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## 1

# From Personal Struggle to Political Understanding and Back Again

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## Introduction

This first chapter originally appeared in the first edition of this book. I decided to include it again because it will still help to throw some light on why I have written the things that appear later in the book as it remains rooted in my own personal biography, which I briefly outline. In the earlier edition I threatened that a more detailed description of my life might one day appear as an autobiography or as a thinly disguised novel. I hope, at this later stage, that I can reassure anyone who might feel worried about featuring in either of those two enterprises that neither is now likely to appear. Having written more than a million words during my academic career I do not intend to spend my retirement slaving over a word processor and I cannot imagine that there is much of a readership out there wanting to hear more from me. So this may be your last opportunity.

This personal account will focus on four areas which, for analytical purposes, I will separate into (1) looking at my growing political awareness, (2) the way my career developed and the influence this had on my growing political consciousness, (3) my growing involvement with disabled people and the organizations which we were creating and the effect that this had on my developing understanding of disability as a personal, social and sociological phenomenon and (4) my gradual retreat from academic and political life in order to concentrate on other things, mainly doing nothing. Bobbie McGee knew the importance of this when she sang ‘Nothing ain’t worth nothing but it’s free’.

### **The personal is the personal**

My own personal experience of disability began in 1962. I was the only son of working-class parents and had recently left the local grammar school as a failure, having only gained three O levels. Stuck in a dead-end clerical job, my life centred around the cricket and football I played for local teams and the macho activities I and my mates often used to pretend to get up to, and occasionally actually did. When I was seventeen, five of us decided to go on holiday together, to a well-known holiday camp in Essex (the present-day equivalent of the package tour to Spain or Greece).

Behaving like latter-day lager louts, it was not long before I got up to something that was to transform my life. I dived into the holiday camp swimming pool, hit my head on the bottom, broke my neck and spent the next year at the world-famous Stoke Mandeville Hospital. As I have written elsewhere (Oliver, 1982), this was not a wholly negative experience, although, of course, things like having a metal frame screwed into my skull while fully conscious are not experiences I would want to repeat.

However, the positive far outweighed the negative. The culture of Stoke Mandeville was definitely macho, and I was encouraged to undertake as much physical activity, loosely called rehabilitation, as I wanted. Additionally, there were the women; nurses, physios, OTs, all of whom were in close proximity and many of whom were required to perform professional acts of intimacy. It is not surprising that the boundaries between these professional and personal acts of intimacy were often blurred in the evenings and at weekends, given that the majority of the patients were young men and the majority of the staff were young women.

I think I learned more about myself and personal relationships in the one year I spent there than I have subsequently in the thirty years or more I spent in another kind of institution, the university. But there were other important gains as well. My relationships with my parents and other family members grew stronger at a time when often for young people such relationships grow weaker as they strive for independence. On leaving hospital, my mates and the working-class community that I had left welcomed me back.

For a while, all was well. My life continued as it had before the accident, except that I did not have a boring clerical job to go to. Soon it became apparent that endless days without boring work were even more boring than endless days with it and, while my family remained

close and supportive, I began to feel restless and that there must be more to life than watching television, being taken out by your mates and drinking. The next major change in my life occurred not because of the successful intervention of skilled professionals but purely by luck.

### **The personal and the professional**

My professional interest in disability did not really come about until some ten years after I became disabled as the result of the spinal injury in 1962. After my year in Stoke Mandeville Hospital, I spent three years unemployed and thinking I was unemployable – a perception that was reinforced by every single professional I met during that time. In 1966, purely by chance, I was offered a job as a clerk at the young offenders' prison near where I lived.

Despite my previous boring experience as a clerk I was persuaded by the charismatic principal of the education centre in the prison that this was a great opportunity. I did not need much persuading and within a matter of months the not-so-boring clerical job had changed and I became a lecturer in the education centre of the same establishment and remained there for six years. However, being unqualified, in 1972 I went to university and read for a degree in sociology. On completion, I remained for a further three years to undertake research and gain my doctorate.

