

# Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/ Challenging Behaviour:

## Technical Document -

### Chapter 4.2 Literature Review – The Experience of Service Users

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## **Guide to Services for Young People with Learning Difficulties/Disabilities and Mental Health Problems/Challenging Behaviour – Chapter 4-2 Literature Review – The Experience of Service Users**

This survey of the literature on the experience of service users presents outline summaries of a number of papers, with references for further reading

Ramcharan & Grant, (2001) present a review of literature on the views and experiences of people with LD,, which they divide into three broad categories:

- 1) ‘testaments of life’, which are mainly ethnographies and life histories
- 2) ‘user movement media’ produced in an accessible format for people with IDs or by people with IDs themselves
- 3) ‘research based studies’ in their varying forms.

This review will follow this typography, distinguishing the last type by its focus on the experience of services.

Ramcharan & Grant argue that no single approach is able to encompass all the interests of knowledge production, policy planning, and action or practice on its own. Testimonies and other accounts of the views of people with LD are remarkably diverse, being found in academic studies, the media, the Internet, newsletters from communities of interest, and various publications by for and with people with LD aimed at enabling the ‘voices’ of these people to be heard.

The social model of disability emphasises the way society and services effectively combine to disable people and asserts ways of breaking down the disabling barriers created through social action. The medical model of disability, by contrast, focuses on the individual’s impairment and seeks to ‘repair’ these through various forms of direct intervention. There is also what might be described as “an emancipatory research interest” (p350), which emphasises active participation by people with LD throughout the research process. Such research methods (for examples, see Habermas 1978; Friere 1983; Reason 1988; Cocks & Cockram 1995) and the emergence of a self-advocacy movement internationally (Bersani 1998), offers a new participatory agenda for research within the LD arena – though it is not clear to what extent people with LD can act fully, independently and equally as participants. Such participation is subject to a number of factors, not least the quality of support that is provided and the ability of people with LD who are able to communicate verbally to speak on behalf of those who cannot.

Testaments of Life: A large and diverse body of work consisting of ethnographic studies and personal narratives has emerged under this heading. Often constructed through the efforts of an intermediary such as a researcher or close associate (e.g. Deacon, 1982), these narratives have sought to act as conduits for the ‘voice’ of the person with LD. A significant publication described by Ramcharan and Grant was *Know me as I am* (Atkinson & Williams, 1990), an anthology of poetry, prose, art and reflection by people with LD. Another was *A Fit Person to be Removed* (Potts & Fido 1991) in which the personal accounts of 17 people who had spent much of their lives in a long-stay hospital were presented. The book showed both the degradation of

people in such institutions and the quality of friendships and support networks of these forgotten people.

The value of such accounts as these is that they “can help people make sense of their individual lives, and can complement and often challenge historical accounts based on documentary sources” (Fido & Potts 1997, p. 45). However, they are not without their limitations, especially in the efficacy of individual testimonies to provide a sufficient, solid and generalised basis upon which to develop policy.

Testaments of life can instruct practitioners, families, advocates and others only to the extent that they are read (in full). Moreover, their relevance to action or policy is one which depends upon the interpretation of the reader (Ramcharan & Grant, 2001).

**User-movement media:** The self-advocacy movement has worked to develop a number of publications that advocate the perspectives and demands of people with LD. Mostly, these have been with local intentions, and with a view to influence policy decisions and to provide some form of official ‘voice’ to the people affected by policy. The authors note that recent years have seen an exponential growth in the number and range of products emerging in this way. There are caveats, however: such recommendations are “rarely considered longitudinally, tested for efficacy nor formally evaluated.” Moreover, the evidence presented does not readily contribute to policy decisions that affect populations of people with varying degrees of need, circumstances or expectations. Arguably, the main benefit of such productions lies in the process of their development rather than their outcome within the policy arena.

**Research based studies:** Under this heading, Ramcharan and Grant describe a number of studies that reflect the growth of community services, ideas such as normalisation, and influential publications such as *An Ordinary Life* (King’s Fund 1980). Some have featured people with LD as informants, and have used a wide variety of service locations inhabited by people with LD. On the whole they focused on assessments of service process and the experiences of people with LD as perceived by others. Outside of formal institutions, studies of community life have explored issues such as the experience of stigma, identity and friendships, leisure, social networks and quality of life.

