

Paradigms in Intellectual Disability: compare, contrast, combineⁱ.

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Abstract

Four relatively distinct traditions in work with people with intellectual disability are identified: ordinary living/normalisation, functional, behavioural, and developmental. These approaches are analysed as paradigms which could be incompatible or compatible. The paradigms are explored in relation to a profoundly disabled man, whose case illustrates the complementarity of these approaches. It is suggested that the ordinary living paradigm is best seen as a basic guide to direction with the other paradigms feeding into it to help chiefly with implementation. However, the possibility is raised that rather than the co-existence of different paradigms, what is really being sought here is a new and super-ordinate paradigm that still awaits its full development.

Introduction

Understanding of people with significant learning disability (and work with them) has changed over the years. There has been an evolution from early notions that emphasised otherness, through theoretical and social administrative frameworks that legitimised segregation and under-resourcing through an emphasis on pathology and deficiency, to the present situation where there is widespread legitimation (if not consistent support) for notions of shared humanity, inclusion, civil rights and need for additional supports.

The last twenty years has been dominated by four relatively distinct traditions, which have sometimes have been in conflict, and sometimes in various kinds of alliance with one another. This paper explores these four traditions, their commonalities and differences of emphasis, with the intention of seeking a more adequate basis for the appropriate support of very developmentally disabled people. The four traditions have areas of overlap, but they can be broadly characterised as follows:

1. Ordinary living, rights, needs-based, normalisation / role valorisation - based perspectives.

Definitive statements about the normalisation principle include Nirje (1969, 1980, 1985), O'Brien and Tyne (1985), Wolfensberger (1972, 1980, 1983, 1992), Wolfensberger and Glenn (1975), Wolfensberger and Thomas (1983). A variety of guides and manuals for practice and service provision has been based on or drawn freely from this body of work (e.g. Brechin and Swain (1987); Firth and Rapley (1990); O'Brien (1987); Perske (1980); Richardson and Ritchie (1989), Sanderson (1995). Different exponents tend to have rather different emphases, but as a whole this tradition emphasises the following:

- social integration (with its corollaries of localisation and dispersal of provision),
- positive social roles and images,

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- the commitment and involvement of community members rather than service system employees,
- dignity,
- autonomy and growth.

It could be argued that it is illegitimate to conflate separate and distinctive ideologies (e.g. the rights approach, normalisation, social role valorisation) into one broad approach, and indeed there is a degree of simplification here. There are two justifications for this. First, there are 'family resemblances' between these orientations, particularly when considered beside the three approaches which follow. None of these subsequent orientations stems in the first instance from consideration of the social position and career of impaired persons - a defining characteristic of the approaches grouped under the 'ordinary living' heading here. Secondly: the movement may be characterised as a coalition of related interests, with their roots in the civil rights movement, as well as in the professions and progressive parent-based groups (Burton and Kagan, 1996, Kagan and Burton, 1995). To define the approach in such 'social movement' terms emphasises the commonalities, while defining it in terms of its philosophers' statements tends to emphasise divisions.

2. Functional, or skills - based perspectives.

The functional approach is perhaps the most practical atheoretical and non-ideological of the four approaches. It emphasises two domains:

- the functional activities of the person with intellectual disability,
- practical ways of supporting the person in personally relevant acts.

The functional approach has roots in the development of alternatives to intellectual assessment (Doll, 1953; Gunzburg, 1968; Sparrow, Balla, and Cicchetti, 1984) the psychology of skill (e.g. Argyle, 1984; Miller, Galanter and Pribram, 1964; Welford, 1958), as well as in behaviourally based work on functional repertoires for community integration

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(Whelan and Speake, 1979; Mcloughlin, Garner and Callahan, 1987). A typical text from within this tradition is that of Peck and Hong (1988). Recent work within this tradition (e.g. Jones, 1993; Nietupski and Hamre-Nietupski, 1987) has emphasised its distinctiveness compared to developmentally - based approaches: Nietupski and Hamre-Nietupski (1987, p. 226) identify their ecological variant as a 'radical departure from the sequential, bottom up sensory-developmental approach'.

