follow-up action. This is, however, still at an early stage.

## **Taking control**

This may explain why disabled people and other groups of health and social care service users, have sought to develop their own research approaches. These include 'user controlled research', 'disability emancipatory research' and 'survivor research' (from mental health service users/survivors). All of these place an emphasis on service users/disabled people being in control of the research and their interpretations of their experience being central to the process of research. Service users have not only argued, therefore, for user involvement in research, but for research where they are centrally involved in the analysis and interpretation of what people (like them) say.



## RESEARCHING DISABILITY.



UNFORTUNATELY THEIR  
WHEELCHAIRS ARE TOO  
BIG FOR THE CORRIDORS  
IN OUR MAZE.

# The quality of knowledge

## What is truth?

Pontius Pilate to Jesus Christ at his trial

This brings us to one of the most difficult and complex issues that this idea, about the relationships between direct experience, distance and knowledge, needs to deal with. This relates to the *quality* of knowledge. It has been argued here that the greater the distance between direct experience and its interpretation, then the less reliable, accurate and *authentic* resulting knowledge is likely to be. But what is 'accurate' and 'reliable' knowledge and who is to judge? Is there more and less accurate knowledge, or is this just a matter of value judgements?

At one level it may be helpful to recognise that all knowledge is open to question and that no knowledge can really be shown to be valid or reliable. In that sense, perhaps, we really can't know anything and we may live in the world of manufactured reality of the Matrix film trilogy. But ultimately, academic arguments that there is 'no valid reality' or 'real truth', are likely to be most oppressive to the most oppressed. It is their knowledge, because they have the least power to back it up, which is most likely to be called into question and rejected. This discussion and the idea being explored here, has to fit the 'real world'. It has to work in the real world and support the rights and interests of people whose 'knowledge claims' have tended to be treated as the weakest.

There may indeed be no truths, but, for example, Manchester United have won a lot of championship cups; under every day conditions, water boils at 100 degrees centigrade and Mrs Thatcher was Prime Minister from 1979 to 1991. This is (commonly accepted) knowledge. These are facts that we generally accept.

Here we have sought to question prevailing views that knowledge based on research values of neutrality, objectivity and distance has a special authority. This kind of knowledge, based on highly valued

research methods like randomised control trials (RCTs), is increasingly coming under question, for example, for being unduly influenced by the pharmaceutical industry; for inherent deficiencies in peer review processes and for being influenced too much by professional and economic interests.

## **Testing the reliability of knowledge**

It is not always possible to test the reliability of knowledge. One way of doing so is retrospectively. The field of disability provides an important and relevant example here.

In the 1960s, some of the future founders of the UK disabled people's movement felt that by being 'shut away' and 'incarcerated' in residential homes, they were being denied choice and freedom in their lives that non-disabled people could take for granted. (Hunt, 1966) They wanted to leave residential homes and live independently in mainstream society with suitable support. They approached professional researchers to undertake independent research on their situation.

In their influential study, the researchers discussed at length their efforts to conduct 'balanced', 'detached' and scientific research. They rejected disabled residents' wish for more independence and autonomy as 'unrealistic' and explained that the psychological problems of 'cripples' and 'incurables' were the inevitable result of being disabled. They concluded that disabled people could not live independently in the community. (Miller and Gwynne, 1972)

Since then, many thousands of disabled people internationally (including some of those involved in the Miller and Gwynne study), with appropriate access and support, have been able to live independently, thus refuting the conclusions of the researchers.

# Measurement

At the heart of the hypothesis being offered in this little book, is the idea that knowledge is likely to be more reliable or accurate the smaller the distance between direct experience and its interpretation. How then, is this to be measured? Do we have an instrument to measure this distance? How is it to be quantified? What are the units of distance?

It is important to take account of these questions. They shouldn't be ducked. They are the kind of questions which conventional approaches to knowledge production have highlighted and attempted to answer. However, this is not how this idea was intended. It was not meant to provide another rigid quantifiable system of evaluating knowledge, like some of the research approaches it has tried to review. Instead it should be seen as a qualitative approach to measurement. What it is trying to do, is think through what could serve to increase or reduce the distance between experience and its interpretation, without framing this in narrow quantitative terms. This hypothesis is concerned with understandings and interpretations and their relationships with experience. These cannot readily and perhaps should not be conceived in numerical terms. The aim is to offer insights, not an appearance of 'mathematical proof'.

