

Bolton Data for Inclusion

The Action Research Centre for Inclusion

(Sponsored by: The Barrow Cadbury Trust)

at

Bolton Institute of Higher Education.

Data No 12 :

July 1997

Author(s) :

Dr Evemarie Knust-Potter

Title :

Inclusion in Berlin

Abstract :

Non segregation andragogy as an instrument for implementing community living for people described as having learning difficulties.

For further information contact:

Karen Barton (k.barton@bolton.ac.uk), Bolton Institute, Chadwick Street, Bolton, BL2 1JW, England

Introduction

In this paper I set out andragogical principles for the development of community-based housing environments for people described as having learning difficulties which facilitate community membership and participation¹. The starting point of my argument is that, without a more holistic approach "ordinary" dwellings for people labelled as having learning difficulties are much in danger of becoming "mini institutions" with institutional structures and similar exclusionary consequences.

A simple change of the spatial situation is not sufficient in itself, if the objective is real inclusion in society for people labelled as having learning difficulties or, more generally, people in marginalised positions. Kinsells (1994) puts it very graphically: you put an institution in a mincer and what do you get out at the other end - lots of little mini-institutions. A reality we can see and experience in lots of so-called community-oriented housing situations for marginalised groups.

That is to say; community living is more than just housing, it involves, for people labelled as having learning difficulties, their whole living situation of every-day life without segregation. This desegregation then has a ripple effect for neighbourhood structures and for all involved parties.

The dimensions of non-segregated andragogy

- A non-segregation-andragogy in the framework of community living is based, in its theoretical orientation, on the normalisation principles.
- The first empirical precondition for non-segregation andragogy is de-institutionalisation, that is to say a reform of the housing situation for people labelled as having learning difficulties and the elimination of imposed segregation.
- Secondly it requires age-appropriate options of activities including adult education, self-advocacy and empowerment.
- Thirdly it requires rethinking the professional value systems and self-images, and reorganising the structures of social service provision.
- It requires fourthly, strategies for the initiation of changes in the consciousness (Bewusstsein) and behaviour of the public (from exclusion to inclusion: spatial and social barrier-freedom; perception and acceptance of interdependence).

It is important to set all this in a holistic, system-ecological frame of reference (Bronfenbrenner 1981, Speck 1990, Huschke-Rhein, 1986-90, Dormer 1987), including the

¹ The following is a very abbreviated account of the arguments in Knust-Potter. 1995.

Inclusion in Berlin

examination/investigation of social conditions, to what extent do they hinder emancipation, which political strategies are necessary and how are they to be implemented.

Normalisation

The normalisation principle is an approach for the valorisation of the individual/existential and social roles of people labelled as having learning difficulties - and people in marginalised positions in general. It was developed in Scandinavia (Nirje 1994, Bank-Mikkelsen 1980) and the U.S.A. (Wolfensburger 1972, Wolfensberger 1983, O'Brien & Lyle 1988, Flynn & Nitsch 1980) and has its foundation in a humanistic oriented value system, which is based on principles of equality, freedom of decision and choice, and right of self determination.

The normalisation principle can in this way be understood as a reform concept, a paradigm shift in the theoretical and practical work with people labelled as having learning difficulties. While traditional approaches can be characterised as medically-oriented, and dominated by professionals (that is to say top-down), new approaches are more pedagogically-oriented, emancipatory and could be termed more as service-user determined bottom up initiatives.

The normalisation principle as the theoretical foundation for work and interaction with people labelled as having learning difficulties changed traditional perceptions and attitudes tremendously. In congruence with this principle, processes of change in everyday life could be initiated and segregation, marginalisation, isolation and social exclusion could be countered. The principle forms a theoretical foundation for the critique of traditional service structures and for the conceptualisation of guiding principles for new service structures (Wolfensberger 1973 & 1983, O'Brien & Lyle 1988, O'Brien & Tyne 1981). Critiques for the normalisation principle are extensive and derive from varied political positions. One constructive critique comes, for example, from the feminist movement (Brown & Smith 1992, Burns & Roberts 1990, Ungerson 1990). Women demand additional consideration for issues of power relations. They also argue in favour of the principle of meaningful association - that is to say the establishment of Self-Advocacy - Groups of service users to speak for themselves for the development of an own identity and for political actions.