3. The behavioural approach.

The behavioural approach entered the field of severe learning disability with Fuller's (1949) demonstration of operant conditioning with a person previously regarded as incapable of any learning. It is this active and optimistic orientation in behavioural work that perhaps explains its appeal to many workers in the field. There are different variants, but the Skinnerian (e.g. Skinner, 1953; Baer, Wolf and Risley, 1968; 1987) approach has had a major influence, and for practical purposes could be characterised by adherence to the following assumptions:

- Behaviour itself is the proper object of study, rather than internal processes or structures.
- Organisms adapt to their environments through processes at phylogenetic (chiefly Darwinian natural selection) and ontogenetic (especially through the selection of operant behaviour by the mechanism of reinforcement) levels.
- Ontological monism: no 'mentalist' explanations.
- Behaviour can be understood as a function of controlling variables
- Science is value neutral.

More recent approaches have stressed the analysis of behaviour in naturalistic settings rather than technological interventions (e.g. Emerson, 1993; Woods and Blewitt, 1993). As with other approaches, the behavioural approach has formed the basis for practical manuals for those not necessarily educated in the more subtle ramifications (e.g. Donnellan et al., 1988; McBrien and Felce, 1992; Zarkowska and Clements, 1994).

4. Perspectives based on theories of human development.

While statements about developmental processes and assumptions appear to be quite widespread among practitioners, perspectives that truly draw on developmental theory are not well developed, and it is unclear whether a pure developmental perspective actually exists. However, there are some statements of what a developmental approach would look like (Khan, 1979; Hodapp, Burack and Zigler, 1990). Other writers acknowledge a debt to the developmental approach, even when they draw more heavily on the behavioural and functional perspectives (e.g. Kiernan and Jones, 1982 ; Foxen and McBrien, 1981). Hodapp et al. (1990, pp 4-9) identify the following core assumptions of classical developmental approaches:

- the organism is active,
- change is non randomly directed to a specific end point,
- behaviour is evidence of underlying schemes,
- change can be both qualitative and quantitative in nature,
- development is not reducible to a simple function of the passage of time, and
- development involves progressive increases in 'differentiation, articulation, and hierarchic integration' (Werner, 1957).

Van Geert (1994, p. 96) captures much of this through the description of development as 'autocatalytic change' as a result of some 'structural possibility'.

One recent approach (Nind and Hewett, 1994) to work with people with very significant disabilities is based explicitly on the study of child development in the care-giver relationship. However, the `sensory approach` or `sensory-developmental approach` has had predominance in the field where developmental notions are used to justify exposing people to

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a wide range of sensory stimulation, often with little theory of how this might promote development and change in practice.

The writers are interested in drawing on all these approaches with a view to promoting a shift in the field to a more adequate theoretical and practical basis for working with people with the most significant impairments (i.e. profound intellectual impairment and/or multiple disability, and also the more disabling developmental disorders such as autism). Were the field to achieve this, it might be possible to: -

1. Discover effective ways of providing support to people with the most significant impairments.
2. Better understand people's needs and hence what activities and interventions are most relevant.
3. Overcome contradictions (apparent and real) between priorities - suggested by these different traditions.

The concept of paradigm

The term 'paradigm' is used to refer to these different traditions. It was used by Kuhn in the ground breaking book The Structure of Scientific Revolutions (1962), to explore the phenomenon in science where everyone works with the same agenda, and with the same set of assumptions and concepts. The term has been used by Cocks (1994) specifically to identify and analyse competing philosophies in current human service provision. The term has a broader scope than 'theory', which refers just to the intellectual, rational aspects. On the basis of a content analysis of Kuhn's usage of the term, Masterman (1970) identified three broad senses in which it is used:

- the philosophical, almost metaphysical sense, where the paradigm determines or organises what is believed, seen, or held to be real;

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- the sociological, or what we would call 'normative' sense, where the paradigm relates to a community who use the same standards for defining something as a scientific achievement, or who follow the same rules of judgement, or are governed by what amounts to the same political institutions; and
- the construct, or artefact, usage of the term, where the paradigm refers to common investigative tools, key texts, and other concrete artefacts.

