

Personality Disorder. Temperament or Trauma?

Castillo, H. (2003) London, Jessica Kingsley Publishers.

As part of the forensic focus series, Heather Castillo's book looks at personality disorder. It describes the process of carrying out an emancipatory research project with service users as co-researchers and more importantly it considers the impact of this label on people attributed with this diagnosis. It begins with an exploration of the historical and contemporary context of this label and includes how personality disorder is attributed. Issues such as childhood abuse and unsatisfactory attachment in younger years are seen as a precursor to attracting this label in later life, hence personality disorder is closely associated with early abuse.

The first two chapters describe that this research into personality disorder came about through Castillo witnessing an increased number of people with Personality Disorder accessing the advocacy service she provides. A wider impetus arose from a service user (Tallis, 1997) writing about her experiences in *The Guardian*, and the newer Department of Health policy proposals for managing People with Severe Personality Disorder, which seeks to contain people in special units if they are deemed dangerous. The historical context and overview of the American and British Diagnostic manuals (ICD 10 & DSM IV) are then explored, identifying that Borderline Personality Disorder was devised in the 1950s to describe people who were 'between' neurosis and psychosis. The essence of this chapter is on the notion of treatability versus risk and containment. These chapters seek to challenge the validity of the concept of this diagnosis.

Chapter 3 focuses on the 'disliked patient' and considers the struggle between the notion of untreatability, the impact on those labelled and the responses from the professionals, many of whom may get tired of the intensity of the relationship between themselves and someone deemed as untreatable. Castillo describes the often-chaotic nature of both the service users and the services and implies the deep level of dissatisfaction experienced by both parties as well as the sense of

frustration that services are not able to adequately offer appropriate support.

Chapters 4-6 explore theories on personality development, complex posttraumatic syndrome and treatability. What comes across clearly from these chapters is that a significant number of people who experienced abuse in their early years are likely to be later labelled with Personality Disorder. Castillo explores the complexity of symptoms associated with abuse and how these interlink with personality disorder and the difficulties of misdiagnosis and mistreatment of people with this label. Types of treatments, which have been seen to be encouraging in supporting people with personality disorder, include psychodynamic psychotherapy, Cognitive Behavioural therapy, Cognitive Analytic Therapy and Dialectical Therapy and these are explored well here.

Chapters 7-12 get to the second focus of the book; namely the development and undertaking of the research study. Whilst not unique in terms of involving service users in research, it is an important study which involves people with personality disorder carrying out the research. Here the book gets much more personal and becomes more of a narrative of events leading up to developing the project, the training of users to interview and carry out part of this research, the problems with ethical committees approving co-user research and the levels of frustration and delay this attracted. However the group overcome the ethics adversity and provide a deeply moving account of the experiences of people with personality disorder, through the use of a questionnaire that they devised and journal entries from participants. This is by far the best part of the book as service users' own views and experiences of having this label and what it means come across very powerfully and clearly - professionals beware, it is not comfortable reading. Chapter 13 and 14 consider the findings of the research against Goffman's Moral Career of the client and the 'diagnostic straightjacket' supplied by professionals and the effect on people when they discover they are labelled with personality disorder.

The final two chapters describe the processes surrounding the growing momentum and

recognition of this research from ‘those up high’. Castillo describes the experiences of her co-user researchers in presenting the findings of the study and how this small group made up of a professional and user-researchers have achieved international recognition from a research study that began from grassroots. What would have added to these final chapters would be some insights from the user researchers themselves as to their experiences of contributing to this research and their feelings about how this research has achieved such recognition; it is hoped that this study will be able to contribute to changing current policy.

66

Mental health, social care and health professionals would find this a useful book, as would those recently diagnosed with personality disorder and their relatives. Students in health and social care fields who are looking to specialise in mental health will find this a valuable resource.

Lana Morris

Social Work Lecturer

**School of Community Health and Social Studies,
Anglia Polytechnic University, Cambridge,
CB1 1PT**

Inclusive Research with People with Learning Disabilities: Past, Present and Futures.

Jan Walmsley and Kelley Johnson (2003), Jessica Kingsley Publishers

Walmsley and Johnson’s intention in ‘Inclusive Research ...’ is to explore how research which seeks to maximise the inclusion of people with learning disabilities has developed, to chart its theoretical roots and to explore the challenges and limitations experienced in practice.

To do this they forward a number of what are termed ‘questions we dare not ask’ regarding the research undertaken in this area. Areas covered include issues of the research’s history, its theoretical influences and social construction. In looking at research in practice they focus on issues including role definition, power relationships and barriers to inclusion.

The authors recognise that writing as two non-disabled academics they are undertaking work

contrary to the current credo of learning disabilities user groups that there should be ‘Nothing About Us Without Us’ and expect to be criticised. Their aim is however to forward the emancipation of the so-called ‘subjects’ of the research, a process they view as having stalled. In order to regain momentum the authors request that we allow them time to clarify their own position before translating their ideas into a more accessible format and this book is therefore not intended to be accessible to people with learning disabilities (though a future accessible version is planned). Instead it is geared towards the ‘non disabled allies’ who seek to undertake inclusive practice.