As a postgraduate student, my interests were in the fields of deviance and crime rather than illness and disability. The positivist view dominated the academic world at this time; according to this, one did not become involved in subjects in which one had a personal involvement or interest because this made objectivity very difficult, if not impossible. However, as a postgraduate student with a young family to support, one of the few occasions when disability became a positive advantage was when the Open University began looking for course tutors for its new disability course. In addition, in my own research I was exploring the supposed links between crime and epilepsy (Oliver, 1979, 1980) and this inevitably meant that I had to read some medical sociology because epilepsy was conceptualized as illness rather than deviance. I quickly discovered that then, as now, many medical sociologists proceed on the assumption that illness and disability are the same thing. Despite several honourable attempts in recent years to bring the two sides of the divide together (Barnes and Mercer, 1996; Thomas, 1999), little progress towards a rapprochement has been made.

When I began to read some of the things that able-bodied academics, researchers and professionals had written, and still write, about impairment and disability, I was and remain staggered at how little it related to my own experience or, indeed, that of most other disabled people I had come to know. Over the next few years it gradually began to dawn on me that if disabled people left it to others to write about disability, we would inevitably end up with inaccurate and distorted accounts of our experiences and inappropriate service provision and professional practices based upon these inaccuracies and distortions. I would love to say that this has changed in recent years but regrettably it has not.

It was during the 1970s that women were beginning to reject male accounts of their experiences and black people were vehemently denying the accuracy of white descriptions of what it was like to be black. This questioning had reverberations throughout the academic world, calling into question the whole notion of objectivity and bringing subjectivity onto the academic agenda.

At this time, as a sociologist I found myself supporting the call for a committed and partisan sociology (Gouldner, 1975). As a disabled person I found myself empathizing with the position of feminists who saw 'objectivity as the word men use to talk about their own subjectivity' (Rich, quoted in Morris, 1992b). As a disabled sociologist I found myself in the 'academic disability ghetto' but determined to render an accurate, undistorted and wholly subjective account of disability. I have no regrets about being in the disability ghetto. It has enabled me to teach about disability issues to students at the universities of Kent and Greenwich, where I have worked as a full-time academic, as well as at a whole range of other assorted universities, polytechnics and colleges. As well as undergraduate and postgraduate students, I have been involved in both initial and post-qualifying training to professional groups, including social workers, teachers, nurses, occupational therapists and physiotherapists and doctors.

Before leaving this academic part of my biography, I need to return to my involvement with the Open University. In particular, its first course on disability issues, 'The Handicapped Person in the Community', had a key influence on my thinking. While it was based upon the assumptions that disability was a condition of the individual and that the way to deal with it was through professional interventions designed to deal with either the medical complications or functional limitations of impaired individuals, it nonetheless provided both an opportunity to read some of the academic literature on disability and an academic

focus to take further my thinking on disability. In addition this involvement gave me the opportunity to work with Vic Finkelstein. While I knew Vic, and that he had had a key influence in the Union of the Physically Impaired Against Segregation (UPIAS) and on the *Fundamental Principles* document they published (1976), it was not until then that I realized the importance of the work we were beginning to undertake in redefining disability.

By the time the 'Handicapped Person' course came to be rewritten, we had both penned major critiques of the individual model of disability, as it came to be called (Finkelstein, 1980; Oliver, 1983), which saw all the problems that disabled people faced as being consequent on their impairments. These critiques had called into question the appropriateness of professional interventions based upon this model and the rewritten course was much more centrally concerned to create a partnership with professionals. In my own work I had established the first postgraduate course in what later came to be called 'Disability Studies' at the University of Kent. At this time I think Vic realized the importance of the work we were beginning to undertake in shaping the future of disability studies and indeed professional education, but for me it was much more about having a job and paying the mortgage.

As our understanding of disability issues grew the Open University produced a completely new course entitled 'The Disabling Society', reflecting these changes. By now disability had been redefined by many disabled people and their representative organizations as the social barriers, restrictions and/or oppressions they face and professional interventions have come to be seen as often adding to these problems rather than seeking to deal with them. These changes are, therefore, a part of my own personal biography for, in one way or another, I have been involved in these courses almost since the beginning, initially as a course tutor and then as a member of the course team for the rewrite and production of the new course.