Within the natural sciences, the distinction is made between A) 'pre-paradigmatic' science, where different workers, or schools, work within different paradigms, B) 'normal science', where the whole of a discipline works within one paradigm, essentially solving puzzles within its boundaries, and C) 'periods of crisis', or 'scientific revolutions', where a new paradigm emerges and defines the parameters of a new period of normal science.

Table 1 identifies the characteristics of each paradigm, in relation to the following critical questions and issues:

1. What is important for the person with a learning disability
2. How does change and development take place?
3. Process or outcome focus?
4. View of people with significant learning disability: a) 'strong' view).
5. View of people with significant learning disability: b) 'weak' view).

Table 1

It seems appropriate to make the distinction between 'strong' and 'weak' versions of the paradigms when considering the prospects for their combination. Inevitably there will be some caricature in this tabulation of beliefs and assumptions.

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Exploring the differences in emphasis between the paradigms

How can the differences between these paradigms be best depicted?

Paradigms can be understood as either,

1. in principle irreconcilable ('incommensurable' in the terms of Kuhn, 1962, and Feyerabend, 1970), or
2. in principle reconcilable, that is 'complementary' (e.g. Oliga, 1988).

Can an approach be built, drawing on the best of each, that leads to better outcomes for people with significant learning disabilities, or are the paradigms saying fundamentally incompatible things that imply radically different approaches? Our answer suggests that the paradigms are incommensurable only in the sense that they generally have different concerns. They differ, for example in the ways in which they give importance to process and outcome (see Figure 1 for a depiction of the weights they appear to give to these two dimensions), and moreover, they are concerned with different kinds of process and outcome.

Figure 1

Yet because of this incommensurability of focus, the different paradigms can often be complementary when brought to bear on the work of supporting people with significant learning disabilities.

One approach that emphasises complementarity is that of the German philosopher Habermas (1979; see Burton, 1994, and Pusey, 1987 for introductions). In Knowledge and Human Interests (1979) Habermas was concerned with the different approaches to knowledge within the traditions of natural science (and the Anglo-American tradition in the human sciences) and the continental philosophies of phenomenology and hermeneutics. As a political radical, he was also concerned with an agenda of human emancipation. His detailed study led to a

framework that distinguishes among three different kinds of knowledge, and three different kinds of human interest (see table 2). For the four paradigms, it could be said

Table 2

that the behavioural paradigm is concerned chiefly with technical knowledge; the developmental and functional paradigms also emphasise technical knowledge, but have some concern with interpretive knowledge, and the ordinary life paradigm, while chiefly concerned with interpretive knowledge is also partly concerned with both technical and liberatory knowledge.

Another way of exploring the different concerns of each paradigm is to try to divine the different key concerns of each paradigm through distinguishing between concerns with values, theory, and methods. The writers first used this simple framework to explore the necessary components in staff training, and suggest that it can also be used to diagnose the emphases of paradigms, texts, services, or professions and disciplines. The ordinary life approach would seem to emphasise values, with some concern for theory and method. The behavioural and developmental approaches are concerned chiefly with theory and method, while the functional approach is concerned with method and to some extent with values.

These are rather gross categorisations, for each paradigm is itself varied internally (and for each of the three Masterman/Kuhn usages). However, this preliminary mapping does suggest that the differences between the paradigms have more to do with different concerns or areas of emphasis and interest than with fundamental and irreconcilable differences over some core content area. For example, they could all be compatible with the general goal of people with significant impairments living in ordinary housing in the community, being supported to increase their skills and competence and to have more influence over their environment: they may have different insights into how best to accomplish this.