Beart et al (2004) review the literature on how people with LD view their social identity. The ‘identity’ of people with learning disability is important because, on the basis of this classification, whole services are created and policies made for a population that may run to about 1.5 million in the UK (see *Valuing People*). For individuals, the label ‘learning disabled’ is one that is professionally determined and imposed on the basis of ‘objective’ criteria (most fundamentally IQ). It is life-long in its attachment. Moreover, it affects every aspect of the person’s life and that of their family, friends and/or carers, in ways that are distinct from the effects of the impairment itself. It is thus neither neutral nor peripheral, and can have powerful effects as, for example, in cases where ‘diagnostic overshadowing’ (Reiss 1982) influences the identification of physical, mental, or social problems. In such cases, stigma is often the result.

People with intellectual disabilities are frequently segregated from people who do not have intellectual disabilities (Khan 1985). They tend to have fewer employment

opportunities (Valuing People: White Paper 2001), and thus are economically less well off (O'Connor 1992), are less likely to marry (Koller et al. 1988), have less satisfying social relationships (Chappell, 1994) and experience fewer community leisure opportunities (Wertheimer 1983) than people without intellectual disabilities. (Beart et al, 2005. p49)

Researchers investigating the experience of stigma have found that it is something familiar to many people with LD. There are a number of studies exploring the experience of disclosure for parents. Beart et al (2004) argue there are, by contrast, very few studies that attempt to explore “how people with LD discover their own ascribed social identity, and how this affects their sense of self.” (p. 50, see also Todd & Shearn 1997). They undertook a search using Psychlit and the key words ‘learning disability’, ‘learning difficulties’, ‘intellectual disabilities’, ‘mental retardation’, ‘identity’ and ‘stigma’, and selecting only those studies that employed qualitative methods involving people with LD, either in whole or in part, thus recording the subjective experience and meanings that people with LD attach to the label. A number of key findings emerged. They cite Jahoda et al’s (1989) and Findlay & Lyons’ (1998) conclusion that there is no simple relationship between social identity and personal identity.

Many people with intellectual disabilities do not appear to see this identity as applicable to them even if significant others do (Jahoda et al. 1989), and when they do it has no bearing on their self-esteem (Finlay & Lyons 1998).

Longo & Scior (2004) argue that in-patient psychiatric care for adults with ID’s and mental health problems is currently delivered by both mainstream and specialist services. Government policies support the use of both models and encourage integration and inclusion as guiding principles. Their study explored the way individuals with LD and their carers experience specific aspects of in-patient care, including admission and various aspects of their treatment. Attempts were made to compare service user’s and carers’ experience of generic versus specialist setting. 29 service users who had been admitted to a generic psychiatric service based in three hospitals or to specialist settings including assessment and treatment units and their main carers were interviewed. Participants each had a dual diagnosis, were able to take part in interviews, and had experienced an admission within the last twelve months. In brief, findings indicate that service users experience feelings of lack of control and disempowerment, and of not having a voice in the admission and treatment process. They lacked information about the key treatments, duration of admission, medication, and place of residence following discharge. Feelings towards staff were mixed, some identifying staff as friendly and communicative, others quite the opposite. Social/environmental factors such as proximity to other service users’ unpleasant behaviour (such as aggression, bullying, shouting and fighting), isolation from other service users, and physical aspects such as access to their own room, quality of the food, and standards of cleanliness were each recorded negatively. Positive aspects of admission included much needed respite from their usual living environment, and some supportive relationships and friendships with other service users.

Generic settings tended to promote stronger feelings of solidarity amongst service users, matched by negative feelings towards the attitudes and behaviour of staff.

Feelings about the environment and of their own sense of power and security were also more likely to be negative in generic settings. By contrast, specialist settings evoked more positive feelings towards staff and the environment, and for the admission to be seen as a sort of respite. Carers also viewed staff in generic services as uncaring and neglectful. They tended to praise specialist settings for their openness and information sharing

In general, then, negative feelings were more widely associated with generic services, particularly with regard to service user/staff relationships. Peer relationships in generic settings were stronger, but this was accompanied by a greater sense of detachment and unease towards the institution and regime within which they found themselves.

