

Introduction

The Candle Project – Background and Aims

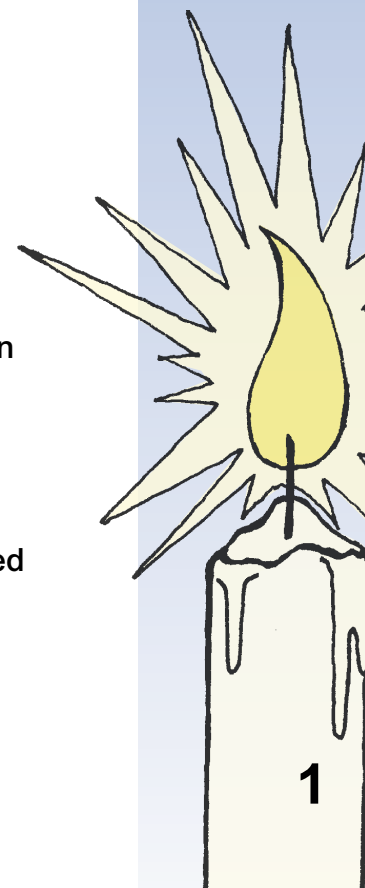
Research has found 3 or 4 in 10 children who have a learning disability experience mental health problems. This is three times the national average for the general population, and is due in part to a range of risk factors that young people who have a learning disability are likely to encounter. **(Borthwick-Duffy, 1994, FPLD, 2005)**

These figures have been corroborated by recent research from Emerson and Hatton **(2007)** that found 36% of young people with learning disabilities will experience mental health problems against 8% of young people generally.

However, research by the Foundation for People with Learning Disabilities **(2006)** stated that:

- Most young people were not aware of the term mental health.
- Families were suspicious of the label of 'mental health' because it emphasised a need for a separate label in addition to having a learning disability.
- Most of the young people had never heard of CAMHS.
- Most young people turn to their teacher, parents or youth worker for advice over their mental health issues.
- Neither the young people nor the people they go to for advice are particularly well informed about mental health or mental health problems.
- For those from minority ethnic communities the situation was even more difficult to address because of the stigma associated with mental health problems in some cultures.

The problems young people experience are often not seen as mental health issues but part of their learning disability. As the recently published Disability Rights Commission report 'Equal Treatment: Closing the Gap' states this can be due to 'diagnostic overshadowing', or, put more simply,



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'a tendency to attribute health problems to a person's learning disability'. **(DRC 2006 p69)** This can be true when we consider behaviours that are called 'challenging behaviour'. The Disability Rights Commission are now part of The Equality and Human Rights Commission.

Having a learning disability is one of the most significant factors identified in increasing the risk of having a mental health problem. Other risk factors such as family breakdown, social isolation, stressful life events, not being able to communicate, either due to a disability or not speaking English, having no control or choice in life are as relevant to people who have a learning disability as the general population. **(DFES 2001)** The DFES (Department for Education and Skills) is now DCFS (The Department for Children, Families and Schools).

Emerson research **(2007)** for the Foundation for People with Learning Disabilities considers why young people with learning disabilities are more likely to experience mental health problems. He suggests that it is less to do with a person's cognitive abilities and more that the young person is exposed to negative life events.

- 65% of young people with learning disabilities grow up in poverty
- 52% of young people with learning disabilities have a parent carer with mental health needs.
- 51% of young people with learning disabilities have a parent carer with no educational or vocational qualifications.
- 25% of young people with learning disabilities have a parent carer with health needs.
- 60% of young people with learning disabilities have been exposed to two or more negative life events. **(Emerson & Hatton, 2007)**

Problems with a diagnosis of mental ill health may also be due to the differences in how a young person may present with mental health problems. A young person may have communication difficulties associated with their learning disability and this means identifying the causes of mental ill health, how they present themselves and any therapeutic interventions can prove a daunting task for workers. This can be compounded by staff and families not being aware of the local

and national services available to support the young person. Even when problems are identified, services are often difficult to find and young people with a learning disability are often 'excluded' from services - although improvements are happening across the country.

When a young person and their family come from a minority community they often encounter further problems to accessing services. Families are often unaware of what support and services are available to support them and information may not be available in their own language or in the places they frequent. The family may have had historically negative contact with services, in particular mental health services. This has been highlighted in research undertaken by the Department of Health, *Delivering Race Equality*, 2005.

