# 'Getting It Right for Disabled Children In Blackpool': A Research and Consultancy Project for Blackpool PCT and Children's Trust.

**Findings and Literature Review** 



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# **Contents**

Executive Summary				
0	Key findings	4		
0	Conditions for success	6		
Background to the research project				
0	Amis, objectives and research deliverables	9		
0	Methodology	10		
0	Acknowledgements	11		
Blackpool: setting the context				
An analysis of the post holder's role and brief				
0	Emerging issues: Challenging behaviours & behavioural problems	22		
0	Sleep disturbances	23		
Fi	Findings			
0	Parental perspectives	24		
0	Views from the professionals	26		
0	CAMHS	33		
0	Challenges experienced by the post holder	38		
Case Load Analysis (Sept 2009- June 2010)				
Re	eferences	45		

# **Executive Summary**

In the interviews that have been carried out both professionals and families consistently spoke very positively about the skills and approaches used by the post holder and of her successful interventions over the course of her existence in this post. There was clearly a need for this post and she is seen to be providing an important service for disabled children with mental health difficulties in Blackpool. This research has found that the appointment of a specialist learning disability CAMHS worker has improved the outcomes for some children and young people and their families, juxtaposed is a marked improvement in service satisfaction locally. Presently this is credited to the work of the post-holder and Complex Difficulties Team (CDT) rather than being identified with CAMHS related activities. These are issues that shall be dealt with later in the report, but it does appear that there are a number of matters that need urgent attention. There is awareness that recently there has been movement on some of the problems that have been identified and raised. However the post holder continues to operate as the only specialist learning disability professional in an environment where her role is perceived (wrongly I would suggest) as extraneous and outside of the service remit or skill base of mainstream Blackpool Child and Adolescent Mental Health Services. Similarly it is essential that everyone who can commission this service has the same expectations of the post holder and commissions from a clear, transparent and jointly owned framework. This should be supported with a published and widely distributed referral route and shared pro-forma documentation to be use consistently from the point of access to the termination of the service.

From these findings there would appear to now be a need for an action plan, designed to focus on:

- Preventive multiagency support services
- Establishing clear referral pathways to access the post holder's services with supporting pro-forma for referrals, recording and closure documentation.

- Raising awareness with Blackpool Child and Adolescent Mental
  Health Services of their roles and responsibilities to disabled children
  under the Disability Discrimination Acts 1995 and 2005 and the more
  recent Equality and Human Rights Act 2010.
- Employment or access to a consultant psychiatrist with training and expertise in working with children and young people with learning disabilities.
- Continuing professional development (CPD) opportunities for Blackpool Child and Adolescent Mental Health Services to enable them to work inclusively with all children, including disabled children who have mental health needs.
- 'Real-time' solution focussed multi-agency learning disability and mental health training drawing on the interventions, methods and approaches currently being used by the post holder
- Sustainability and succession planning. 'Future proofing' this role and building on it to enhance case load capacity and reducing the reliance on a single lone specialist worker.

# **Key Findings**

- The need for timely, proactive multi-disciplinary services for children and young people with learning disabilities, which are child focussed, premised on working with partnership with parents and other related services has consistently emerged as fundamental to meeting local demand. Currently the Complex Difficulties Team is the agency accredited by local families as the organisation meeting this criterion for success.
- There is a need to establish a clear referral pathway for parents and professionals who want to access the post holder's services. This may include the adoption of a single point of intake model e.g. through the CDT or the through the development of a care pathway that is able to link the work of CAMHS, CDS and the CWDT in this area.