It should be noted, however, that the paper does not present a discussion of any factors that distinguish the two settings beyond the terms ‘generic’ and ‘specialist’ and a few details about the place of each within the structure of the service. There is no mention of any differences in levels of training, or of staff selection procedures, no discussion of staffing levels, or the way staff are encouraged to interact with users. There is no mention of the quality of staff attitudes or behaviours. There is an implicit assumption that the role of service users is essentially passive; and the authors’ call for greater involvement of service users as a factor contributing to better prognosis is not supported by discussion of what form that involvement might take or how power balances might be changed. It thus falls within the medical model of care.

Goble, (1999) provides a phenomenological investigation of the way a small group of seven people with LD living in a single community residential setting perceived the staff who worked with them. The initial impetus for the study was a realisation that the people he worked with saw the situation in which they lived and the relationships within that setting in ways that were very different from those of staff. He cites as emblematic the view of one female resident that she was there as “‘punishment’ for past ‘badness’” and wonders if “‘misperceptions’” such as this in fact “‘...reveal deeper, disempowering assumptions on the part of staff and service providers...was her perception ...not the truth as she perceived it?’”

Using thematic analysis of audio taped conversations with each of the participants, Goble identifies three categories or themes:

- (1) perceptions relating to the physical presence or absence of staff
- (2) perceptions relating to the emotional impact of interaction with staff
- (3) perceptions relating to the political impact of interaction with staff.

Participants saw the staff as central to their wellbeing in each of these domains, and their influence to be generally positive. Their attention was positively sought, sometimes competitively. To what extent this was a genuine response, however, was called into question by what Goble calls the “‘emotional blandness’” of their accounts of incidents, over which they displayed a marked reluctance to display any strong emotion. Most references to other service users were negative, other people with LD being seen as “‘irritants or tormentors’”. Participants generally saw their status as determined by staffs’ perceptions of them, rather than their own accounts of emotions or experiences, or that of fellow residents. Moreover, they recognised that staff were

‘in charge’ and held the key to any changes in their lives, but had little understanding of the systems by which they did their work or of their own place in them. Such acknowledgement as there was of a ‘system’ seemed to imply a monitoring or even a punitive purpose to the work, as suggested by a few references to ‘assessments’ and ‘checklists’. Where awareness of such lists did occur it was in the context of a record of ‘bad’ behaviour. In summary Goble (1999) comments:

“The perceptions of participants regarding staff roles and identities give insights into the nature of the inter-relationship between them which...are revealing of the nature and extent of their disempowerment. They live in a world where they are almost completely reliant on staff for their physical and emotional well-being, but where they have little or no knowledge of the rationale or structures defining the roles of staff in their lives and thus no means of negotiating what those roles should be. They clearly perceive themselves to be subordinate, but with no clear idea why. They appear to live subject to the vagaries of mysterious, powerful others who they call by their first names, refer to as friends, but who they hardly seem to know at all as people, still less as agents of what [one participant] aptly called ‘the secret service’.”

(Goble 1999, p 457-8)

Goble argues for a “straightforward and materially uncostly” (sic) solution – introduce staff to service users as equals on the same terms they would expect in situations in which staff are introduced to other members of staff – with full and active life histories, families, friends, strengths, weaknesses, loves and hates. “...(S)uch reciprocity seems to be largely unknown. The mystery of who we are, what we do and why, is almost complete and the recipients are left to glean what they can from our comings and goings, language and behaviour.” (p458).

Such a gulf between the people who use services and those who provide them is emblematic of a tradition of medicalised and custodial models and practices.

It is now apparent that simply moving people from large institutions to group homes and hostels does not, in itself, eradicate institutional practices and organisation (Sinson, 1994). Indeed, pressure to maintain, and even to extend medical and custodial models and practices into community-based settings continues as a result of political, professional and financial expediencies despite their supposed retreat in the face of the challenge from normalisation philosophies (Collins, 1992).

Goble (1999) expresses concern at the “blanket assumption” that people with cognitive impairments are of infantile status when it comes to issues such as choice and control. Philosophies of care that see change in the individual with a learning disability as the means to the reduction or elimination of ‘problems’ are in danger of disempowering the very people they set out to help.