Inclusion in Berlin

This is not the place to set out all the controversies which the normalisation principle initiated in Europe and the USA.. One should just point out that the normalisation principle can be seen as the battlefield in which the proponents and opponents of de-institutionalisation, community membership and the empowerment movement of the marginalised groups, fought and still fight. Equally, here we can situate the watershed from a medically-oriented approach to an holistic approach which includes the whole person (not just her handicaps) in her spatial and social environment.

De-Institutionalisation: living and housing in the local community

Over time the guiding principles of working with people with disabilities have changed. The appropriateness of the institution as the location and therapy as the intervention has more and more been called into question. Three steps can be identified (cf Bradley & Knoll 1992):

- Institutionalisation (medical model), until now
- De-Institutionalisation (developmental model), started around the 1980's
- Community membership (inclusion model/assistance model, from the 1990's

This is to be understood as a change from institutionalisation, via de-centralised living, but in a professional-determined way to self-determined living and housing with professional assistance.

In the second step there has been a movement towards de-institutionalisation, that means, changes from a medical-deficit-oriented approach (with its concomitant static professional stances of protection, caring and risk avoidance), to a developmentally oriented approach. The complexity of this approach, unfortunately, became very often reduced to a change in the housing situation. Having an apartment or a house in a normal local community is a beginning, but doesn't mean automatically, that you become a participating member of the neighbourhood (Towell 1988, Towel & Beardshaw 1991, Knapp et al 1992).

This is where the third movement takes over: the neighbourhood membership and the assistance-principle. This step demands system change. The particularities of this third movement are the following (Kinsella 1993, Lovett 1993, Ward 1994):

Inclusion in Berlin

- focusing and facilitating of self advocacy/self determination/empowerment
- inclusion of every day life and the environment of the people and
- calling into question which actions and conditions are identity-enhancing and which are identity-reducing.

People in marginalised positions themselves have stepped into the debates over these issues and have, reflecting their own experiences, questioned traditional services and professional performances (People First 1994, Dowson 1991).

The users: adult status, self-determination, empowerment

If we look at service provision for people who have been labelled as having learning difficulties, we can identify three more or less clear cut stages (Knust-Potter 1993):

- provision in the form of teaching and training programmes within specialised institutions and hospitals
- specialised programmes within mainstream institutions, for example cooking or woodwork for people with learning difficulties in community adult education centres
- self determination, self advocacy, empowerment.

Here we have reached another turning point: Here we enter new paths which are founded on the discovery of abilities and potentials of the people in focus, themselves. With this I mean paths, where the individual person with her individual potential and her human rights is placed in the foreground. Keywords here are: **empowerment, normalisation principles, integration and participation, inclusion, personal development with its aspects, self confidence, self esteem, resilience to conflicts** etc. (Szivos 1991, Sutcliffe 1993, Ward 1994, Nirje 1993, Theunissen 1995, Knust-Potter 1994, Herriger 1995).

This means the dimension which explicitly focuses on the self-image (Selbstbild) and the other-person's-image (Frembild) of the individual in a marginalised position. By means of appropriate personality-building services, including counselling, the objective is to gain a realistic attitude towards one's persona and social condition and thereby facilitate the coping with one's disability. Realistic self-image is aimed for, which does not just prevent the development of secondary handicaps (via an internalisation of negative, devalued role-attributions), but what is more identifies and questions them.