The theory could be set out as a mathematical formula, but this should be seen as no more than a quantitative metaphor for a qualitative approach. The formula would look like this:

$$x \propto \frac{1}{y}$$

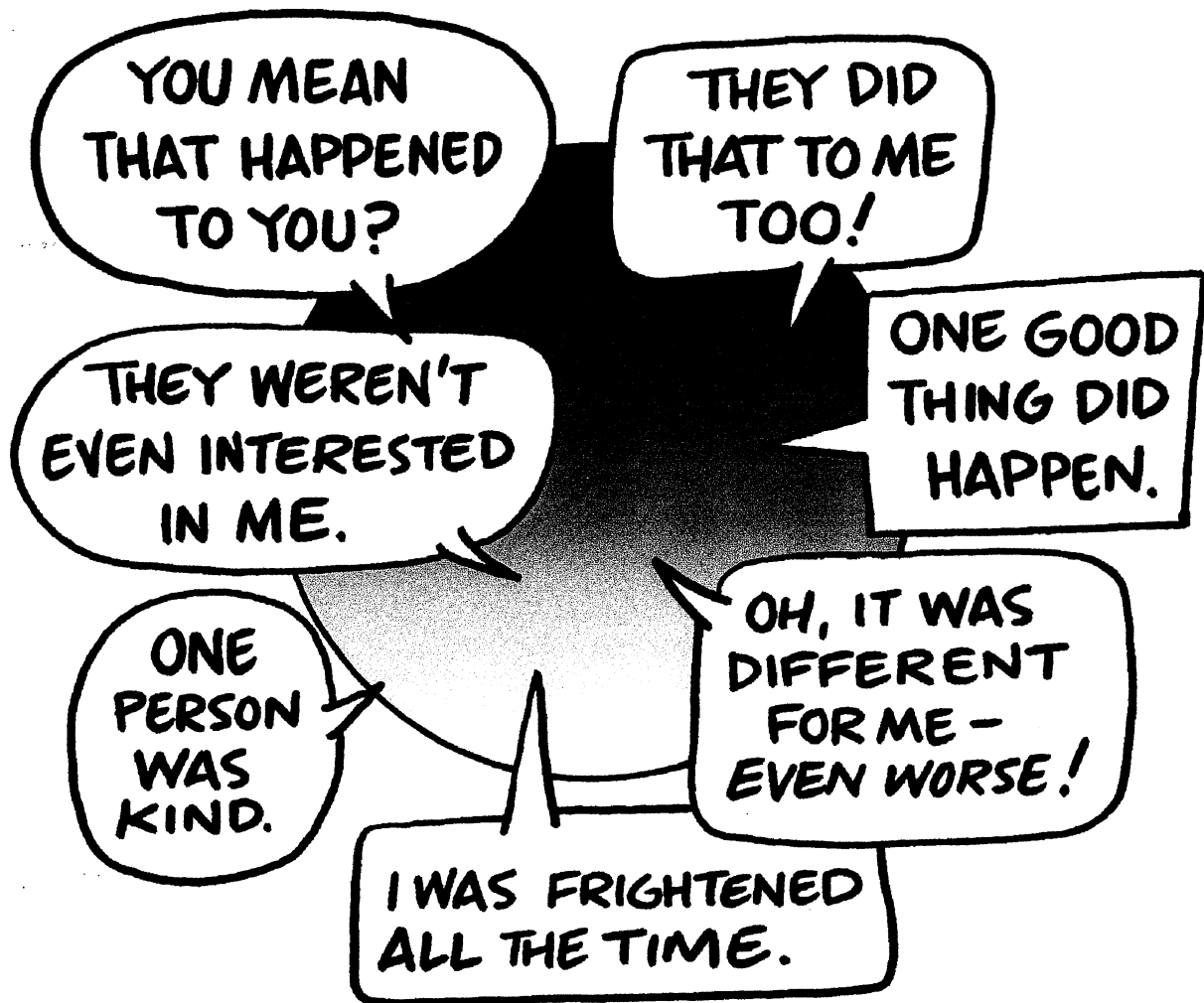
When:

**x** equals the reliability or accuracy of knowledge

**y** equals the distance between direct experience and its interpretation

## BUILDING OUR KNOWLEDGE TOGETHER.

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# From individual to collective knowledge

**Who can teach it other than people who were there?**

Auschwitz survivor (1995), Talking About The Holocaust,  
Channel Four News, 24 January

A major reservation raised about experiential knowledge is that it can only tell us about individual experience. Someone can speak about their own experience, but they cannot speak (any more than anyone else can) about someone else's. Thus while this approach to knowledge may be worthwhile, it is one that is inherently limited. This is an important point, which demands further consideration. Can we get beyond individual interpretations of experience as a basis for knowledge and if so how?