We can demonstrate this assertion with a case example:

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Derek is a young man in his late twenties. He is described as having a profound learning disability, but he walks and we believe that his vision and hearing are unimpaired. He lives in an ordinary community house and is supported by staff 24 hours a day. Staff report that they think he enjoys swimming and walking. Left to his own devices Derek will do little, except to seek and acquire food and drink. He will occasionally get up and change his position. He can do little for himself, although he has learned spoon feeding, door opening, and masturbation in the last 15 years. He has a great deal of self stimulatory behaviour, and this shades into head banging, particularly when there is little external stimulation.

Derek is someone we find it difficult to serve effectively. It is difficult to understand what he needs (and his repertoire for telling us is small), and it is difficult to create and sustain change for him that we are confident makes a real difference.

Taken on their own, the paradigms would suggest the approaches described in Table 3. That is, the approaches have distinctly different emphases, and imply different priorities and practices.

Table 3

However, when viewed as broadly complementary to one another, a practice can be suggested that takes inspiration from each of the paradigms. For Derek, this looks rather like this:

Practice

Derek's place is in our community, where he can have access to a broader variety of experience than in special segregated environments. We can extend his experience of ordinary places and activities beyond the rather limited menu of activities and places that his staff team have considered: one key to this is regularly being in places where people can come to know, understand, and like him (so no supermarket 'big shops', or large anonymous pubs). People who already know him, or who have cared about him will be encouraged and supported in renewing and maintaining regular contact

As yet Derek shows little discrimination between people, (and it does not help him if we pretend otherwise), so for now relationships are more important for what they bring to Derek, than for what they mean to him

We can try to associate different people with different activities and different salient stimuli, in order to begin the process that for us began in our first months.

Paradigm

Ordinary life, informed by community and social network analysis (Burton and Kagan, 1995, Chapters 3 and 6; Johnson, 1985).

Ordinary life approach, but kept from being over-romantic by an emphasis on behavioural observation (Burton and Kagan, 1995, Chapter 2; Firth and Rapley, 1990)

Behavioural and developmental paradigms (Bijou and Baer, 1978; Hobson, 1994)

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We can build on this with interactive games that provide strong augmentation of his natural propensity to respond to others and to repetition of very simple activities

Developmental paradigm (e.g. Nind and Hewlett, 1994)

We see Derek's high frequency of self stimulatory behaviour as getting in the way of opportunities for incidental learning. Indeed, for Derek to 'move on' in his learning and development he will need much more intensive learning experiences than he has had access to so far. We have established that regular learning sessions, involving simple repetitive modular tasks (e.g. picking up objects, inserting them in containers, taking them out, using each hand and both hands, etc. etc.) become acceptable to him once we have 'worked through' his initial resistance, and he shows learning from session to session. He perhaps needs an hour of such activity most days in order to maintain progress, and to 'disorganise' his well practised repetitive routines

Behavioural and developmental approaches (Ager, 1987; McGee et al., 1987; Waldon, 1985; Fallon and Whitaker, 1996)

The modular nature of these tasks makes them highly generalisable to everyday functional activities in the house that are naturally reinforced.

Functional approach (Jones, 1993).
Behavioural work on natural reinforcement (Ferster, 1967)

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Through both the artificial activities, and the everyday shared task performance of ordinary activities Derek is learning about his body and its relationships with sensory inputs (touch, vision, sound, proprioception), and properties of objects and three dimensional space

Developmental approach with functional approach.

Specific hypotheses about the causes of Derek's head banging have been identified and we are testing these. They include medical problems (e.g. sinus congestion), self stimulation, and adjunctive - type behaviour elicited by periods of waiting for things to happen.

Behavioural approach with augmentations (e.g. Iwata et al., 1982; Guess and Carr, 1991; Jones, Walsh and Sturmey, 1995; Woods and Blewitt, 1993).

Each suggests various courses of action, in his case less about specific behavioural 'treatments' than about improving the quality of his environment and the support he gets from staff.