- Operationally the post holder requires clearer guidelines around interagency governance, supervision, monitoring and support mechanisms
- Findings from this study suggest that there is a need for a marked cultural change in Blackpool CAMHS if its services are going to be genuinely accessible to all professionals, children, young people, their families and carers who need support.
- The post holder has received some 'inappropriate' referrals from
  within CAMHS; these usually concern definitional ambiguity over the
  terms- 'learning disability' and the wider educational construct of
  'learning difficulty'. This would suggest a need to produce clearly
  delineated eligibility criteria, which are shared and owned across all
  agencies and stakeholders.
- Most of the children and young people being referred to the post holder have a diagnosis consistent with various aspects of Autistic Spectrum Conditions. While this report has not specifically focussed on ASC's, this trajectory needs to be acknowledged by the specialist services working with these cohorts of children
- There is a corresponding need to focus any training and related CPD activities on initiatives aimed specifically on autism awareness.
- There is a need for a local multi-agency CPD programme that adopts
  a case study approach to training and which is aimed at developing
  participants skills and understanding of appropriate intervention
  strategies which can be confidently used with children and young
  people with learning disabilities who have additional mental health
  problems.
- This report should be seen in the context of the need for much earlier and timely intervention available to these children, young people and their families, especially around the area of managing challenging behaviour and associated behavioural difficulties. The professionals similarly spoke of a very real need in Blackpool Children's Services for the employment of community learning disability nurses (CLDN.) This was based on practice and experiences in adult learning services

- where CLDN's work in multi disciplinary teams addressing, managing and intervening early to prevent family and placement breakdown.
- Finally, problems relating to sleep disturbance seemed to create more
  problems for families than any other aspect of their child's needs. It
  may be area that local services want to focus on in any subsequent
  parent and carer training courses that they offer.

Without an increase in resources then there are likely to remain significant challenges in meeting local and national targets. There are, as the various professionals who were interviewed testified, based on their day-to-day working experiences, high levels of unmet need in the locality. Moreover the sentiments of more than one parent who while praising the work of the present post holder, led them to conclude that her services and interventions were "too little, too late". It is suggested that the above developments are designed to occur whilst simultaneously planning for the long-term future and expansion of this role.

# **Conditions for Success**

In order to meet the above the following conditions for success have been drawn from the literature, policy, personal experience and the findings from this study.

- Strategic commitment
- Involvement of commissioners and users
- A disability 'champion' in the Children's Trust
- Strategic level steering group/management board
- Specialist dedicated posts and service configurations
- Administrative support
- Clinical and practice governance, accountability and quality assurance mechanisms
- Workforce development, CPD infrastructures and training opportunities
- Published eligibility criteria with clear referral pathways and information sharing protocols

By commissioning this research Blackpool Children's Trust should be commended for the innovative and insightful way in which it is aiming to develop services for disabled children. In particular the interviews with the Service Managers and those professionals based at Progress House, demonstrated staff who enjoyed strong and respectful working relationships. This reflected a Children's Trust that emerged as a learning organisation; one able to communicate across organisational boundaries and which acknowledged and respected professional contexts and skills.

# Background to the Research Project

A specialist Band 6 post for a Child and Adolescent Mental Health Services Learning Disability (CAMHS: LD) nurse was created in Blackpool Child and Adolescent Mental Health Services in early 2009. Original discussions relating to this post date back to June 2006. The rationale to appoint a specialist learning disability/mental health practitioner to work within Child and Adolescent Mental Health Services reflects a growing national and local awareness and commitment to address the mental health needs of disabled children and young people. Evidence suggests that 40 – 90% of children and young people with learning difficulties will have significant mental health needs including a diagnosable mental health disorder (Foundation for People with Learning Difficulties 2005.) This incidence is significantly more marked for these diagnosed with autistic spectrum conditions (ASC,) with the National Autistic Society (Madders, 2010) recently estimating that 'as many as 71% of children with autism have mental health problems, such as anxiety disorders, depression and obsessive compulsive disorder (OCD) and 40% have two or more difficulties' (Madders, 2010: p. 4). Clearly while most children and young people with learning disabilities enjoy good mental health these figures compare to a prevalence role of approximately 10% in other children. Government policy in this area highlights how those who experience co-mobility need to be able to access appropriate services and support. To be effective these services need to be timely, accessible and learning disability/autism friendly (National Autistic Society 2010)

