

ADVOCACY FOR PEOPLE WITH LEARNING DISABILITIES

My talk will encompass the following:

- ?? The different types and models of Advocacy in England
- ?? Advocacy in the local context in Kensington & Chelsea
- ?? Advocacy for black and minority ethnic people with Learning Disabilities

I apologise that it will be very brief in the light of the time allocated.

ADVOCACY AND LEARNING DISABILITY

We all agree that services for people with Learning Disabilities should embrace the qualities/attributes of an empowering service, which encourages client empowerment and an active client context over their lives. A well accepted and increasingly well developed mechanism/or enabling people to become more autonomous is the concept of advocacy which can best be understood by looking at the different types/areas of advocacy, self advocacy, citizen advocacy, legal advocacy, professional advocacy and the types of models that go with it.

The principals of advocacy now have a visible place in central government policy as well as local statutory government services as well as services provided by the Voluntary Sector. The Valuing People document by the Government in 2001 identified this. The government has promised funding for the development of advocacy schemes with its emphasis on social inclusion rights, independence, choices and the development of person-centered services. The document also signals the aim of having independent advocacy services available in each area, within funding provided to establish a national Citizen Advocacy Network for people with Learning Disabilities.

That is highly commendable within the English context for people with Learning Disabilities.

For the record, I need to define the broad approach advocacy offers and how it is defined.

`Advocacy is defined as' the process of identifying with and representing a person's views and concerns in order to secure enhanced rights and entitlements undertaken by someone (Hendersons and Pochin, 2001, page 1)

Teasdale in 1998 stated that advocacy is concerned within a person or organisation, that will speak for those who lack the power to do so and intercede on their behalf. We know historically the people with Learning disabilities have been unable to speak up/ advocate for themselves therefore advocacy has developed as a way of "Speaking-up for those who would be otherwise disempowered"

Tyne (91) has asserted that an advocate must have a genuine commitment to represent a service user's best interests.

For the record it would be useful to briefly look at the different advocacy models.

Henderson and Pochin (2001) identify the diverse paradigms of support and intervention, associated within a range of approaches in advocacy.

- ?? Legal Advocacy
- ?? Professional Advocacy
- ?? Citizen Advocacy
- ?? Self Advocacy
- ?? Collective Advocacy

Self Advocacy

Involves speaking for oneself or as a group who share the same views. Gates (1994) states that in self advocacy people are encouraged to speak up for themselves, this being about an element of self-empowerment, that is, people speaking for themselves, rather than having an advocate speak for them. Self advocacy is based on a tradition of self help which includes personal empowerment, pride and social justice, making decisions, taking actions and changing things.

The example of self advocacy groups in England include

- ?? United Kingdom Advocacy Network (UKAN) in mental health
- ?? People First in Learning Disabilities
- ?? Lewisham Older Women's Network

In Kensington and Chelsea, there are the: -

- ?? 'It's My Life Group'
- ?? PCP Group (?)
- ?? ? Quality Network
- ?? Individual Projects in which service users are shown how to chair meetings, how to interview in a selection and recruitment panel for new posts

The following self advocacy skills are identified

- ?? Being able to express thoughts and feelings with assertiveness if necessary
- ?? Being able to make choices and decisions
- ?? Having clear knowledge of rights
- ?? Being able to make changes
- ?? Being independent
- ?? Taking responsibility for oneself
- ?? Getting things going

The challenge for us as professionals/service providers is to find out how individuals communicate and to open up pathways, with augmented communication. systems or intensive one-to-one work, which enables service users to express their needs and wants.

Citizen Advocacy

This refers to the supportive partnership, which results when a volunteer develops a relationship with a service user.

Citizen advocacy draws in tradition of community action, pressure and interest groups with its key characteristics being longer term one-to-one relationships in the advocacy partnership, unpaid commitment, accountability to the partner, independence from service agencies and the advocates drawn from local communities.

Citizen advocates are people who are independent of those providing direct services to people within Learning and Disabilities working on a one-on-one basis. Citizen advocates attempt to foster respect for the rights and dignity of those they represent.

This may involve helping to express the individuals concerns and aspirations, obtaining day to day social, recreational, health and related services and providing other practical and emotional support.

The benefits of a partnership within a citizen advocate falls into two broad categories according to the nature of the needs met.