Inclusion in Berlin

Self-determination and empowerment means the realisation of one's own strengths and power and rights. It is a concept of "self-enabling" of the person. In contrast to expert-oriented interventions, empowerment starts with the abilities of individuals and groups for self-organisation and self-advocacy/ self-determination of their own lifestyles. The principal goals are not adaptation, but rather self-determination and self-advocacy; not integration but inclusion and the appreciation of difference. Integration presupposes segregation and implies very often an uncritical position toward that into which one is intended to be integrated (Miles-Paul 1992, Whittaker 1991, King's Fund and VIA 1992).

The self-advocacy/ self-determination continuum ranges from very elementary activities (like choosing tea or coffee, accepting or refusing food) to more complex aspects determining the individual life such as empowerment, political actions towards a non-segregated life or against stigmatising labelling etc.

The objective is to overcome social injustice, discrimination and inequality. This is to be carried out through establishing the greatest possible control and command over one's own life. Without this political dimension of the service users themselves as active actors, self advocacy and self determination would not be more than just another attempt by the service-providers to guess what the service-users "need".

The Staff: new working situations, new status and self-perception.

Not just the housing and living situation of the people described as having learning difficulties are in a process of change but there are also immense changes in the working conditions and the professional roles for the staff to recognise. The displacement of the workplace and service structures from the hospital and big institution into the community has a great impact on the work of the involved staff. The staff in small, de-centralised, community integrated settings need different skills and knowledge than what has been traditionally expected of them (cf Felce 1991, Lowe & de Paiva 1989, PSSRU 1991, Allen 1990, Mittler 1985).

The change could be described as:

- **from outside to inside the community:**

Inclusion in Berlin

The work no longer takes place in closed institutional settings, segregated from society but in small settings within ordinary housing estates and neighbourhoods.

- **from duality to plurality:**

Interactions in institutions take place in dualities, between staff and service users. In the community, on the other hand, at least after leaving the house, the interactions become plural, interactions with the total mix of people of a neighbourhood. The possibilities of social encounters are not dual and limited but plural and varied.

- **from dominance to interdependence:**

Traditional training for work with people described as having learning difficulties was based on the assumption that professionals had to take the leading function and had to take all necessary decisions. A process of rethinking is now under way, which involves all actors concerned - including staff, service users, service planners and service providers.

- **from the planned and plannable to the unplanned and unplannable:**

If the community is really to be included in the life of the users, the kinds of interactions and the contents of the work of the staff need to be changed. For the staff and for the users this means extending individual and social action competencies (Handlungskompetenzen), and locating learning processes in real situations in the community (Situationsansätzen - Zimmer 1984) - in contrast to artificially, constructed situations (therapeutic laboratories) in segregated institutions.

The public: recognising interdependence

It leads to a vicious circle, if people with disabilities are seldom present in the public and society, because of this absence, has little or no chance to change prejudices and overcome fear of contact. Communities are not just prepared for people labelled as having learning difficulties suddenly to come and live with them, expressing themselves and behaving in their own particular ways. Here it is important and necessary to initiate consciousness-raising and reflection processes in the public (Mittler 1987 & 1989). That means:

- **new forms of relations with the public:**

Away from the purely charity-oriented public relations, which very often is connected with a lack of dignity in the presentation of the people concerned. People labelled as having learning

Inclusion in Berlin

difficulties are very often presented as special persons, who live in special situations, being taken with special buses to special schools and special workshops. This kind of public relation is one-dimensional and passive (cf VIA 1994).

▪ **facilitating the change of public attitudes:**

Important tasks for the present are to initiate public debates. Community education has an important role to play here: Community education, understood as an action-oriented intervention, which includes interaction and shared activities and experiences in real situations (Blunden 1988, Zimmer 1986). This approach focuses on the importance of people talking for themselves. People who have lived or still live in marginalised positions, are the best and the authentic voices for informing about their situations (McConkey 1991). It is important to give those people the opportunity and the space to talk, act, participate and contribute. Shared activities of people with and without disabilities can open chances for the building of solidarity groups, for example for the enforcement of demands for physical accessibility and spatial barrier-freedom - from which incidentally other groups with special mobility requirements (older people, parents with prams etc.) can also profit. Keywords here are citizen advocacy (Williams 1989) and circle of support (Perske 1980).