## From individual experience...

In this discussion, we started with the individual interpretations that a person places upon their own direct experience. However, this is itself complex. Even one person may put more than one interpretation on what happens to them. That interpretation need not be constant. It may change over time. It may be constantly in flux. We 'know from our own experience' that the meanings we put on something can change, as we reflect on it, gain new insights and acquire new information. As one woman mental health service user/survivor said to the author:

**For me experience is something that I have *lived through*. The trouble with this is that I can have different understandings of the same experience and it is almost as if the experience changes with these different understandings.**

All these issues are relevant and can be helpful. Unfortunately, they are often raised to challenge the validity of knowledge based on direct experience. Yet each person's experience and interpretations of it, have a validity in themselves. This should be acknowledged, but often it has been ignored or rejected.

However, there are further complexities to address. Not everybody who has the same or similar experience, will necessarily interpret it in the same way. It is important, therefore, as a first step, to move beyond relying solely on one person's interpretation of an experience (although it should be remembered that one person's interpretation is still probably going to be a lot better than nobody's). It is likely to be helpful to include the interpretations of a range of people who have been through the same or similar circumstances.

There has been a lot of discussion about this issue in the context of the 'user involvement' or participation of health and social care service users. Here service providers have frequently argued that service users who 'get involved' are 'unrepresentative'. There is a simple remedy here. This is to seek the views and support the involvement of a larger number and range of people.

In a discussion of emancipatory disability research, Geof Mercer said that to begin with there was a 'notion of a homogeneous category of "privileged knowers"'. Disabled people were seen as having particular insights, understanding and knowledge to offer. But there then came to be increasing recognition of the need to acknowledge that there were different 'discourses, voices and experiences within the disabled population; that there were people with different impairments and it was necessary to take account of (overlapping) differences according to age, gender, sexuality, race and so on'. (Mercer, 2002, pp234-5)

## **...To collective knowledge**

Starting with people's individual interpretations of experience does not mean having to stop there. Clearly one person can't speak for everyone. We are all different, in a range of ways. However, it is

possible to move from individual to collective knowledge. We can share our experience with others and relate our different interpretations and understandings of experience to each other. In this way, it becomes possible to develop knowledge which synthesises people's different understandings and perspectives on their common (and varied) experience.

The first and crucial way to do this is by getting together with other people with such shared experiences. This has become a feature of modern societies and politics. Such 'new social movements', based on issues of common identity and shared experience, have become central to popular politics and campaigning. Getting together in groups which we control, working together, we can develop our own shared understandings, views and goals. We can begin to construct shared understandings and interpretations, finding out how other people understand what has happened to them; gaining familiarity from them of different ways of making sense of experience.

It makes possible a social process of generating our own collective knowledge, based on our common experience. Doing, this, movements like the disabled people's and psychiatric system survivors' movements have developed their own ideas, strategies, cultures, arts and research. In this way they have found out where there are common themes in their understanding of their experience, personal differences and differences related to other aspects of their identity. Clearly such collectivities need to take account of difference; seek to be inclusive and address issues of diversity.

Making contact with other people with similar experience and getting together to do things together, provides the basis for the second way in which people's own interpretations of their experience can provide the basis for collective knowledge. This happens when they begin to produce their own recorded body of knowledge, available to each other and to others. This offers a dynamic and developing source of experiential knowledge. User controlled research has an important role to play here, pulling together 'user knowledge' in a systematic way. In this way groups can develop their own discourses, to set next to and sometimes challenge prevailing views and understandings. These may be expressed in written material – books, newsletters and



magazines - as well as through art, via electronic media and on websites. What starts as people's own analysis of their experience, can become sophisticated and influential forms of knowledge, impacting on and fundamentally transforming popular understandings.

# Distanced from our own experience

**The past is a foreign country: they do things differently there.**

L P Hartley, *The Go-Between*

**Time is the longest distance between two places**  
Tennessee Williams

The process of people interpreting their own experience, is complicated, subtle, ambiguous and sometimes unclear. But this is not an argument for devaluing direct experience as a basis for knowledge. It is important to avoid the relativism that encourages us to think that the complexity of experiential knowledge makes it unusable.