Hence, it would not be inaccurate to say that changes in my own thinking about disability were both reflected in and influenced by changes in the OU and Kent courses. By the 1990s, the fledgling disability studies had flown the nest and courses began to appear elsewhere, notably at Leeds and Sheffield. And later, following my own appointment as the first UK professor of disability studies, a number of similar chairs were created to support these initiatives. Hopefully they have had some effect on the way others have thought about disability, among them disabled people and professionals in particular. I will

discuss disability studies further elsewhere in this book, notably in the final chapter.

### **The personal becomes the political**

To return to my own developing consciousness of disability issues, my original attitude was one that is not uncommon among disabled people today. It can perhaps be best characterized by the term 'denial'; not denial as it is usually seen by professionals, that is, as a pathological response to my own impairment, but a denial of the fact that I might have anything in common with other disabled people. So I actively sought to avoid contact with other disabled people wherever possible, either on the street or by joining organizations.

This avoidance was only partial, however, because prior to my accident I had been a keen sportsman and my interest remained. Hence, for many years I participated in what were then called the 'Stoke Mandeville Games', at both national and international level. While I think the value of sport for disabled people is overstated in therapeutic and rehabilitative terms, there is no doubt that it was valuable to me personally; it enabled me to maintain a positive self-identity, it made my denial only partial and it embedded me in a network of social relationships, many of which remain today.

It also provided me with my first experience of collective action. There was a move to exclude tetraplegics from some of the more prestigious international events because it was argued that their needs for personal assistance were too great. The real truth was that providing personal assistants to disabled people would have drastically reduced the places available for the hangers-on who bedevil all sports. A few of us organized ourselves and mobilized support from other competitors and the plan was quickly dropped, publicly at least. The victory was only partial, of course, because behind the scenes machinations continued to exclude some of us but the experience of political action was an empowering one, even if I did not see it as political at the time.

Around this time I was also trying to acquire the educational qualifications I had missed out on as a working-class failure of the grammar school system, and this was proving no easy matter. Poor access to educational buildings coupled with the disablist attitudes of many educators meant that a thick skin was a necessary prerequisite for kicking open the door of educational opportunity. I soon realized that if that door was not only to be kicked open for those individuals powerful

enough to do so, but also was to remain open, individual action could never be enough.

As my undergraduate career was coming to an end, I heard of an initiative to keep this door permanently open by creating an organization that became the National Bureau for Handicapped Students (NBHS), later to rebrand itself as SKILL, as many outdated organizations tend to do. I attended the inaugural conference and eagerly joined its council of management. At the same time, there was a move to form an impairment specific self-help group for people with spinal injuries. Again I attended the inaugural meeting, and as soon as my studies permitted, I joined the management committee of the Spinal Injuries Association.

Over the next few years, my experiences of collective action in these two groups differed radically. SIA was controlled by disabled people, it knew its mission was to represent people with a spinal injury and it was not afraid to speak out, tread on toes or offend vested interests. I was never sure who controlled NBHS but I quickly came to realize that its (unspoken) mission was to protect the interests of educational establishments and the staff who worked in them; it rarely spoke out on anything and most of the vested interests were represented on its council of management.

As a result I left NBHS in disillusion after a few years, but remained with SIA for sixteen. Furthermore, these experiences left me convinced that only organizations controlled by disabled people could properly represent the wishes of disabled people. My own personal experience had convinced me of something of general importance and I found support for this in the sociological literature.

Social theories are grounded in the knowledge the theorist has gained through personal experience. Facts, rooted in personal reality, are of course utterly persuasive to the theorist. He becomes involved in, sees, experiences, such things as the French Revolution, the rise of socialism, the great Depression, and he never doubts the factuality of his experience. (Gouldner, 1975, p. 70)

As Gouldner concludes, I have not since doubted the factuality of that experience. Nor indeed have I had cause to; I have not since encountered a non-representative, non-democratic organization that properly addresses, let alone represents, the collective interests of disabled people. Thus, when there was a move to form a cross-impairment, national coordinating organization of disabled people, I used whatever power and influence I had within SIA to ensure they fully backed it. The British Council of Organizations of

Disabled People (BCODP) duly emerged and has gone from strength to strength; more will be said in this regard in later chapters. The point here is that, with the emergence of the BCODP, my personal journey from individual denial to the collective embracement of disabled people was complete.