Behavioural approach with both functional and ordinary life influences (e.g. Horner et al., 1990).

The above is not a comprehensive life plan for Derek, but should give an appreciation of how ideas from the three paradigms can be combined together cohesively.

The authors contend that without all of them we will miss crucial clues about how to support people with the most complex needs, and also forget why we are doing it. We started the above vignette with an emphasis on community inclusion and relationships. The ordinary life

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philosophy acts as the basic guide to direction and the other paradigms feed into it chiefly to help with implementation. Figure 2 illustrates this.

Figure 2

It may be helpful to practitioners to understand that the seemingly very different functional, behavioural and developmental approaches can be complementary when guided by the ordinary life approach. This is consistent with the view that meaning well and focusing on rights and roles will usually be insufficient to make a real difference for someone like Derek: technical knowledge from other sources is needed, in conjunction with both interpretive and liberatory knowledge.

Beyond the argument for practical complementarity of the paradigms, it is likely that a more adequate paradigm is emerging. It embraces the defensible core of each of the paradigms, while rejecting their unnecessary ideological baggage. The worked example above points the way to this new and more adequate paradigm, while leaving many questions unanswered, and practices to be developed.

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Paradigms in Learning Disability: compare, contrast, combine.

FIGURE 1: AUTHOR'S ESTIMATES OF THE PARADIGMS' RELATIVE EMPHASIS ON PROCESS AND OUTCOME

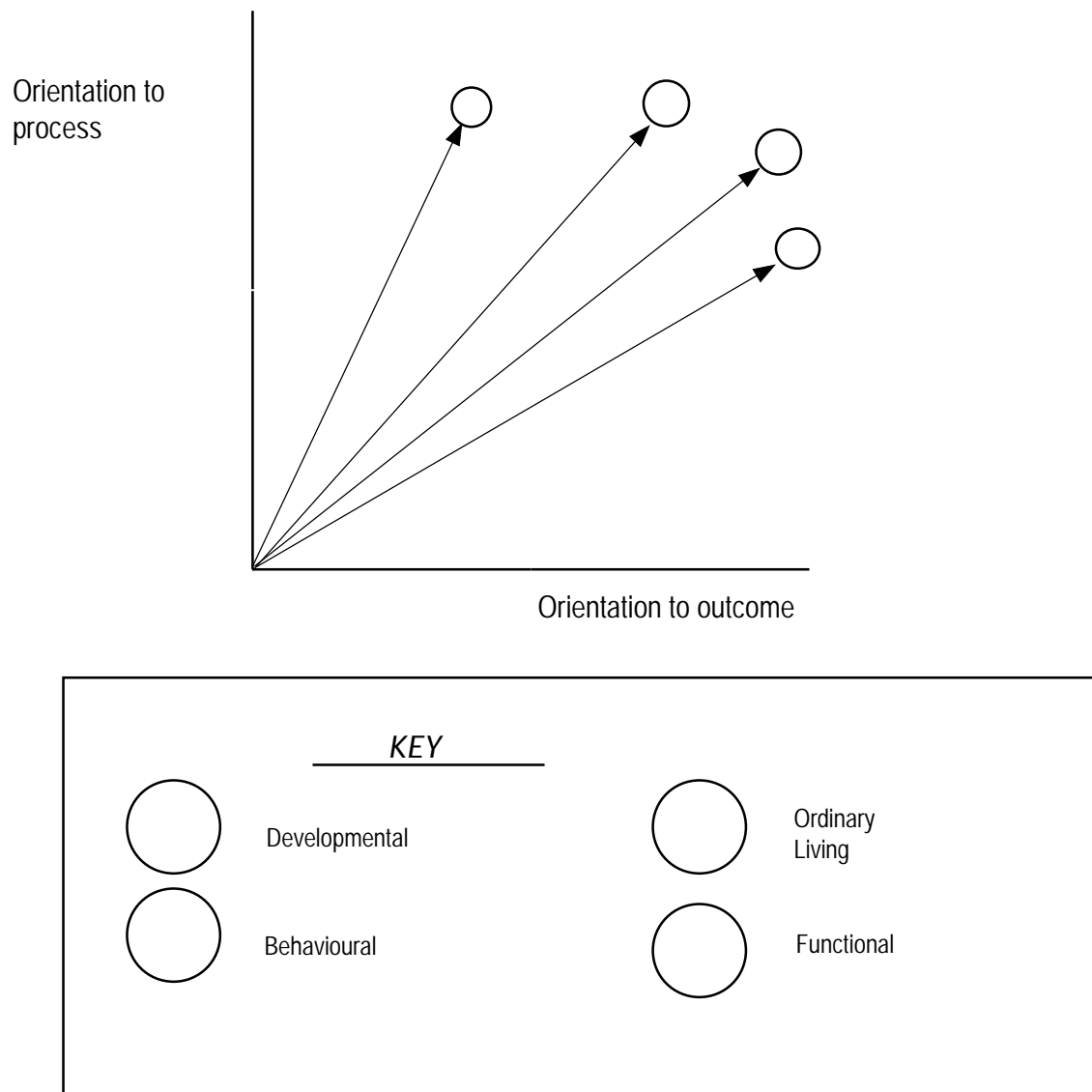


FIGURE 2: POSSIBLE CONNECTIONS BETWEEN THE PARADIGMS

The diagram indicates a possible hierarchical structure among the paradigms. It is not intended to be complete or definitive. The ordinary life paradigm incorporates elements from the other three paradigms, but can not be reduced to them. Similarly the functional paradigm draws upon both behavioural and developmental ideas. The question mark indicates that functional, developmental and behavioural paradigms are not exclusively tied to the ordinary living philosophy. Line thickness indicates strength of relationship.