A theme of this book has been that people's own interpretations of their experience can result in the most authentic knowledge because experience and its interpretation can be closest to each other. But this is not to say that we cannot be distanced from our own experience. The distance between our experience and our understanding or interpretation of it, is not a constant. It may not always be as small as it might be. A range of conditions or factors can increase this distance.

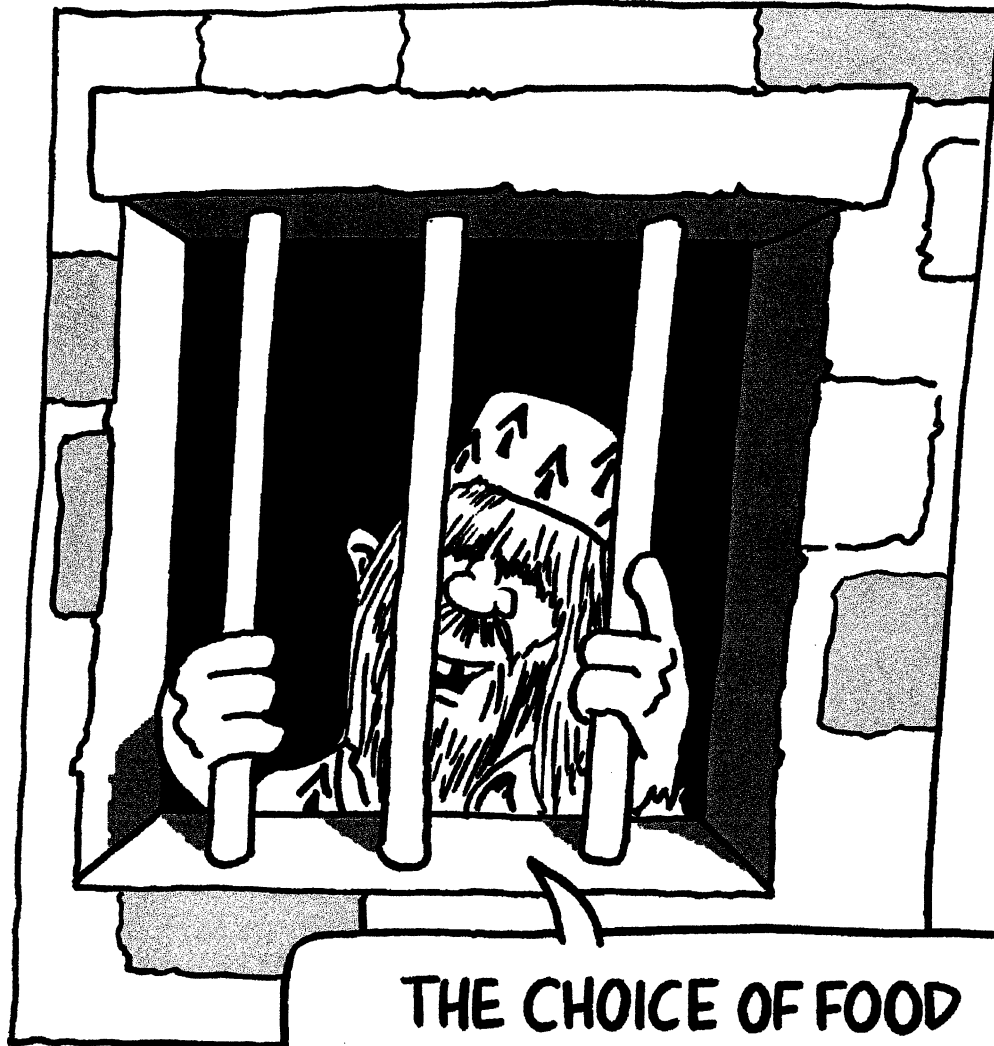
## Time

**And was it all spring weather?  
Nay, but we were young and together**

A simple and familiar example of what can distance us from our experience is *time*. The passage of time changes our interpretation of things that we have experienced. 'Time is a great healer'. Things that may have been terrible, may come to seem less unpleasant (or

**ALWAYS LOOKING ON THE BRIGHT SIDE.**

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THE CHOICE OF FOOD  
HAS DEFINITELY  
IMPROVED SINCE THE  
RATS AND COCKROACHES  
CAME...

sometimes even worse!). Some experiences may be remembered as completely positive, although they were a lot more complicated than that. Love can have that effect! Historians have learnt that 'oral history'; that is to say history based on people's recollections, can sometimes be inaccurate – as we remember things differently with the passage of time. That's why people's accounts of their experience are most powerful when they are most immediate. They can still have a value as knowledge later, but then they may also tell us about what such experience later came to mean for them and their lives.