The challenge of gathering service users’ views of care within the context of specialist inpatient units is discussed by Young & Chesson (2005) in their discussion of methods of working with people with learning disabilities and severe mental health problems. They used two different tools – analogue scales and photographs – to elicit responses from 6 respondents. They conclude, with some caveats, that these tools are appropriate, and that inconsistent replies could be justified by self-commentary or body language denoting ambivalence to questions, change of mind or fluctuation in

mental state. The analogue scale was sensitive to strength of feeling, but interpretation of responses required careful consideration. Photographs were meaningful to all participants and encouraged discussion around the topic of investigation. Concerns are discussed over the extent to which consent was freely given. For example, the presence of a nurse may have resulted in patients giving answers to please them. Likewise, the process of seeking views from those with severe challenging behaviour and profound learning disabilities was problematic because of communication problems and possible risk of triggering distress in patients.

Their research highlights the considerable resources and skills required in obtaining meaningful involvement from respondents of this type. A range of practitioner skills is necessary for facilitating involvement: including the selection of appropriate methods; use of the right tools and approaches; good working knowledge of communication strategies; good knowledge and understanding of respondents; and skills in building relationships and negotiation.

In his review of the literature on research and therapy for emotional difficulties in people with learning disabilities, Arthur (2003) acknowledges the significant lack of understanding of the subject:

“Numerous authors criticize the almost complete lack of direct psychological attention paid to emotions in people with learning disabilities (e.g. Hollins & Evered 1990; Tharinger et al. 1990; Garber 1991; Wagner 1991; Jones & Bonnar 1996; Wenz-Gross & Siperstein 1996). Particularly, they comment that when it come to emotions, there exist few studies investigating psychological treatments for depression (Lindsay et al. 1993), anxiety (Lindsay et al. 1997) and the effects of having a ‘stigmatized identity’ (Szivos & Griffiths 1990); a history of ‘therapeutic disdain’, prejudice, resistance and lack of attention towards providing psychodynamic (Bender 1993), psychoanalytic (Beail 1998) and cognitive-behavioural psychotherapy (Dagnan & Chadwick 1997). There is a lack of standardized instruments for accessing emotions (Clark et al. 1991), including sadness (Reed & Clements 1989) and as part of need assessments (Newman & Beail 1994); a lack of knowledge (Lindsay et al. 1994) and neglect (Black et al. 1997) about emotions and emotional disorder; and there are comments that this client group has been one of the most ignored in terms of mental health services and psychological research into therapeutic techniques (Reed 1997).”

(Arthur, p25)

He notes the importance of emotional welfare, arguing that:

“What is the use of a better physical environment if their existence is characterized by loneliness, isolation, fear and apathy (Sullivan et al. 1988), their social interactions remain limited (Dagnan et al. 1995), there is little attention to the ‘ . . . subjective quality of the individual’s experience or, indeed, to the individual as a feeling sensate being’ (Szivos & Griffiths 1990; p. 334) and if healthcare professionals promote ‘ . . . independent living skills and the treatment of challenging behaviour at the expense of the client’s emotional well-being’ (Reed 1997; p. 55)? Efforts to improve physical environments by living in the community may be considered wasted if they are put under the pressures of community living (Lindsay & Olley 1998).”

(Arthur P. 26)

Beart, (2004) and Beart et al (2005) considers the possible implications of self-advocacy groups: how people with learning disabilities understand and define the label learning disabilities and how salient they find this identity. There has been a consistent finding that a high number of participants do not associate the label 'learning disability' to themselves. This can be explained by people with learning disabilities not having access to the meanings of and discussions about learning disabilities as a categorisation and because of the emotional impact of this label.

Beart, et al (2004) explored the experience of 8 participants who were members of a self-advocacy group and their own assessment of the impact membership has on their lives and sense of identity. Participants reported a gradual change in self-concept as they made the transition from being outside the group to identifying themselves as group members. Changes included feeling more confident, speaking up and sticking up for oneself. 6 categories emerged to offer an explanation as to why these changes occurred. It was identified that change occurred through participants becoming aware of the aims and identity of the group, seeing these as meaningful, and gaining new roles and responsibilities which gives them status. Experiencing a positive social environment is important in providing participants with friendships and support which facilitate change in the self concept. These changes also brought about difficulties in emotionally processing upsetting experiences such as bullying and discrimination. The authors conclude that emotional support is important in maintaining changes in self-concept. This can be facilitated by taking time to talk and reflect back on what is said.