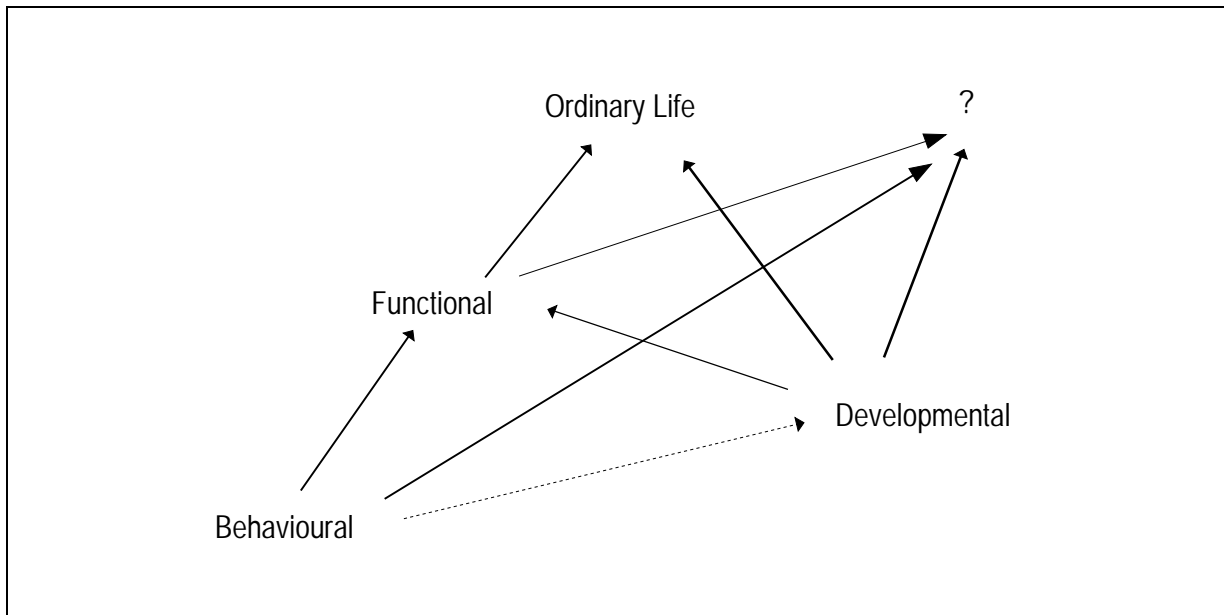


TABLE 1

Key Question or Issue	Ordinary Life	Functional	Behavioural	Developmental
<p>What is important for the person with a learning disability?</p>	<p>Various interpretations give different (or equal) weights to different dimensions of experience.</p>	<p>Skills and support needed to participate in everyday life.</p>	<p>Various versions:-</p> <p>a.) Increase appropriate or adaptive behaviours and decrease inappropriate / maladaptive ones.</p> <p>b.) Behaviour theory doesn't by itself define what behaviour is appropriate, relevant, etc.</p> <p>c) Reliance on cultural / evolutionary definition of what's adaptive for an individual.</p>	<p>Experience, knowledge and repertoires that are strategically relevant in the process of becoming a more developed human (e.g. from baby to toddler; from adolescent to adult).</p>

Key Question or Issue	Ordinary Life	Functional	Behavioural	Developmental
How does change and development take place?	General statements about modelling, experience, opportunity, inclusion.	Cumulative acquisition of behaviour (may draw on behavioural and developmental)	Cumulative acquisition of behaviour: <i>'By psychological development we mean progressive changes in interactions between the behavior of individuals and the events in their environment.'</i> Bijou and Baer, 1978	Developmental theory usually stresses, in some form, 1) 'Autocatalytic change', that is 2) a result of 'structural possibility'. Various versions which may overlap, e.g.: a) Emphasis on largely fixed structure and order of development. b) Emphasis on social construction. c) 'Dialectical' views (person takes part in the construction of themselves).

Key Question or Issue	Ordinary Life	Functional	Behavioural	Developmental
Relative emphasis on process or outcome. (see Figure 1)	Outcome (and some process)	Outcome	Process and outcome	Process