There may be other cultural issues, including perceptions of mental health that may vary with those of the professionals and the services they offer that means many services are culturally inappropriate and go unused. The numbers of people from BME communities is increasing. The National Statistics website analyses the data taken in a ten year period,

In Great Britain the minority ethnic population grew by 53 per cent between 1991 and 2001, from 3.0 million in 1991 to 4.6 million in 2001. (www.statistics.gov.uk/) This increasing population need services that are culturally competent and staff that are trained and able to provide this.

The aim of the '**Candle (CAMHS and New Directions in Learning Disability and Ethnicity)**' project is to give confidence to and support frontline staff by providing guidance, resources and information regarding learning disability, mental health and ethnicity as well as links to useful national organisations. This will allow interaction with young people and their families, to promote positive mental health, to identify any issues or concerns early and refer these onwards.

The Candle project is a three-year project, developed by ARC, the Association for Real Change, with funding from the Department of Health. The resource is easy to access and offers guidance that can be used in a number of ways, including:

- As a 'pick up and read' resource for teams and individuals facing general or specific problems.

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- To help find out about and map local CAMHS services (and highlight any gaps in local provision).
- As a tool for discussion within team meetings or with other professionals.
- As a tool for discussion with families and/or community representatives.
- For individual personal development and training.
- A simple to use resource with individual sections that can 'stand alone', with cross referencing, key points, case studies and good practice examples.
- Developing a training programme for staff.
- A signpost to other resources and material that will assist staff.
- A signpost to other organisations and government departments involved in CAMHS provision.
- Tool for mapping any training to national standards, regulations, codes of practice and training requirements.

This resource highlights what workers should be looking out for, what it might mean, how services are provided differently across the country and how workers and people supported can access them. It also highlights the national guidance and pathways that CAMHS services should be using to support young people with a learning disability and mental ill health.

The resource aims to be holistic as possible, recognising the different roles, responsibilities, and experiences of those who will use it. Therefore, no timescales are attached to the resource as it can be used in a range of styles as detailed above. The resource is flexible enough to meet the needs of individuals and organisations and no prior understanding of the individual sections is required. The style and range of provision does differ across the country. People need to be aware of the local issues and resources available and it is hoped that once this is done it will be shared with colleagues throughout and across organisations.

Additional sources of advice and support are highlighted throughout the resource these can help with specific problems. **Individuals or organisations can freely photocopy the handouts, case studies and tips within the appendix.** These can be used to help think through the key issues individually or as a team during team meetings, away days or informally. As well as the resource itself a short 'How To Use Guide' is available. This will aid anyone wishing to use the resource to develop training to specific groups of staff.

The development of the resource has involved professionals from all aspects of care and support for young people and their families. It encompasses a range of research projects involving families and young people themselves. It highlights and encourages good practice throughout. It equips people who would not consider themselves to be experts to identify early warning signs of mental health problems and intervene appropriately. The resource was correct and up to date at the time of writing.

About ARC the Association for Real Change

ARC has many years of experience and expertise in the area of learning disability and has worked closely with the Department of Health on a number of projects.

ARC (www.arcuk.org.uk) is a national charity that supports those providing services for people with a learning disability. The organisation offers a national voice on relevant national discussion bodies, organises local and national meetings and conferences and can offer NVQ, LDQ and other specific training such as the handling of medication in social care settings for members and non-members alike. Members range from large national charities to small independent providers.

In 2001 ARC developed 'Services for All', information and guidance for staff working within learning disability services to ensure they provide a culturally sensitive service and highlights areas of best practice in the UK. The guidance contains comprehensive information in written form and on video that help staff learn about and address key issues in their practice. Part of the project included a Handbook of Useful Information for families, which, with support from Mencap has recently (2006) been revised, updated and translated in a range of community languages.

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This is available to download from www.mencap.org.uk/ethnicity (hard copies of the Handbook are also available from ARC)

For the last four years ARC has hosted and developed the 'Learning Disability and Ethnicity Network' (www.liden.org.uk) that has over 1400 members. The network co-ordinates an annual conference and produces a newsletter three times a year to keep members informed of current developments, policy and best practice that affects people with learning disabilities from minority communities.