▪ **Interdependence**

Only when the public, the neighbours in the house, in the street, in the shops etc perceive that it has its advantages, if people labelled as having learning difficulties live within the community – only then does segregating become unnecessary (Dossa 1992). There are often little things, which make this consciousness-raising possible: watering the plants and looking after the pets when people go on holiday, collecting the post if nobody is at home, keeping an eye on the flat, when people are at work all day, looking after older people or doing some shopping if people are ill – but also being asked to help in the shop, not being ignored and not living in a totally anonymous world.

People with the label “learning difficulties”, for example, are more generally in need of assistance in the community. For them, a life in anonymous, singularised life worlds (*lebenswelten*), in which each atomised individual in isolation just looks after himself Mitscherlin 1965, Beck 1986), is not possible. People have a need for assistance and this could be combined with social interactions and human encounters and relationships. That means that the presence of people labelled as having disabilities in the community calls for alternative value systems. Human interactions become necessary which also creates opportunities for anonymity.

Inclusion in Berlin

Anonymising environments without communication and social interactions cannot be the basis for a meaningful living-together of people with or without disabilities. It is important to achieve insight into the fact of dependence on one another. This means it is necessary to realise that the segregation of people in marginalised positions means a restriction in the variety of humanity. Segregation produces an artificial homogeneity instead of a natural variety.

Non-segregation-andragogy on the basis of the normalisation principle in the historical-social context cannot all be achieved from one day to the next. It is its very movement which needs lots of time and stamina from all sides. This means also to rediscover slowness. Perhaps in our society the speed a new paradigm which can shift our view of the world a little is needed.

BIBLIOGRAPHY

- Allen, P., Pahl, J., Quine, L. Care Staff in Transition. HMSO, London 1990
- Bank-Mikkelsen, N. "Denmark", in Flynn, Nitsch, (Hg.) Normalization, social Integration and Community Services. Baltimore 1980.
- Beck, U. Risikogesellschaft. Auf dem Weg in eine andere Moderne. Frankfurt a.M.1986
- Blunden, R. (Hg) Ties and Connections, King's Fund, London. 1988
- Bradley, V., Knoll, J., Shifting Paradigms in services to people with developmental disabilities. Human Services Research Institute, Cambridge. 1992.
- Bronfenbrenner, U., Die Ökologie der menschlichen Entwicklung Stuttgart. 1981
- Brown, H., Smith, H. Normalisation. A reader for the 90s. London 1992.
- Burns, J., Roberts, T. A Feminist Analysis of the Normalisation Principle, London 1990.
- Domer, K. Neue Praxis braucht neue Theorie. Ökologische und andere Denkansätze für gemeindepsychiatrisches Handeln. Gutersloh 1987
- Dossa, P.A., Ethnography as narrative discourse: community integration of people with developmental disabilities. In Int. J. of Rehabilitation Research. 1992 Band 15, S. 1-14
- Dowson, S. Moving to the Dance VIA, London 1991.
- Felce, D. Published Material from Research Programme on small Homes. Konzept, Cardiff. 1991
- Flynn, R.S., Nitsch, K.E. (eds) Normalisation, Integration & Community Services. Baltimore. 1980.
- Herriger, N. Empowerment und das Modell der Menschenstarken. Soziale Arbeit %/1995
- Huschke-Rhein, R., Systemische Pädagogik (4 Bände) Kolh 1986A1990
- King's Fund Centre, VIA LASA oack-learning about self advocacy. London 1992.
- Kinsella, P., Group Homes. An ordinary Life? Manchester NDT 1993a
- Kinsella, P., Supported Living. A new Paradigm. Manchester NDT 1993b
- Knapp, M. et al Care in the community. Challenge and Demonstration. Canterbury 1992.
- Knust-Potter. E., Erwachsenenbildung ein Fundament für normalisierte Lebensbedingungen, in: Erwachsenenbildung und Behinderung, (4) 2/1993, S.8 14
- Knust-Potter, E., We can change the future in: "Geistige Behinderung", 4/94, S. 319 330.