However, the world does not stand still and, although I retained some involvement with BCODP for many years, when I retired I retired from everything. While I remain as committed as ever to the disabled people's movement, the world of disability politics has not stood still. Many of the big charities have attempted to rebrand themselves, like SKILL, and have convinced ignorant governments and other funders that they are an integral part of what they like to call the disability movement. BCODP itself has been less effective partly as a consequence of this and has even gone through its own rebranding exercise, emerging as the United Kingdom Council of Disabled People (UKCDP).

If this shift in power away from organizations of disabled people and back to the big charities continues then, in my view, the future for disabled people in the twenty-first century will be bleak. I remember what it was like trying to build a decent life for myself and my family when there were only the big charities around. I also remember just how empowering it was when I had the collective strength of other disabled people around me. I'm glad that I'm not trying to build a decent life for myself in the here and now and I'm scared about whether I will be able to hang on to the life I've got as I continue to age. But perhaps I worry too much and the collective power of the big charities will save me and the thousands of other disabled people currently going through the same experience.

### **The personal is the political**

So far, my description of my journey towards understanding has been rooted in events that happened in my life. There is a more personal aspect of the journey, however, which is about the transformation of my own consciousness of disability from personal trouble to political issue. Kickstarting the transformation from the personal to the political is a problem. For me it was resolved not by becoming active in left politics, which is the traditional way for working-class children, but rather through listening to the music of Bob Dylan. His descriptions of injustice, inequality and moral outrage in his early songs had a far

greater impact on the development of my political consciousness than did my working-class background.

While this exposure led to a growing political awareness, it was a generalized awareness only. The links to the politics of disability were non-existent at this time; there were no disabled role models, heroes and heroines who could link my growing awareness of inequalities and injustice, and my own growing sense of moral outrage, to my experience as a disabled person, nor, indeed, to the experience of disabled people generally. Of course, impaired role models existed in large numbers – heroes and heroines as well as victims and villains: Douglas Bader, Beethoven, Julius Caesar, Richard III, Mr Magoo and many more (Rieser and Mason, 1990; Barnes, 1992). However, none of these role models made sense of my own experience as a disabled person. I felt neither heroic nor victimized, I was neither brave nor pathetic and I certainly did not see myself as a villain, made bitter and twisted by my impairment. But I was beginning to realize that my experiences as a disabled person had a political as well as a personal dimension.

The connections between disability and politics, however, were not easy to make. It was almost as if they were deliberately kept in different cognitive spheres. Even where there were specific links between politics and disability in the lives of individual disabled people, these links were often deliberately covered up. For example, the two most famous impaired Americans were probably Franklin Delano Roosevelt and Helen Keller. He became president but most people did not even know he had an impairment; she was known for being deaf and blind but hardly anyone knew or now knows she was a committed socialist who strongly supported the Russian Revolution and the government that came after it, when it was far from safe to do so in America.

The links between politics and disability in these two cases raise interesting questions – a politician whose impairment is denied and a disabled person whose politics is denied. It is difficult to decide which is the most unfortunate. In Britain, on the other hand, there are some disabled politicians who neither deny their impairments nor their politics. The problem is that they don't see the connection between the two and they fail to embrace their impairments as part of a politics of personal identity.

An example of this was the Special Award for Word Blindness that the Greater Manchester Coalition of Disabled People gave to David Blunkett, then Shadow Minister for Health and a blind person, on the grounds that 'since his arrival at Westminster and promotion to the Shadow Cabinet [he] has never been heard to speak those immortal

words “disabled people” (*Coalition*, December 1993). Even when the Labour Party came into power in 1997 and he occupied some key positions in government, he continued to show his ignorance of ‘real’ disability politics. Since his fall from grace, little has changed. The British Prime Minister Gordon Brown, on the other hand, follows a different path. Though he has a visual impairment you wouldn’t know it, either from his self-identity or his political ‘convictions’.

Two of my own heroes, Antonio Gramsci and Woodrow Wilson Guthrie, were impaired but would not have understood these impairments as part of a politics of personal identity either. One died, imprisoned in Mussolini’s jails for his political views, the other died imprisoned in his own head because of Huntington’s Chorea. Neither saw his impairment as an essential part of self. Neither saw his politics as influenced by the personal restrictions he experienced as a consequence of his impairment. This, I suppose, is not surprising if you’re confronted with the social restrictions imposed by fascist police, racist rednecks or anti-union thugs.