ARC has developed the 'Moving On Up' project (www.movingonup.info) which has an accessible website for young people with a learning disability from a BME community to assist them and their families through transition, with funding from the Diana Project and more recently Vodafone. There have been more than one million hits received by the site.

ARC also developed the 'Framework For Action' toolkit that all Learning Disability Partnership Boards can use to review their services and ensure they meet the needs of the BME communities within their area. This is available from the Valuing People website. (www.valuingpeople.gov.uk)

ARC can signpost its members to information around issues to do with working with people with learning disabilities from minority communities. The team may not be able to answer all questions but will be able to give you as much information as possible and links to other services who may be able to help. (www.arcuk.org.uk Tel: 01246 555043)

What is CAMHS?

CAMHS or Child and Adolescent Mental Health Services can be a tricky term to define. People use it in two ways. The Every Child Matters website suggests:

1. *"It is commonly used as a broad concept that embraces all those services that contribute to the mental health care of children and young people, whether provided by health, education, social services or other agencies. This definition includes universal services whose primary function is not mental health care, such as GPs and schools. This explicitly acknowledges that supporting children and young people with mental health problems is not the responsibility of specialist services alone."*

2. *“However, the term is sometimes used more narrowly to refer only to specialist child and adolescent mental health services.”*
(www.everychildmatters.gov.uk)

This means organisations and agencies that focus on young peoples’ mental health. These might be based in a hospital or community mental health centre setting. Sometimes they are part of social services or a voluntary organisation. CAMHS workers are split into four ‘tiers’. Any workers engaging directly with a young person in any capacity are considered to be Tier One.

CAMHS Tiers

Child and Adolescent Mental Health Services (CAMHS) and those who work within them are differentiated by the term ‘Tier’. This may be about the levels of expertise specialism those working within them have but is also likely to regard the amount of support the individual needs to manage their mental health.

Tier One

Tier One is a term that is clearly defined and used within CAMHS settings. However, it is not used elsewhere with social care or educational settings. Tier One staff are *“all ‘non-clinical’ staff who all children/young people have access to”*. **(Health Advisory Service 1995)**

Examples include school nurses, teachers and teaching assistants, after school club workers, speech and language therapists, GP’s, health visitors, community nurses, social workers, residential social care workers, youth justice workers, voluntary agencies, leisure and play workers.

Workers at the direct interaction level of work with young people and their families have an essential role to play, especially those working with young people who come from ethnic minority communities. Research by the Foundation for People with Learning Disabilities **(2005)** suggests that often the only services the family and the young person come into contact with are education and primary healthcare, making the role of those working in these settings essential.

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For example as stated in the Disability Rights Commission report, *“Receptionists are of enormous significance in the primary care experience.”* the (Tier One) role can be as important as that of the Doctor themselves. *“Those we talked to often felt there was a lack of understanding among reception staff about their needs due to their learning disabilities and/or mental health problems...”* (**Disability Rights Commission, 2006 p57**)

This resource is aimed at those who are classed as Tier One staff. The role is defined by the Health Advisory Service (now HASCAS – Health and Social Care Advisory Service) as:

- Identifying mental health problems early in their development.
- Offering general advice.
- Pursuing opportunities for mental health promotion and prevention. (**HAS 1995**)

The importance of the role cannot be understated and the benefits of early interventions that can be put into place cannot be stressed highly enough. These may be short, informal things but they can save emotional harm, resources and stress for individuals and families in the longer run. The problems of identifying, supporting and giving information to young people and families with learning disabilities and mental health issues from ethnic communities have been known for some time. A number of research projects have highlighted these problems recently (**DFES 2001, FPLD 2004, Mental Health Foundation 2005**). The Department of Health made early intervention a *“key target”* (2000) and something we should all be working towards. This resource will give ideas about what can be done and how other people have been supported with positive results.

Tier Two

Practitioners at this level tend to be CAMHS specialists working in community and medical settings.

For example, this can include primary mental health workers, psychologists and counsellors working in GP practices, paediatric clinics, schools and youth services. They are less likely to be working for the Primary Care Trust (although some of them might be), and more likely to be working for another NHS trust (or the local authorities in the case of educational psychologists).

Practitioners offer consultation to families and other practitioners, outreach to identify severe or complex needs which require more specialist interventions, assessment (which may lead to treatment at a different tier), and training to practitioners at Tier One.