The Count Us In inquiry (Carpenter & Morgan 2003) looked at the mental health needs of young people with mild to profound learning disabilities. Ages range from 13-25. They found that young people with LD want to be included, to have friends, a social life, education, work. Positive mental health should be promoted among young people with learning disabilities. Effective communication is essential. It is important that young people who have communication problems are given ways of communicating their wishes. The preferences of young people approaching adulthood about where they live must be taken seriously. Trauma, distress and loss are all risk factors for mental ill health. Their impact must be acknowledged and support given to communicate, grieve and move on.

Schools have a big part to play in contributing to a child's emotional well-being. Drop-in counselling services and mentoring systems need to be applied with those with LD and MH problems to facilitate emotional well-being. Young people need chances to voice their views of their transition. Schools need to be aware of the range of the modes of communication and find out how individuals prefer to communicate.

The inquiry heard from young people how they value just doing the ordinary things:

'I just like hanging out with my friends.'

'It makes me sad when they don't ask me to play football.'

'Well, me being with my girlfriend makes me happy.'



Young people also mentioned that they enjoyed leisure activities including swimming, cycling, running and playing, watching football and martial arts. Getting out was frequently cited as sources of happiness and enjoyment.

Circles of support can help people develop relationships in a safe environment. They contribute to well-being through promoting inclusion, supporting relationships, preventing isolation and keeping power firmly in the hands of the individual. Young people and those close to them told the inquiry that there are many barriers in their way stopping them from leading fuller lives. If they experience emotional stress, it is often difficult to get appropriate help.

May's book (May (ed.), 2000) includes a number of relevant chapters. In brief these include:

**Shepperdson B, Negotiating Adolescence**

For adolescents with learning disabilities the chronological age at which adulthood occurs varies greatly. Personal assertiveness differs with individuals with ID. Isolation from peers often compounds on their attempts at independence. Without initiatives from parents, children with ID may remain in this childlike dependence forever. Parents of young people with ID have a particularly difficult task, unlike other parents, because they are in the position to control their offspring's lives and prevent them from making a mistake. Their natural fears combined with a lack of assertiveness on the part of the youngster may well result in the young person remaining stuck in the transitional stage between child and adult.

**May D, Becoming Adult: School leaving, jobs and the transition to adult life**

Adulthood is an emergent status realised through the gradual acquisition of certain rights, privileges and responsibilities. These difficulties arise from parents and exclusion from the job market. Hickey and James (1993), suggest that it shapes the structure of the individuals life and social encounters and providing a sense of self and social identity. Denied access to work leads to a state of no longer children but not yet adult. On leaving school the real importance of work for people with ID lies not so much in the financial rewards it promises or the social contacts it facilitates, but rather that it is an indicator of social competence.

**Simpson MK, Programming Adulthood. Intellectual Disability and Adult Services**

Asks how the broad objectives of community care are translated into services at the individual level. There is a lack of studies attempting to elucidate or analyse the views of adults with intellectual disabilities. True in all areas: personal accounts of ID, experiences of receiving services, involvement in research planning etc.

**Atkinson D, Bringing Lives into Focus. The Disabled Persons' Perspective**

Looks at life-story research as the ultimate means of self-representation. It allows otherwise oppressed and powerless people to speak for themselves. Richards surveyed up to 20 years' research before 1984 and could identify only 5 British studies in which people with ID were informants. The process of deinstitutionalisation has played a big part in the development of the life story research. There has been a growing recognition that people with ID are an oppressed group. Increased life expectancy of those with ID. Life story research covers both biographical (narrative)

research, which seeks to draw together individual autobiographies or life stories and oral history, which involves individuals and groups in recording their lives within an historical context. Is powerful at a personal and social level. The growth of the self advocacy movement has paralleled the development of research studies which aim to include people with an ID. Life stories give an insider's perspective, they offer a corrective account (ie contrary to general thoughts regarding ID), demonstrate people's resilience and invite a reflective view.

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