In my striving to relate my personal experiences of impairment to the social restrictions of disability, I found few disabled heroes in fiction, television or film. As far as writing is concerned, where impairment or disability does feature, it is usually seen as personal tragedy (Rieser and Mason, 1990). Where disabled people have written about themselves, it has all too often been within the ‘how I overcame my impairment/disability’ genre. Film and television provided, and continue to provide, a mass of super-cripple and emotionally stunted disabled stereotypes. In recent years, however, largely due to the influence of the disabled people’s movement on film or television, a few candidates for hero-worship are beginning to emerge.

My own personal favourite is paraplegic ex-war hero Luke Martin, played by Jon Voight in the film *Coming Home*, which was first shown in 1978; not just because of what he did to Jane Fonda, but also because his personal disillusionment with the Vietnam War and its aftermath drove him to chain himself to the gates of an army recruiting station. In him, the personal nearly becomes the political, but not quite. His protest was an individual one and thus ultimately doomed to failure. He may have saved himself but the disabling society lives on; the USA continues to fight imperialistic wars in the name of freedom and by so doing continues to create impaired people in their thousands.

While there may be emerging a variety of role models which will enable impaired people to understand their personal experiences

in political terms, there still remains the problem that the cultural discourse on disability remains structured by the tragedy principle (Hevey, 1992). The 'triumph over tragedy' principle still rules the mass media in newspapers, books and films and disabled people are constantly stereotyped as heroic victims or embittered villains. The complexities of the way impairment interacts with other personal characteristics are barely considered and, among disabled people, this may be worse for some than others:

Ask yourselves, when you last saw a film or television drama or soap with a lesbian or gay relationship at the centre of the story? . . . Far from pulverising you with lesbian and gay material – we are deprived of personal, political and cultural representation! . . . This cultural and informational deprivation is imposed BY A SOCIETY THAT TAKES LITTLE OR NO ACCOUNT OF THE NEEDS OF lesbians and gay men! Where have I heard something like that before? (Gillespie-Sells, 1993, p. 24)

With films like *Brokeback Mountain*, among others, this may no longer be the case, but such offerings don't portray the needs of disabled lesbians and disabled gay men.

There are non-disabled real-life heroes who helped me to link the personal with the political. For me, Muhammad Ali was not just the greatest boxer who ever lived but also one of the most important figures of the twentieth century. He embraced black pride, confronted religious bigotry and combined this with an opposition to the most obscene war in the history of humankind at great personal and financial cost. For him it was not just a matter of the personal being the political but, equally importantly, the political being the personal. He would not fight in Vietnam because he saw it as the white race making war on others. He also knew about the importance of being called by the name he wanted and he vigorously resisted being named by others, something that is also important to disabled people.

Two of my other heroes, Tommie Smith and John Carlos, used personal triumphs to make political statements. Having won a gold and bronze medal respectively at the Olympic Games in Mexico City in 1968, both men stood on the victory rostrum and raised their black-gloved hands in victory salute. In so doing, both knew they were giving up the potential riches that white society would offer if they sold out. To this day both have remained true to the beliefs that underpinned this gesture and work within black communities in their struggles against racism.

It is not all heroes or leaders who remain true to their communities. Working-class movements have been bedevilled by leaders who became part of the bourgeoisie; black movements have encountered similar problems, naming the black bourgeoisie as ‘uncle Toms’. Disabled people have a similar word for their bourgeoisie – ‘tiny Tims’. This stems from Charles Dickens’ use of the disabled child character tiny Tim in his novel *A Christmas Carol*. Tiny Tim was portrayed as pitiful and ultimately became the beneficiary of a rich man’s charity: a position not unfamiliar to some disabled people these days.

Over the years we have seen media stories of disabled people climbing mountains, trekking in jungles or across polar icecaps and sailing the stormy seas. In order to do so they are happy to reinforce stereotypical media imagery of disabled people and become the modern day ‘tiny Tims’ in the eyes of other disabled people who feel such imagery should be challenged rather than embraced.

Many of these charitable exploitations have become institutionalized now; in the USA they have ‘the telethon’ and in Britain we have *Children in Need*. Through no fault of their own, many of these children are coerced into becoming modern-day versions of tiny Tim.