View taken of people with significant learning disability: a) 'strong' version).	<p>People who (just?) need extra support. Otherwise just the same as the rest of us. Everyone is gifted in some way.</p> <p>May emphasise one or more desirable aspect, e.g. social valuation, society's obligation, inclusion, social role, image, etc.</p>	<p>People who need to be taught the skills necessary for functioning in society.</p>	<p>Members of the species who obey the same behavioural laws as other members, although certain parameters may differ (e.g. rate of acquisition)</p>	<p>People stuck in their development.</p> <p>People who need intervention to restart their trajectory through a more or less determinate developmental sequence.</p> <p>People whose development needs external catalysis.</p>

Key Question	Ordinary Life	Functional	Behavioural	Developmental
<p>View of people with significant learning disability: b) 'weak' version).</p>	<p>People who may lack some or many of the things we'd normally count as necessary for adulthood / personhood, but who can and do have same / similar experiences of pain, disappointment, pleasure, anxiety, anger, ecstasy, etc. People whose access to a social identity is imperilled by social and societal management of them as a class. Emphasis on person's experiences rather than formulaic prescriptions.</p>	<p>People with both impairments and rights, which together imply the importance of receiving effective training in the skills the community regards as necessary for membership. May need help in the partial performance of skills.</p>	<p>People who have impairments in learning and responding adaptively, but who will benefit from technology based upon the analysis of behaviour.</p>	<p>People whose emergence as community members can be aided by an understanding of the properties of normal development. I.e. if we understand how development proceeds in the absence of impairment, then we can harness teaching efforts to it, to reduce wasted effort in teaching things that will not be assimilated / understood / utilised.</p>

TABLE 2: THREE TYPES OF KNOWLEDGE.