Some things that happen to us may be so awful or traumatic that we cannot even remember them (even if sometimes we know that they have happened) This has become a major issue for discussion in relation to so-called 'false memory syndrome', where there has been questioning of people's recollection of childhood abuse after receiving counselling.

There are also experiences which have been so painful that people find thinking about them or analysing them very difficult and try to push them away. There is talk of 'getting back in touch with our feelings' and 'experience' when we have been distanced or alienated from them.

## **Pushed away from our experience**

How we think about ourselves, other people and our experience, can also affect how we interpret direct experience and distance us from it. One (frequently intentional) effect of disempowering and subordinating people, can be to distance their understanding from their experience. They are encouraged to see their situation as *their* fault. They blame themselves. This is particularly likely to happen if they have been encouraged to have low expectations, low self-esteem and little self-confidence. They may come to think badly of themselves, as if this is all they are worth. If they have had few choices and opportunities, they may not know how it could be different.

They may also be exposed to dominant models of interpreting them and their experience which emphasise their own deficiencies, pathology and inadequacy. People frequently internalise such models, since these may be the only ones they have learnt and which were available for them to interpret their experience. In modern times, countless people with learning difficulties, older people, mental health service users and people with physical and sensory impairments, have been taught to understand themselves in terms of medicalised individual models of understanding which devalue them (like the medical models of 'mental illness' and disability). Groups like lone parents have been subjected to similarly devaluing models of understanding based on a view of them as morally deficient.

## **Pressured to reject our experience**

People can also be distanced from their experience by being encouraged to fear and reject it. For many years this is what has happened to gay men, lesbians and bi-sexuals. In many western societies, black people have not only sometimes been physically segregated, they have also been expected to see themselves as inferior. Researchers have regularly generated 'knowledge' from research findings to back up this view.

If you have perceptions of reality that don't fit with the 'normal', then you can expect to be seen as mad (however common we may know such perceptions to be). You quickly learn that you should not have or admit to such experience. People's reality is denied and dismissed. They are ridiculed, belittled and told they are wrong. Few of us want to be different to other people. We generally want to fit in and not have different experiences or thoughts.

Knowing that your interpretation of your experience may be too difficult or painful for other people to accept or acknowledge, you may be forced into one of several alienating strategies. You may learn either to keep quiet, pretend not to think like that, or internalise the dominant way of interpreting your experience (while, of course, still having it)

## Internalised oppression

People who are oppressed, as has been said, sometimes 'internalise' the oppression; that is to say they accept the view of them and/or their behaviour as bad, defective or pathological. They are made to feel bad about themselves, who they are and what they do. Turning the oppression in on yourself (something that oppressive institutions and organisations are only too well aware of), distances people from their experience. It can also distance them from the experience of others. When this happens, sometimes they may also interpret the similar experiences of other people in negative ways too. This can (we should stress this is only a matter of *can*) result in them not only being oppressed themselves, but also oppressing others. It is important, however, here, not to 'blame the victim', but instead to remember how often people subjected to such intolerable pressure, do *not* do this.

Sometimes internalised oppression is a consequence of people doing really bad things and seeking to deny them, for example abusing children or being violent to women. Much more often, it happens to people because of the negative way in which they are treated or can expect to be treated because of who they are or what has happened to them; for example, for being gay or using mental health services or being a member of a cultural minority.

This does raise another issue which needs to be discussed. What about the argument that if we are emphasising the value of 'experiential knowledge', then that means that we are also saying that the interpretations of people who do cruel and terrible things are to be valued and privileged? It is important to make clear that this is not what we are saying. This hypothesis is concerned with supporting the empowerment of people who are disempowered, not supporting those who disempower and restrict the rights of others. We need to give value to the knowledge of people who are abused and disempowered. However, it is also likely to be worthwhile to find out more from people who oppress others, how they see and explain what they do, as a basis for preventing, dealing with and stopping this. This will though, need to take account of the fact that they will

have reasons for offering the interpretations that they think are best suited to public consumption and which will best serve their own interests.

Thus having direct experience doesn't necessarily ensure that people's interpretations and understandings will stay close to it – especially when they are subjected to massive external or social pressure. Having direct experience (of something), may be a necessary, but not sufficient condition for reducing the distance between experience and its interpretation.