The above provides some context regarding the challenges faced by the post holder when she took up post in May 2009. Simultaneously funding was obtained from the Child Health Division of the Children and Young Persons Department (a joint NHS Blackpool and Blackpool Council initiative) for 'An Independent Evaluation of the Duel Diagnosis Learning Difficulties/Children and Mental Health Services Provision within Blackpool Specialist Child and Adolescent Mental Health Services'. UClan (School of Social Work) were approached and commissioned to undertake this research. In September

2009 the following aims and objectives were jointly agreed with the commissioners of the research:

# **Aims**

To evaluate learning disability provision within Blackpool Child and Adolescent Mental Health Services (Phase one.) Phase two of the evaluation is planned for 2012 (Subject to re-commissioning) and will provide a progress review and an update of these findings.

# **Objectives**

- To explore the views of key stakeholders, service users and their families regarding the new service being provided by the post holder.
- To consider the role, activities and challenges faced by the post holder appointed to this new role.
- To establish the extent to which the post has impacted on meeting need in the local area.
- To offer information for future policy formation and developments in relation to the delivery of services for children and young people with learning disabilities and mental health problems in Blackpool.
- To evaluate the training provided by the post holder as part of her role.
- To provide a brief literature review for the commissioners of the research.
- To disseminate the findings through a stakeholder event organised and funded by the commissioners.

# **Research Deliverables**

The researcher was asked to deliver a concise but informative report that attempted to address the above aims and objectives. This was commissioned to provide an evidence base and a clear strategic direction for the future focus of Blackpool's Child and Adolescent Mental Health Services (CAMHS) for children with disabilities. The research was premised on a brief literature review which is attached as Appendix One. The data has been transcribed and analyzed using a thematic approach. The themes are those identified in the objectives or have emerged during the collection of the data.

# Methodology

In order to meet these aims and objectives (above) the research was designed around:

- The collection of local and national data and an evaluation of existing research findings in order to provide contextual information about the needs of children and young people with learning disabilities who have additional mental health problems. This has been complied into the literature review contained in Appendix 1
- Questionnaires and an offer of a face to face interview with all of the families accessing the support of the post holder. The questionnaires were primarily completed by using tick boxes or marking points on Likert scales. Respondents were encouraged to provide optional additional comments. Topic covered included:
  - -Background and demographic information
  - -Child/ young person disability details and behaviour
  - -Nature and perceived helpfulness of the post holder's advice
  - -Details of other services used
  - -Overall satisfaction ratings
- An offer of a face to face interview with the children and young people
  from the families who returned the questionnaires. The original project
  design was premised on interviews with children and young people.
  Although ethical approval was gained to engage in such research, no
  children or young people were actually forth coming. This is not
  surprising given the complexity of their needs and nature of their
  mental health difficulties
- Focus group meetings with staff from various agencies connected with
  the post holders role and service. These where used to gather a richer
  contextual understanding of how the post holder operates; how these
  professionals saw her role and an opportunity for them to provide
  insight on their perceptions for future developments in this area of
  their work.

- Semi structured interviews with staff from the key agencies that work with disabled children and young people with learning difficulties who have additional mental health problems.
- Semi structured interviews with mangers form the Children's Trusts.
   These managers were selected as they were directly linked to the three services that contribute to the funding and management of this role.
- An analysis of the post holders case load from September 2009- June 2010
- Regular discussions with the post holder.

Please note this is a very small scale investigation which was premised on an overriding commitment to confidentiality and research ethics. A number of individuals and agencies asked to remain anonymous; therefore no quotes are attributed to professionals, agencies or individuals. A large amount of data was generated from the interviews. In order to make sense of this information, the data has been categorised under chapter headings, however there is some overlap between the separate headings and the report should be read and considered as a whole.

# **Acknowledgements**

Acknowledgements are offered to staff and managers from the following organisations in Blackpool who took time out from their busy schedules to meet or talk to me:

Clinical Psychology Services
Complex Difficulties Service
Children's Social Care Services
Children with a Disability Team
Child and Adolescent Mental Health Services

In particular I would like to thank the families of the children and young people who responded to my requests for information. Leading already challenging and complex lives their willingness to engage in the research was highly appreciated.