Inclusion in Berlin

- Knust-Potter, E. , Community Living: Normalisierung der Wohn und Lebensbedingungen von Erwachsenen, die als geistig behindert bezeichnet werden. Diss. FU Berlin 1995.
- Lovett, H., Foreword In: Kinsella, P. Supported Living, A new paradigm. Manchester 1993.
- Lowe, K., de Paiva, S., NIMROD. The Evaluation of the NIMROD. the Service, Staff and Clients. fingerprints, Cardiff. 1989
- Lowe, K., de Paiva S., NIMROD an overview. A summary report of a five year research study. Fingerprints, Cardiff 1990
- McConkey, R. Opening doors. Scottish Society for the Mentally Handicapped, Glasgow 1991.
- Miles-Paul, O., Wir sind nicht mehr aufzuhalten. Behinderte auf dem Weg zur Selbstbestimmung. Munchen 1992.
- Mitscherlich, A., Die Unwirtlichkeit unserer Stadte. Frankfurt, 1965
- Mittler, P., Quality of life and services for people with disabilities. BIMH, Kidderminster 1985.
- Mittler, P., (Hg) Forward, towards education for all. Cassell, London 1987
- Mittler, P. The involvement of families and the community in curriculum development. Vortragsskript Oktober 1989
- Nirje, B. Das Normalisierungsprinzip - 25 Jahre danach. In VHN 1994, Band 63 Heft 1, S. 12-32
- O'Brien, J. , Lyle, C., framework for Accomplishment, Responsive System Associates, Georgia 1988
- O'Brien, J. , Tyne, A., The Principle of Normalisation. VIA London 1981.
- People First Outside but not inside yet. London 1994.
- Perske, R. Circles of Friends. Partenon Press, Nashville USA 1988
- PSSRU (Hg.) Staffing Community Services. Canterbury 1991
- Speck, O. Menschen mit geistiger Behinderung und ihre Erziehung. Munchen 1990
- Sutcliffe, J., Simons, K., Self Advocacy Leicester 1993.
- Szivos, S. Consciousness Raising: An Attemp to Redress the More Repressive Aspects of Normalisation, but not its More Positive Ones. In Clinical Psychology forum, 6/1991.
- Theunissen, G., Empowerment und Heilpadagogik. Freiburg i.B. 1995
- Towell, D. an Ordinary Life in Practice. King's Fund, London 1988
- Towell, D., Beardshaw, V. Enabling community integration. London, King's Fund 1991

Inclusion in Berlin

Ungerson, C. Gender and Caring. Work and Welfare in Britain and Scandinavia. Hemel Hempstead 1990

VIA, Information London 1994.

Ward, L. Values and Visions. Changing ideas in services for people with learning difficulties. Manuscript. 1994.

Whittaker, A. Supporting Self Advocacy. King's Fund. London 1991

Williams, P. The value of citizen advocates. In Nursing 1989, Band 3, Heft 44.

Wolfensberger, W. The Principle of Normalisation in Human Services National Institute of Mental Retardation, Toronto. 1972

Wolfensberger W., In Mental Retardation 1983 Heft: 6, Band: 21.

Wolfensberger, W., Glenn, L., Program analysis of service systems (PASS); A methodology qualitative evaluation of human services. Toronto 1973.

Wolfensberger, W., Thomas, S., PASSING (Program analysis of Service system's Implementation of Normalisation Goals). Toronto 1983.

Zimmer, J., Der Situationsansatz als Bezugsrahmen der Kindergartenreform In: Zimma Erziehung in fruher Kindheit. Enzyklopadie Erziehungswissenschaft Bd. 6 Stuttgart

Zimmer, J. Die vermauerte Kindheit. Weinheim 1986.