# Getting closer to our own experience

**Question: Do you think about death?**

**Answer: Yes, I'm not frightened of death. I just don't want to be there when it happens.**

Spike Milligan, interviewed by John Stapleton, ITV, 12 March 2000

Our relationship with our experience is not fixed. How far we are from it in our understanding can change. There are things that we can do to try and get closer to our experience. There are ideas we can offer to other people to help them get closer to their experience. The list is a familiar one. It relates to our understanding of how to challenge our powerlessness and become more empowered. Some of the ways of bringing our understanding of our experience closer to that experience to strengthen our knowledge include:

- Being able to meet and talk about our experience with people with similar experiences;
- Getting together with such people to do things together. A key route to empowerment comes from becoming involved in collective action and mutual aid and support groups. Then people can both explore different ways of interpreting what has happened to them and who they are – and have support on hand to help do so;
- Having opportunities for 'consciousness raising' including confidence building and assertiveness training to increase our understanding. This is especially valuable when it is provided by 'people like us,' helping us to feel better about ourselves;
- Being able to access independent information, particularly from other people in similar circumstances, based on shared experiential knowledge;



- Being able to access social models and understandings of our situation that don't assume our deficiency, but which help put our feelings and circumstances in their full context and offer us supportive tools for understanding;
- Developing chances to gain new skills which will help us to access more opportunities which can change our objective situation in the world;
- Challenging people's segregation in separate, institutionalised settings and creating opportunities for them to take part in mainstream activities.

As groups facing oppression and discrimination develop their own accounts, record their own histories and develop their own discourses, all this becomes more possible. When people who have experienced powerlessness develop their own media and forms of communication, they are at last able to offer their own interpretations, their own knowledge on their own, more equal terms and counter prevailing versions of them.

One woman who had used mental health services said of her experience:

**I guess you might say that the objective truth didn't change. I wasn't consulted about changes to my medication – I was just given something different when I turned up at the drugs trolley, but I didn't experience that as something awful at the time. My complaint was that they didn't *tell* me about the changes – just handed them out to me, not that they didn't consult me or ask if I *wanted* to change my medication. Retrospective 'consciousness raising' made that experience different – or made me interpret it differently.**

# Other people's distance from direct experience: Making it worse

**It's something that unless it happens to you, you can't explain.**

Les Perry, Suffolk Regiment, talking about D Day (when he was aged 18), Remembering Private Smith and Jones, BBC 2 TV  
12 September 1998

Not having a particular experience can sometimes create an enormous gulf in understanding and even a great gulf between people. Soldiers returning from wars often find it very difficult to talk to anyone else about their experience – even people close to them – because they feel they will not be able to understand. But there are also additional barriers in the way of understanding other people's experience. These not only exaggerate the distance between understanding and experience, but they make it even more likely that resulting knowledge will bear little relation to what people know from their own experience.

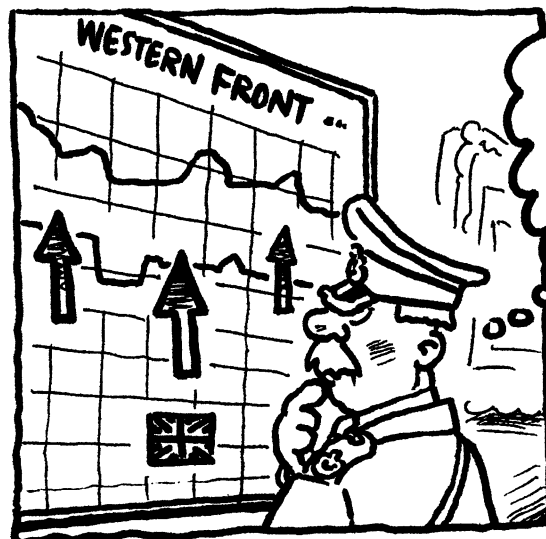
There are extreme examples of this, when the aim is actually to divorce knowledge from direct experience. The best known of these are 'disinformation' or 'misinformation' and propaganda, where the specific aim is to distort and misrepresent. Knowledge developed in this way frequently has no basis in or relationship with actual experience. It is simply made up, or its relation with reality is tenuous. More recently, we have heard about 'spin' where the aim is to present things from a particular (distorted) angle. Here the intention is not to reflect anyone's experienced reality, but to offer information as a basis for knowledge where the primary purpose is either to put people off the track or to present things in an inappropriately positive light.