# Blackpool: Setting the Context

Given its geographic size then Blackpool with a population of 142,500, is described as a densely populated town (Blackpool Children's Plan 2009-2012). It has an estimated population of 33,700 children and young people aged 0-19 years residing in the authority. At 24% of the local population this represents a growing populace (up 2% since the 2001 Census). Like many seaside towns the population is characterised by its somewhat transient nature and above average numbers of older adults- 19.9% of the population are aged 65+. At just 1.6% there are a relatively low proportion of minority ethnic groups living in the town. The local economy is largely focussed on tourism, the service sector and government administration. There is no heavy industry and tourism is built on seasonal employment. With 23% of the working age population claiming an unemployment related benefit then worklessness is high across the town but particularly in the inner town wards. According to DWP statistics an estimated 27.5% of Blackpool's children live in households where parents are claiming work related benefits. This is compounded by high levels of people who are dependent on incapacity benefits and who have below average levels of educational achievement. Moreover even where parents do work low wages exacerbate parental and household poverty and need.

This is reflected in the high levels of social and economic deprivation that characterise the town. In 2007 the Index of Multiple Deprivation (IMD) ranked Blackpool in the top 4% of the most deprived local authorities in England. This was an increase in its 2004 position in the IMD index. The umbrella term' social and economic deprivation' needs to be understood in the context of the highly complex issues that it presents for both those experiencing this trajectory and those charged with planning and providing services to address such needs. It is recognised that social and economic deprivation has particular impacts on the well being and associated life chances of children and young people (Child Poverty Action Group 2010). As outlined in the literature review, Emerson and Hatton's (2007) research findings provide a detailed insight into how poverty exacerbates the vulnerability for these

children with learning disabilities in developing mental health problems. Blackpool's Children's Plan (2009-2012 page 12) captures this through its children in need' model

# Children at risk of significant harm / or has suffered abuse and for whom there is continued risk.

and for whom there is continued risk.

Child in household where parents / carers have mental health, substance dependency or domestic abuse issues which put child at risk of significent harm. | Persons identified as posing a risk to child identified as living in the house. | The child's life is endangered. | There is evidence of serious or significent injury or illness. | The possibility of non-accidental injury. | Evidence of gross neglect. | Children who are persistently missing from home and who put themselves at significent risk. | Actually homeless and no housing agency able or willing to assist. | Unsanitary or dangerous home conditions, | Sexual exploitation and/or abuse. | Serious injury/harm/abuse to self or other. | Seriously challenging behaviour. | A child abandoned. | Life threatening drug abuse. | Trafficked child. | Risk of long-term psychological damage / deprivation. | Significent impairment of physical / emotional development. | Damaging history of separations. | Children at risk of forced marriage. | Children who abuse other children. children.

## LAVAL 3

Children whose vulnerability is such that they are unlikely to reach or maintain a satisfactory level of health or development.

Children with disabilities. | Children with high level needs whose parents, for whatever reason, are unable to Children with disabilities. | Children with high level needs whose parents, for whatever reason, are unable to meet those needs. | Children from families where there has been one serious or several significant instances of domestic violence. | Children where a CAF Action Plan has had no significant impact. | Children who have been subject to a CP Plan, or who have been previously looked after where there are new / further concerns. | Children with high level / unassessed needs whose parents have a history of non-engagement with services, or fail to recognise concerns of professionals. | Pregnant women where the safety of the unborn child might be compromised. | Children in families experiencing a crisis that is likely to result on a breakdown of care arrangements. | Persistent and serious offending. | Unaccompanied asylum seekers.

# Level 3a

Children who are persistently going missing from home. | Children with a significant emotional and / or behavioural disorder. | Young carers. | Children with chronic absence from school. | Children in families without permanent accommodation. | Children with chronic ill health / terminal illness. | Children involved in substance misuse. | Child in households where parenting is compromised as a consequence of parental discord, mental health, substance misuse or domestic abuse, although child's needs are not at a high level. | Children and young people involved in acrimonious contact / residence disputes. | Children who are experiencing adverse effects from bullying.