- (i) Expressive (ie. Human, emotional and social needs)
- (ii) Instrumental (material needs)

These can be shown likewise –

<u>Possible Gains From Citizen Advocacy</u>	
Expressive	Instrumental
Affection	Access to financial benefits
Attention	Access to services
Companionship	Accommodation
Friendship	Leisure and Recreation
Identify	Transport
Love	Training and Education
Developing Social Networks	Citizenship Rights eg. Voluntary
Warmth	Access to facilities eg. shops, restaurants, medical and other health care etc.

In Britain, it has been used most commonly who have supposed exclusion and institutionalisation, particularly for people within who are disadvantaged and who are not in a position to exercise or defend their rights as citizens.

Collective Advocacy

This approach is about user representation with an important nuance here between advocacy and user representation. Self advocates represent their own interests, citizen advocates uphold the rights of their partners.

User organisations cannot represent each individual's views but they can promote the cause of minority groups (like people within Learning Disabilities) by raising public awareness, and lobbying policy makers on their behalf.

Key organisations in Britain are:

MENCAP, PEOPLE FIRST, BRITISH INSTITUTE OF LEARNING DISABILITIES, VALUES INTO ACTION, AND SCOPE (formally the Spastics Society), ? BLACK PEOPLE FIRST.

In Kensington and Chelsea Advocacy Alliance.....(Hector, please advise....)

Professional Advocacy:

This approach is about the role of professionals working in different areas of work in Learning Disabilities but located generally within the local state/local authority, or national health service/medical, housing, employment services and the voluntary sector/working in social care.

One of the difficulties, as would be expected is the potential conflict between promoting or protecting a service user's interest and line management and

accountability of the staff to their line managers or via professional or organisational accountability.

Legal Advocacy

This advocacy has a potentially vital role in adult protection issues and decision-making, particularly if police are involved and if criminal offences, such as abuse, has been alleged and committed. This work will primarily come from outside of the Social Services and Health Service Departments – depending as it does on an expert lawyer or police role focussed on advising particular legal outcomes.

The potential importance of legal dimensions has been observed. The fact that it is often based on legal power or economic relationships means that it risks domination by professionals or professional interests.

Advocacy and Learning Disability Population From Black & Ethnic Minority Backgrounds

In our past discussions in Rotterdam and Hamburg and in ones own experiences, we need to be alert about people who cannot speak up for themselves or that their Learning Disability impairs them to communicate exactly what they want to say.

Similarly, we need to take up the cause of certain segments of the population of Learning Disabled people coming from black and minority ethnic communities in Britain, who might see the risk of not being heard nor being provided the full opportunities to speak up without feeling threatened.

The 1991 Census reveals that black and ethnic minority population make up – 6.5 % of the total population in England and Wales. It is predicted that by the year 2021, 1 person in 10 in England and Wales will be coming from a black and ethnic minority community. Unfortunately, no figures exist of the black and minority ethnic learning disabled population in England and Wales.

Issues to be considered for Advocacy for black and minority ethnic people with Learning Disability.

?? The inherent bias that exists in Learning Disability Services.....

“All needs are the same, being judged against dominant westernised norms and thoughts on behaviour, dress, childrearing practices, attitude to independence, etc.

?? Where black and minority ethnic people with Learning Disabilities are made to feel guilty and embarrassed by the fact that they are different they want to be treated with respect and have acknowledgement of that difference (respect of cultural and religious beliefs, different appearance, etc)

(A study on the South Asian communities in North England for people with learning disabilities found that this group saw themselves within their own racialised identities but that staff in the day centres did not appreciate that aspect at all)

?? Against the background of social realities of ‘race’ class and gender, black minority ethnic people are not confident to speak up for themselves because

of: Fear of being excluded

Fear of being misunderstood and services not meeting their required needs

Fear of being seen as acting aggressively

Fear of ‘rocking-the-boat’

There should be assistance and methods of support concerning communication, self advocacy, citizen advocacy, self determination, fulfilment of fundamental rights and access to appropriate correct services for this group.

To be in a position to help people to represent their rights and interests, one must first build a relationship with them. This will involve getting to know and value black and ethnic minority disabled people, to understand their differences based on the different

religious and cultural belief systems, to get them to understand about their rights and choices that can be made, etc.