## GOING UP THE LINE.



IT'S HELL  
HERE, SIR!

I THINK  
THEY ARE  
FINDING  
IT TOUGH,  
SIR.



JUST ONE  
BIG PUSH  
SHOULD  
DO IT.

The UK tabloid press are another important example of how we can be set apart from each other. They have developed enormous skills in finding ways of encouraging people to misunderstand and hate others, placing the most negative interpretations on people, their behaviour and experience. Refugees, lone parents and gay men and lesbians are among their favourite targets. Their special ability, from which we can learn here, is to turn ignorance and fear of the unknown, into hate and aggression.

Another way of creating misleading 'knowledge' is by using grand words. This frequently happens in descriptions of war, where we have long been told 'the first casualty is truth'. Thus the talk of 'our lads going in', 'an heroic attack' or 'the courage of the wounded', none of which (and not by accident), tell us very much about what it might actually have felt like to be there.

But mostly what adds distance, between one person's experience and another's interpretation of it, are a range of structures, attitudes, systems of belief and assumptions which get in the way. These include

- Unequal power relationships between the two, resulting in either hostile or paternalistic understandings;
- Seeing people as inferior, pathological or 'other'.
- A lack of awareness on the part of outside interpreters of their own position in relation to other people's experience, cultures and perspectives;
- Where people or groups are separated by discriminations relating to class, race, gender and other forms of difference;
- An unpreparedness to consider other cultural positions, perspectives and realities;
- Commitments to ideologies, agendas, values and vested interests which pull people away from valuing or being able to appreciate the other person and their experience;

- Socialisation into and reliance on models of understanding which subordinate and pathologise people;
- A lack of awareness of the issues and concerns of the particular people and groups under consideration;
- Professional training which further distances people from those with whom they work by stressing their controlling role, 'expertise' and 'boundaries'.

# Reducing the distance between experience and its interpretation

**Historians should talk to people who suffer from it...He never spoke to a single Holocaust survivor.**

Freddie Knoller, Auschwitz survivor, Channel Four News 11 April 2000 following the defeat of the revisionist historian David Irving in a libel case.

**Did we really send men over that?**

General Charteris, Chief of General Staff, (reportedly in tears) on visiting the front line at the end of the war, 1918.

As we have just seen, there are ways in which the distance between us and other people's experience can be increased. But there are also ways in which this distance can be reduced and minimised. What the hypothesis that is outlined here suggests, is that where that can be done, then the knowledge resulting from such interpretation is likely to be more helpful and useful. It is also more likely to support the empowerment of the people that it relates to.

There is one further point to make at this stage. This hypothesis is particularly concerned with supporting people's *own* interpretations of their experience as a basis for knowledge. But it does not suggest that this is the only basis for knowledge. We are not saying here that interpretations of direct experience by those who do not share it are inherently defective or inadequate.

We do take the view that the validity of people's own interpretations of their experience should be acknowledged and that they have a particular contribution to make. But other people also have a role to play in the development of knowledge – especially if they aim to get closer to people's own direct experience and experiential knowledge.

This is not achieved by denying there is an inherent difference in standpoint between those with and without direct experience, but rather to place value on that which may help bring the two closer together.

After all, no one can (or would want to) experience everything. There are some things some of us can't experience. Men can't (as yet) experience having a baby. We can't know what it is like to be dead (while acknowledging accounts of 'out of body' and 'near death' experiences).

Equally there are minor experiences which it may not seem important to have, to be able to understand them and which can easily be shared (although even something ordinary like going to the supermarket may be a very rare event for someone living in residential services). A surgeon, (for some reason this seems to be a favourite example), does not have to have had an operation to be able to perform it effectively. (although it may be that (s)he could support a person undergoing it better if (s)he did have!)

So there is a value in knowledge constructed by people without direct experience. They have a contribution of their own to make. However, it should never be at the expense of those with experience. It should never deny them the chance to develop and offer their own knowledge.

Some things seem to equip people better to get closer to the experience of others, even when they don't have it themselves. For example, if they have experienced another form of oppression or discrimination; if it has happened to someone close to them that they love and value. Face to face contact with people with direct experience sometimes transforms other people's understanding, acting as a 'Road to Damascus experience' for them.

There are also simple practical steps that can be taken to reduce the distance between first hand experience and external interpretations of it. A straightforward way of doing this, for example, is by reducing the number of intervening steps and stages that there may be between the two. These may involve different perspectives, individuals and

interests, creating myriad opportunities for confusion and distortion. Shortening 'the loop' here can play a positive part in reducing this problem.