# Disadvantaged children who would benefit from extra help - to make the best life chances. Services operating at a preventative level.

Parents unable to secure some aspects of health or development; poor health; poor school attendance. | Inappropriate age related behaviour, which is difficult to handle. | Inhibited / restricted development opportunities in own home and community. | Demands of caring for another person undermining aspects of health and development. | Poor standard of physical care or health causing concern; unhealthy diet; unsatisfactory accommodation. | Insufficient stimulation to achieve full potential; no opportunities to play with other children; experiencing difficulties in relationship with peers. | Scape-goating or victimisation causing emotional harm including continual / regular periods of stress, conflict, tension causing instability and insecurity in relationships; absence of appropriate stimulation. | Relationships strained; normal health and development constrained by environmental circumstances and/or limited play opportunities.

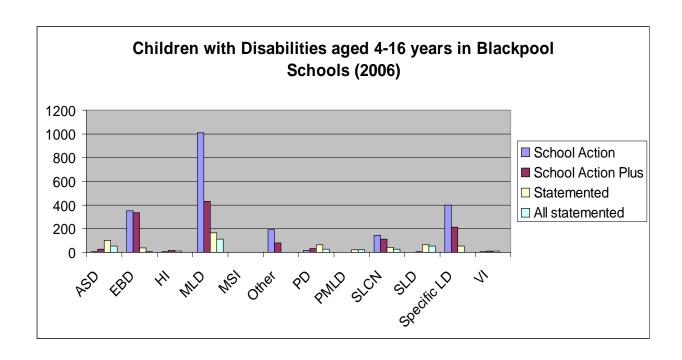
All children within the borough and who are routinely in receipt of community services. Assumes backdrop of universal Education and Health services.

(Source: Blackpool Children's Plan 2009-2012 page 12)

In terms of this report, as can be seen, disabled children and young people are at the threshold for Level 3B intervention being 'children whose vulnerability is such that they are unlikely to reach or maintain a satisfactory level of health or development' with a number possibly needing support for

needs which meet the L4 thresholds'. It is the needs of these children that are the focus of this report. The numbers and needs of some of these children are presented in more detail below.

Children with Disabilities aged 4-16 years in Blackpool Schools (2006)									
	SENDA status			Special schools					
	School Action	School Action Plus	Statemented	All statemented					
ASD	5	29	102	53					
EBD	348	334	36	6					
HI	6	17	13	1					
MLD	1009	431	167	114					
MSI	0	1	0	0					
Other	193	81	1	1					
PD	14	33	66	27					
PMLD	0	0	20	20					
SLCN	142	110	43	26					
SLD	2	6	66	52					
Specific LD	398	215	55	0					
VI	4	8	13	2					
Total	2122	1265	582	302					



Using the above figures then the predictions of mental illness in Blackpool amongst children and young people with ASC; SLD and PMLD based on the January School Census 21st January 2010 - Special Educational Needs Summary (4-19) are as follows:

	Autistic Spectrum Disorder	Profound & Multiple Learning Difficulty	Severe Learning Difficulty	Totals
Census summary	120	15	81	216
NAS prediction (1)	84			84 (ASD only)
Emerson & Hatton prediction (2)	48	6	32	88

- (1) using NAS (2010) prediction of a 70% incidence of mental illness
- (2) using Emerson & Hatton (2007) prediction of a 40% incidence of mental illness

NB Early Years are not included in this analysis.

Using very narrow criteria based on diagnosis the above highlights a potential demand from at least 88 children and young people who are known to the authority. Given that many children and young people present with complex and diverse needs making precise diagnosis very difficult then this number is likely to be an underestimate of local need. Presently the post holder is carrying a case load of 9 children and young people which represents an approx service response rate of 10%.