type	main characteristics	relation to other people
1. technical	based on natural science; emphasises objectivity, prediction and control	distancing, objectifying
2. interpretive	based on social science, arts and literature; emphasises shared understanding	understanding others viewpoint
3. liberatory	based on liberation movements and therapy; emphasises reducing mystification and exposing hidden power in order to free people	participatory, shared action

After Habermas (1979); Burton and Kagan, (1995)

TABLE 3

Key Question	Ordinary Life	Functional	Behavioural	Developmental
What is important for Derek?	The important things for Derek to have in his life are: relationships, community participation, autonomy, respect, and competencies in areas which will contribute to the other accomplishments.	It is important for Derek to develop the necessary skills to communicate with people, participate in everyday activities (eating, drinking etc.) and community activities.	Derek needs to decrease his maladaptive behaviour of head banging and increase his adaptive behaviour - e.g. seeking assistance to gain reinforcers.	Derek needs to build on the skills he has developed, focusing on the next logical stage e.g., building on visual tracking and search for partially hidden objects to full object conservation.

Key Question	Ordinary Life	Functional	Behavioural	Developmental
How are these identified?	<p>A process of getting to know the person as another human being.</p> <p>This might involve completing a personal profile with/for Derek. This would identify: Derek's history and background; what choices Derek makes and what are made on his behalf; what relationships he has; where Derek goes in the community; What contributes to Derek being respected and what hinders it; What Derek's preferences and skills are. Derek's experiences may be compared to that of a person of a similar age/culture/gender who is not 'labelled'.</p>	<p>Functional Assessment:-</p> <p>Covers current skills for everyday life, e.g. 'Scale for Assessing Coping Skills'. (Whelan and Speake, 1979). Derek would be assessed using such a tool, probably over a number of occasions, since co-operation with the tasks and faitgue are likely to be limiting factors.</p>	<p>Behavioural (functional) analysis and ecological assessment:-</p> <p>Aim to identify causal relationships between behaviour and environmental events/states through direct observation, third party interview. Those in direct contact with Derek may be encouraged to record events over time using formal recording schedules. (e.g. Willis, La Vigna and Donnellan, 1989). For some bahaviours tachtology such as video and real time computer recording might assist in identifying relationships among events.</p>	<p>Developmental assessments:-</p> <p>These may be largely theory referenced, e.g. Kahn (1987) Uzgiris and Hunt (1975); or norm referenced, e.g. Griffiths (1954), Schopler et al.(1990). Skilled and experienced workers often internalise the theory and norms in day to day work. Again Derek would be assessed over several occasions to build up a picture of performance in the different developmental domaions.</p>

Key Question	Ordinary Life	Functional	Behavioural	Developmental
How will change and development take place?	By giving Derek access and support to participate in everyday activities and opportunities in the community. To build on his existing interests of swimming and walking and seek ways to develop others. This will give him opportunities to meet people and develop relationships although this may take a long time.	May use behavioural techniques e.g. task analysis, backward chaining etc. directly on the task to be learned in the environment where it takes place naturally. So Derek might be encouraged to participate some activities of ordinary living at home, carrying out simple tasks with prompts (e.g. pulling a sheet off the bed), or being taught other tasks (e.g. opening a coffee jar).	Through altering the contingencies (relationships) between behaviour and environmental events. Behaviour 'comes under the control' of these contingencies. For example: Derek might be encouraged to participate in putting bedding in the washing machine after breakfast instead of sitting unattended and self-stimulating while staff carry out this activity.	Augmentation of 'natural' developmental process e.g. 'scaffolding' with a more experienced adult.
Process or outcome focus?	Both outcomes and process would emphasise use of community resources and activities, having more relationships, autonomy, competence and greater respect. Valued ends are approached through valued means (Wolfensberger, 1980).	Process of teaching skills in the environment where they naturally occur and with 'natural' cues is important. Success is measured by outcomes.	The focus is on both outcomes and process. Emphasis on the practical arrangements for altering behaviour-environment relationships with outcome as the measure of success.	The emphasis is on the development of competence as an (externally assisted) process which eventually leads to more mature performance.

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