For choice to be meaningful for the black and minority ethnic learning disabled person, and against the social political context of Britain, a number of conditions need to be met: -

- ?? An awareness that a choice is needed
- ?? An awareness that a choice is being offered
- ?? A real understanding of the choice concept
- ?? A self picture of worth and goodness
- ?? A choice to be offered
- ?? Information about the options
- ?? The capacity and time to respond to the choice offered
- ?? An understanding of the consequences of the choice

It is important to bear in mind that a whole range of factors will affect choice making of the black and minority ethnic population with learning disabilities.

- ?? A person who has had little opportunity to make choices as his/her voice has never been heard has understood due to language difficulties.
- ?? A person who is always made to feel and see himself differently or in a non-accepting manner by the rest of his colleagues.
- ?? A person who has limited knowledge and social networks.

It is also important for the black and minority Learning Disabled person to know he/she can access advocates who the person feels has the knowledge about that person he/she is advocating her. That is the advocate must have a proper knowledge of the person's religious, cultural and ethnic background and that the advocate is able to make a distinction between cultural awareness and knowledge versus Equality Training Diversity management and cultural competence of the organisation from which his service partner receives a service.

Let me now look at the practice issues for front-line staff/advocates.

Practice Issues For Front-Line Staff/Advocates & Other Staff

- ?? What training do black and minority ethnic staff and other staff receive to ensure that their practice is anti racist/anti discriminatory
- ?? Does 1 black advocate know what services are available & can be negotiated on behalf of the service user, which goes beyond learning about other people's culture. How mindful is the advocate of the differences in Family values, the cultural and religious belief systems from the white western culture....How sensitive is the advocate to realise cultural differences in modes of expression and communication which may facilitate or impede communication between people at times of stress and/or distress?
- ?? How trained is the advocate on knowing about the distress of his/her clients caused by the person's political and social reality and being sensitive to the lived experience of a black and minority ethnic person living in Britain? How trained is the advocate on issues of power, disempowerment, marginalisation, exclusion and the triple disadvantages as a result of race, age and sex.

What power do black advocates have when they find issues and social harassment/abuse.

- ?? Are advocates used with a view to informing better the Care Programme Approach & Service user documentation & systems?
- ?? How does the Health & Local Authority ensure that people from black & minority ethnic groups have appropriate skilled and confident advocates.
- ?? What training & level of seniority does the advocate have when identifying problems within service delivery?
- ?? Is there a policy in place for working with black & minority ethnic communities
- ?? Does Local Authority &/or Health services have sufficient – black & minority ethnic advocates which care for the black & minority ethnic learning disabilities population within the borough?
- ?? Are black advocates consulted & communicated with as part of the local Authority & Health Service consultation & communications strategy?
- ?? Are black advocates helped in assisting the involvement of representatives from black & m ethnic groups/communities.
- ?? Are there clear protocols & guidelines for staff on the use of interpreters?
- ?? Are black advocates trained to understand the context of Social Services/ Health Services work in relation to referral & assessment arrangements? (Do these arrangements take account of social, cultural, religious & language needs & get a good contribution from the carers?)

Other issues to be considered for Advocacy for black and minority ethnic people with learning disabilities:

- ?? Is the advocacy part of local authority payment or totally independent of the costs.
- ?? Does the advocate know about the race equality and equal opportunity strategies for employment and services delivery issues within Health and Social care settings?
- ?? Does the local authority and Health Authority consult with the advocate on race equality monitoring reports to the Partnership Board, Joint Strategic Commissioning group etc?
- ?? Does local authority and health service set targets and take positive action to recruit black staff as advocates when required and requested.
- ?? Are there policies that ensure a competent black advocate/interpreter when service users and carers cannot speak English.
- ?? How are black and minority ethnic people with learning disabilities involved in the different setting up of black Advocacy Groups.
- ?? Are service level agreements in place with Advocacy organisations for provisions of advocacy organisations of advocacy and interpreting services together at specific black and minority ethnic groups to ensure choice are available.
- ?? Are all staff rather than some staff trained in 'race' culture and anti discrimination practices.
- ?? How confident is 1 advocate that there are clear policies and strategies on 'race' culture and ethnicity which are then incorporated into the community care assessment and community care plan?

Issues To Be Considered For Independent Advocacy

- ?? Encourage and support people with learning disabilities from black and minority ethnic communities to develop their presentation and confidence skills.
- ?? Ensure that when they are trained that they are paid for such contributions
- ?? Support these people to join local advocacy groups to consider how they can influence and support other people with learning disabilities.
- ?? Develop skills which identify them as 'local advisers' with specialised knowledge, skills, confidence to raise issues of culture and 'differences from their white peers.