It is widely acknowledged in Blackpool that the town's transient population present a particular challenge to service providers. According to the Children's Plan 2009-2012, 'the town experiences one of the highest levels of population mobility of children and young people in the country, presenting

considerable challenges for agencies providing services to them and their families'. In a town where the economy is largely focused on tourism, families are seemingly attracted by relatively low cost privately rented accommodation, the bright lights of Blackpool and the associated availability of unskilled seasonal employment opportunities. For families of disabled children transience has added dimensions, these include a high dependency on service provision, complex housing and educational needs coupled with a lack of potential extended family support. Moreover parental poverty is compounded by disability (Every Disabled Child Matters 2007).

While this study focuses on children and young people, disability across the life span has a close association with poverty. There are approximately 777,000 disabled children in the UK (Every Disabled Child Matters 2007). Given the contested nature of defining 'disability and impairment' then any statistical analysis relating to numbers must to be considered very cautiously. However it is generally acknowledged that the numbers of disabled children aged 0-16 is rising (Aiming High for Disabled Children 2007). This growing population contains proportionately more children and young people with complex needs (Prime Ministers Strategy Unit 2005), most notably those with Autistic Spectrum Conditions and / or complex health needs. The nature of these children's needs means that they require support from a range of services (Department for Children, School and Families/ HM Treasury 2007). Research by Sharma (2007), demonstrates a correlation between low income, social exclusion and disability within families who have disabled children. Families with disabled children, especially those headed by lone parents (Russell 2003) or ethnic minority families are found in disproportionate ratios amongst those living in poverty (Audit Commission 2003 and Aiming High for Disabled Children 2007). In the comprehensive survey undertaken by Emerson and Hatton (2005), only 6% of families with disabled children described themselves as 'comfortably off' while 93% reported some sort of financial difficulty. Mirroring earlier findings the campaign group, Every Disabled Child Matters (2007) describe childhood disability as a 'trigger event' spiralling families into poverty. This is result of increased financial costs, relationship breakdowns, parental unemployment

and reduced opportunities for paid work. Carers UK (2006) estimate that 10% of families of disabled children care for more than one disabled child. These findings need to be seen in the context of government policy premised on a social investment model which views work as the prime guarantor of a reasonable level of house hold income (Lister 2006a). In an authority characterised by high levels of poverty and associated social deprivation then these indicators are particularly pertinent.

Psychological health and well-being are strongly correlated- factors that are explored in more detail in the next section. While Blackpool is currently characterised by a population with poor levels of physical and psychological health (Children's Plan 2009-2012), its Children's Trust emerges as committed to addressing these issues for **all** of the Borough's children, including those who are disabled. An examination of the Children's Plan 2009-2012 highlight the ambitious targets that the Borough Council and Children's Trust have set themselves. The findings in this report provide some insight into the challenges that lie ahead in relation to meeting the needs of children and young people with learning disabilities who have additional mental health problems.

There now exists an ample evidence base to support the need for early intervention for children experiencing difficulties. The impact of cognitive challenges associated with learning disabilities suggest that for the children and young people under consideration then this is probably more so.

# Meeting the Mental Health Difficulties of Children and Young People with Learning Disabilities: a wider analysis of the role of the post holder.

The starting point for this research is that the development of mental health problems needs to be understood in the context of the influence of wider social factors on the development of identity and wellbeing. The average age of the young people who are accessing the post holder's services is 13 years. Psychiatric diagnosis is mainly premised on functional communication skills in which people outline a set of signs and symptoms primarily through spoken language. For people with learning disabilities communication may be impaired as a result of their learning disability compounded by cognitive impairment or autistic ideation or behaviours. This is not an insurmountable problem, those who are prepared to get to know the child or young person and work closely with significant others in their lives are able to elicit reliable and valid responses over time. The practice demonstrated by the post holder illustrates this well. It has however caused some researchers such as Sturmey (1999) to challenge the application of standard psychiatric criteria (most notably ICDC 10 and DSM) and their associated assessment tools when working with cohorts of people with learning disabilities. While clearly not without its challenges making assessment tools and therapeutic interventions child friendly is part of the recognised CAMHS skills set and specialist brief for its child focussed interventions. Work undertaken by the post holder to date clearly suggests that this while demanding, is an achievable objective. This can be seen in the way that she has generated adapted assessment tools and intervention strategies to facilitate her day to day work with the children and young people. Various professionals and especially the social workers commented on how they would also like to develop skills in this area to enhance their direct work with children and young people.