In charting the current ideological influences and social construction of the relationship between those researched and the researchers Walmsley and Johnson attempt to demystify the process of inclusive research and promote honest reflection on the compromises which have to be made to ensure researchers respond to and accommodate the inherent ‘impairment’ of the learning disability whilst minimising assumptions which would disable or limit inclusion. Much of the book chronicles the refinements made to the two authors’ own approaches to research through the well known projects they have undertaken over the last fifteen years. They then broaden the context to describe developments in both the participatory and emancipatory fields of research as well as assessing the extent of ‘user’ led organisations involvement in and control over the research agenda. The book is therefore an excellent example of reflective practice placed in a solid theoretical framework. Its recommendations have implications for both policy and practice, which encourage an approach of capacity building to enable people with learning disabilities maximum control of the research agenda at both an interpersonal and organisational level.

If I were to criticise, it would be on the areas omitted from the book. Walmsley and Johnson choose not to define how the ‘people with learning disabilities’ they work with have been so labelled. The authors might defend this omission on the basis that it is not their focus however an increasingly clear ‘clinical’ definition of learning disability has emerged and is currently determining who will be labelled. To avoid this issue is to deny

the reality that the 'group' is evolving which contradicts the social constructionist viewpoint forwarded. Why for instance have the authors not used the term 'people with learning difficulties' preferred by many user groups?

In this and other areas the authors' choice is to focus on the 'how' of current practice and omit the 'why' underlying the social reality of people with learning disabilities experience.

A further area where I felt the picture was incomplete followed from the authors' assertion that the majority of inclusive research has been undertaken by female researchers. Whilst this is undoubtedly true I would question whether this has encouraged an approach where women with learning disabilities stories have been more actively canvassed within the research undertaken to date and whether the separate voice of men with learning disabilities has, as yet, been equally heard.

Overall however I found this book challenging and refreshing in its honesty. Whilst I suspect some self advocacy groups will indeed criticise the seeming contradiction between a book about inclusion that is not inclusive in its authorship or language the intended readership of 'non disabled allies' will benefit from its insights.

Paul Winstanley
Senior Social Worker
Kneesworth House Hospital,
Partnership in Care, Bassingbourn-cum-
Kneesworth, Royston,
Hertfordshire, SG8 5JP

Surviving user-led research: Reflections on supporting user-led projects

The Mental Health Foundation, £30 or £15 to service users and survivors

This is a refreshingly written piece of work, which is open and honest about the pitfalls as well as the benefits of user research. Helpfully, it is written in plain English, with a minimum of technical language and jargon, so as to be accessible to the widest range of potential readers.

This is the second phase *Strategies for Living*,

which supported research projects by providing training in research and encouraged survivors to investigate areas of interest. The authors highlight this process from planning the three year programme; to advertising for people with experience of mental ill health or distress; to putting forward a proposal to carry out research and for Research Support and Training Workers (RSW's); to the training, ethics and dissemination of the projects and the overall experience as a whole.

There are notes about terminology and how user, survivor, and service user are used interchangeably. The introduction describes what is meant by user-led research and how it differs from research carried out by clinical researchers, for example. It describes the roles, relationships and boundaries of individuals involved in research with reference to their experiences.

The authors (Vicky Nicholls, Sarah Wright, Rachel Waters and Stephanie Wells) give several examples of the problems experienced such as the lessons learned, the limitations, and expectations of the organisation and the researchers involved. It demonstrates how difficult it can be to get diversity and be inclusive when there are few applications from minority groups. Reasons and recommendations are given to try to prevent this happening.

This report clearly reflects how the experience for both the Mental Health Foundation and the individual researchers develops and grows through the learning process. It talks about projects, which were not completed and offers reasons why and ways that could perhaps prevent similar events happening. It emphasises the importance of relationships throughout the process and how different roles can be perceived. It gives examples of how, although the RSW's role was that of support and communication, it was seen by some researchers as more of a supervisory role or that of a 'friend'. It discusses the range of abilities and skills of the different researchers and the differing requirements in the training and help and support given.

Throughout each chapter, tips are offered: perhaps these could also have been put in the appendix for

easy use. Recommendations are offered at the end of each of the chapters discussing the process, and these neatly tie up each section. The layout of this report is easily accessible and the ring binder format means that it can be used in different ways. Each project is summarised separately at the end so that the reader can identify to what the report is referring.

Overall this report is a well written reflection ‘on supporting user-led research projects’, openly showing the difficulties that do and can happen in user-research. It does, however, demonstrate the important role of user-led research and how valid it can be in discovering what is important to users of mental health services and people who experience distress. It will hopefully encourage people who perhaps had not thought about taking part in or doing research, to have a go.

The report is available from:
The Mental Health Foundation, 83 Victoria Street,
London SW1H 0HW.
Tel: 02078020300
Email: mhf@mhf.org.uk

www.mentalhealth.org.uk

Debbie Tallis
User Researcher
Anglia Polytechnic University
Member of Involve consumer research
committee