There do seem to be a number of ways of getting closer to other people's experience to understand it better. These should not be seen as mechanistic 'techniques', but rather a set of value based principles. Again these are not offered as special or unique. All seem to relate to valuing, taking account of and respecting direct experience. Such a list includes:

- Listening to what people say;
- Seeking to develop *empathy* with the perspectives and situations of others. 'Sympathy' is unlikely to be what is wanted;
- Working to be open-minded and non-judgemental and challenging discrimination in yourself and others;
- Recognising what you do and don't 'know';
- The capacity to value rather than devalue people's direct experience;
- A readiness to accept the possibility of there being knowledges, other than your own;
- A preparedness to accept something you may not fully understand, instead of rejecting it without consideration;
- Being willing to move out of your own territory, to go out to people on their own ground and see how things are for them, where they are;
- To act upon knowledge that is based on direct experience – not just saying that you accept that this is how it is for someone else, but also being prepared to work with them to change it (active knowledge);



- To involve people with direct experience (for example service users) in the development and provision of professional education and training.
- To value direct experience as a service user in health and social care and to encourage the recruitment of service users as workers.
- Increasing access to research training for people with direct experience (for example, as service users) as well as supporting their involvement in research structures and processes to influence the process of knowledge production.

Finally, we should not forget the role of new technology in bringing direct experience and understanding closer together. Technology is neutral and can be used to undermine understanding between us. But it can also play a very helpful role. All the generals' and politicians' phrases about glory and victory during the war in Vietnam were undermined when people saw images of what soldiers were going through brought into their living rooms by television the same day.

The internet has made it possible for us to connect with people's direct experience all over the world in ways that could not previously have been imagined. Tiny hidden video cameras have validated service users' accounts of abuse and neglect (which would never have been believed on their own). Such possibilities were inconceivable in the past. More positively, by making video diaries, people previously denied a voice, have been able to offer their own accounts directly to small and sometimes large audiences – telling it like it is.

# Next Steps?

There is one last question to ask about the hypothesis that has been outlined here. Can it be tested? Can we find out if it works? Is knowledge more reliable and authentic when the interpretation of direct experience is closer to it, rather than further away as has traditionally been argued?

Perhaps a first step would be to check this out with a range of people involved in the production of knowledge to see what they think. This could include health and social care service users, service user researchers and other researchers. They might also have ideas for other ways of taking this idea forward.

We could also try and assess some specific initiatives concerned with knowledge production, whether service user knowledge or knowledge produced in more traditional ways. We could do this systematically with the full range of people involved, exploring their different perspectives and views to find out what they think.

# Follow-up Reading

- Barnes, C. and Mercer, G. (editors), (1997), *Doing Disability Research*, Leeds, The Disability Press.
- Beresford, P. and Evans, C. (1999), Research And Empowerment, *British Journal of Social Work*, No 29: 671-677.
- Beresford, P. (2002), User Involvement In Research And Evaluation: Liberation or regulation?, *Social Policy & Society*, Vol 1, No 2, pp95-105.
- Campbell, J. and Oliver, M. (1996), *Disability Politics: Understanding our past, changing our future*, London, Routledge.
- Docherty, D. Hughes, R. Phillips, P. Corbett, D. Regan, B. Barber, A. Adams, M. Boxall, K. Kaplan, I. Izzidien, S. (2003 forthcoming), This Is What We Think, *Disability Studies Quarterly*.
- Harding, S. (1993), Rethinking Standpoint Epistemology: What is 'strong objectivity'?, in Alcoff, L. and Potter, E. (editors), *Feminist Epistemologies*, London, Routledge.
- Hunt, P. (1966), reprinted in, Shakespeare, T. (editor), *The Disability Reader: Social science perspectives*, London and New York, Cassell, pp7-19.
- Hunt, P. (1972), Parasite People, *Cheshire Smile*, Autumn, Vol 18, No3, p15.
- Mercer, G. (2002), Emancipatory Disability Research, in Barnes, C. Oliver, M. Barton, L. (editors), *Disability Studies Today*, Cambridge, Polity, pp228-249.
- Miller, E.J. and Gwynne, G.V. (1972), *A Life Apart*, London, Tavistock Publications and Lippincott.
- Nicholls, V. Wright, S. Waters, R. Wells, S. (2003), *Surviving User-led Research: Reflections on supporting user-led research projects*, London, Mental Health Foundation.