Since writing the first edition of this book, I would like to say that new heroes have emerged to shape my disability consciousness further, but regrettably this has not been the case. There are three reasons for this I think: first, events in the world have changed considerably and recent years have seen the re-emergence of many villains on the world stage; second, the media in all its forms has moved on from its interest in disability issues, although it claims to have incorporated these issues into its mainstream agenda; and, third, my own retreat from academic and public life has been accompanied by a change in my own interests and there is not the space here to write about some of my current heroes, such as ‘Roy the Boy’, ‘Crazy Horse’, ‘Dodger McCartney’ or ‘Eddie the Shoe’.

### **The personal is still the personal, after all**

For a number of reasons, 1996 was a pivotal year for me. Professionally, I had published the first edition of this book and one on the history of the disabled people’s movement with Jane Campbell (Campbell and Oliver, 1996). The Sociology Department at Greenwich had undergone two successful government assessments, one for teaching and one

for research. I was in demand to speak at international conferences and to provide lucrative consultancy services to a variety of different organizations and some of my earlier work was being translated into several different languages. In my personal life, I was very happily married for a second time. My two children had left home, though, as many parents will confirm, they never really leave. And for the first time in my working life, I had money left over at the end of each month rather than being in debt.

However, there was a downside to all this as well. In terms of my writing, I felt that there was little more I wanted to say. In terms of research, the only projects I was interested in undertaking weren't fundable at the time, though government agendas now appear to have changed at least in terms of the language they use. Sociology was suffering a slow decline in popularity for two reasons: the competition from psychology and criminology fuelled by the popularity of television crime series; and many sociologists were embracing postmodernism and/or retreating into philosophy. Internally, the universities were changing to accommodate government demands for accountability and greater productivity, making them much less friendly places to work. All this left me looking for a way out, though it was not until 2002 that my university and I came to a satisfactory agreement about this.

Personally, I had no wish to work until I exhausted myself to the point where I was unable to enjoy my retirement. I had seen my father do this out of financial necessity and I was fortunate not to be in the same situation. I was also becoming increasingly aware that, as I aged with my impairment, my abilities to live a full and demanding life needed more attention and that I needed to make regular changes to the way I managed it. Not only that, but also, psychologically, I came to feel that I was no longer able to take things in my life for granted as I previously had and this led to periodic panic or anxiety attacks. So when my university eventually decided to make me a reasonable early retirement offer I was delighted to accept.

In trying to understand the journey of my life myself, the black-and-white film *The Incredible Shrinking Man* provided a key to my understanding. In it the hero, Scott Carey, is contaminated by a radioactive cloud combined with pesticide and from that point he starts to shrink. I remember watching it with my children on television when they were very small and they were terrified when Carey fought a life and death battle with a very large spider armed only with a pin. I was terrified too by the film but it took me many years and

the help of a real ‘shrink’ to understand why. The story mirrors all of our lives: we come from infinity and grow continuously to the point where we start shrinking until we again disappear into infinity.

It feels like I started shrinking in 1996 at precisely the point in my personal and professional life were ‘as good as it gets’, but, despite this, panic and anxiety attacks were becoming a problem for me. Not everyone reacts to their own shrinking in the same way that I did, however. Some accept it and grow old gracefully; others rage against ‘the dying of the light’ and still others ignore it and continue as if they’re still growing. Personally, I hope that I’m in the first camp because I’ve always been against the triumph over tragedy frameworks used to interpret people’s reactions to impairment, chronic illness or impending death. The film also helps me to understand why my favourite Leonard Cohen song is ‘Dance Me’. It is also about the journey of our lives and certainly there are echoes of mine in it in the line:

‘Dance me through the panic til I’m gathered safely in.’

(Lyrics by Leonard Cohen)

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So where am I on the journey of my life? Well, I’m still shrinking but I’m also still dancing, as I hope the rest of this book will demonstrate.

## **Conclusion**

The purpose of this revised chapter has been to show how my own developing consciousness – my personal biography, my attempts to theorize about disability, my growing involvement with the disabled people’s movement and, finally, my gradual retreat from the political to the personal – have shaped my thinking about the rest of the things you will read about in this book. I hope that the road map you now have from the Introduction and the window you have on my life from this chapter will serve you well in trying to understand what follows and that you won’t end up wasting your time.

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