Tier Three

This is usually a multi-disciplinary team or service working in a community mental health clinic or child psychiatry outpatient service, providing a specialised service for children and young people with more severe, complex and persistent disorders.

Team members are likely to include child and adolescent psychiatrists, social workers, clinical psychologists, community psychiatric nurses, child psychotherapists, occupational therapists, art, music and drama therapists. The main difference between tiers two and three is that in three the young person is seen and supported by members of the team rather than an individual professional as in Tier Two.

Tier Four

These are essential services for children and young people with the most serious problems, such as day units, highly specialised out-patient teams and in-patient units. These can include secure forensic adolescent units, eating disorders units, specialist neuro-psychiatric teams, and other specialist teams (for children who have been sexually abused, for example), usually serving more than one district or region.

The tiers are all interlinked and should be able to work in a joined up way. For example, a Tier Four service such as an in-patient hospital ward setting may have Tier One workers within it and a Tier One service such as a mainstream school setting may have input from Tier Four professionals. People need to work together across a range Tiers, services and settings.

Local issues

In some areas of the country CAMHS include children and young people who have a learning disability with all young people, this is called an integrated service (such as Sheffield CAMHS). Other areas provide support in specialist CAMH learning disability services (Birmingham). The nature of the services provided also differs so it is important to find out what is happening in a local area and how the services are structured.



Exercise

Try typing the name of an area and CAMHS into a google search to see what comes up. It is a good idea to make note of what services there are to be shared with colleagues.

There is a mapping tool which will help in the resource – see Appendices/ Exercise 1. It should include how to contact those detailed within it and outline their roles and responsibilities – it is essential that everyone supporting the individual and family works together in the best interests of the person.



Good Practice Example

Quest

Quest is a joint initiative between Sunderland Social Services and South of Tyne and Wearside NHS Trust. It is a specialist service that works with children who have a severe learning disability and whose behaviour presents a severe challenge to families and services. In practice this means direct work with the child and their family in providing an assessment and then working to find ways to reduce the behaviours. Much of this is achieved by changing the environment and helping family members to better understand the underlying causes of the behaviour so that they can find more successful ways of dealing with it. The psychology input into the Quest service is provided by staff who also work into the Hillview Psychology Service and vice versa. Children who access Quest are those with severe learning disabilities (using Health Service Criteria) whose behaviour results in them causing injury to themselves or others, or prevents them from participating in their local community. quest@ssd.sunderland.gov.uk

The Candle Resource – Values

It is important to consider these values, especially if the resource is to be used across a range of settings and services. Organisations and individuals have different policies and protocols to follow and these must be respected.

This resource is holistic

Consider all aspects of a child or young persons life not just one area at a time; that is the people around them and the circles within which they are valued. This might be the people closest to the young person at home, school or college and people they know in the community or through clubs and activities. This is especially true when supporting young people from ethnic minority communities where family interactions and cultural values may differ from those who support them. The method of working with the young people must respect these differences and aim to encompass them in a holistic manner.



Good Practice Suggestion

Many organisations will have separate training courses on Diversity, Mental Health Awareness and Disability Awareness. Staff can have large periods of time in between these training courses when they do not have the 'whole picture'. However the learning gained on all these respective courses must be used when dealing with individuals and their families.

The Candle resource may help highlight the complex nature of the influences on an individual's life that could be used to develop Induction training for new staff members or to highlight the links between these for more experienced members of staff.

People should work in a (young) person centred manner

Working in a person centred manner fits closely with the need to be holistic. All aspects of a young persons life must be considered and explored when supporting people. Working in this way should ensure the values and culture of the young person are identified, understood and respected.

It is vital that the focus is on the individual not the service. For example respite settings have traditionally offered overnight stays and not more flexible arrangements that may be better suited to members of BME communities who need a break but do not want a family member to stay overnight elsewhere. Every young person is unique and focus on services will mean some young people who need them do not access them

Families from BME communities can face double or even triple oppression and often receive a poor standard of service. The input of these 'point of contact' workers can have a significant influence on a family's decision to seek further support.

Joint working is essential

No one person or organisation can solve all the problems and issues faced by an individual and their families. Working with a range of services across a wide specialist area will be essential when ensuring person centred support.

The resource does not assume prior knowledge for those using it

There is no assumption that those reading the guide will have any prior skills and knowledge of all aspects of the information included.