Looking beyond the medical model and adopting a social model perspective such as that proposed by commentators such as Emerson (2007) then it is highly likely that these young people have already experienced a number of challenges and difficulties that could potentially exacerbate their risk of

developing subsequent mental health problems. These include growing up in stressful and difficult family situations, stigma, humiliation and bullying, high levels of anxiety. Sturmey (1999) suggests that the label 'learning disability' is not neutral; rather it generates various challenges in relation to problem-solving and coping strategies in an often hostile world. For some of the young people environmental stressors, self elected and sometimes self-imposed restrictive lifestyle including social withdrawal were hiding or masking what were actually mental health problems for example depression. As one mother commented

"We knew she was quiet. She was always quiet and a bit different when she was little and in primary school she didn't have many friends. We just thought that was her. We didn't know that she was trying to keep all this inside her. Then one day, I think it all just got too much for her. It was like a lid blowing off....Inside it must have been so hard for her keeping it all in..."

Similarly the high levels of anxiety manifested in children and young people with autistic spectrum conditions as a result of hyper or hypo-sensitivity to a whole range of mediums can place them under enormous pressure and stress. In an attempt to avoid these children and young people develop coping strategies through hyper vigilance. For children experiencing hyper vigilance the world can be become a most threatening and unpredictable space. Various commentators have discussed how this in turn generates heightened levels of anxiety and distress (Howlin 2004; Boucher 2009).

Like many children and young people, those with learning disabilities may have difficulties in recognising and describing their complex emotions and feelings. This can be further compounded by their restrictive or idiosyncratic emotional vocabularies (Rojahn et al 1998a). Specific language impairment co-occurred in a number of these young people. Most typically the language problems were most acute with those who had severe learning disabilities with their receptive language, comprehension and meaning most severely and persistently affected. Those with Asperger's Syndrome were characterised by pragmatic difficulties. The role of speech and language therapy has not been explored in this study but the pioneering work of

Phoebe Caldwell (2007) et al provides a rich context for understanding the impact of communication difficulties on behaviour.

Addressing these challenges demands an ability to generate intervention strategies that are personalised and child-focussed, creative and sensitive to individual needs and difficulties. The present post holder is currently utilizing a range of interventions 'adapted' from strategies and therapeutic interventions that are already used widely across most CAMHS teams. These include behaviour management, anxiety management training, cognitive behavioural therapy and other psychotherapeutic approaches which are adapted, purchased or used specifically to make them age and cognitively appropriate for children and young people. Her work is underpinned and coupled with a partnership approach that involves working very closely with parents, carers and significant others such as specialist staff from education services. This has facilitated a rigorous 'joined-up' consistent approach to managing these children or young people's difficulties. It is possibly the rigour and consistency of these applications that is most effective. Carrying such a small and protected case load appears to enable the post holder to visit frequently, report widely and critically review the child's progress. There is evidence of a high level of parental satisfaction with this approach and a keenness articulated by other professionals to learn more about some of her interventions in order to apply these skills to other services users. Her role in offering consultations and practical advice to other professionals was seen very positively by those accessing this aspect of her role

Most of the children were displaying co-morbidity- juxtaposed with their diagnoses of autism, Asperger's Syndrome or severe learning disability were symptoms of hyperactivity, impulsivity, self-harm, sleep-disturbance, depression and anxiety. At the most extreme one young person presented behaviour that ranged from unpredictable catatonic inactivity to alternative situations in which they presented as ceaseless and chaotic, sometimes leading to an urgent request for in-patient services. Frustratingly for local services, rather than address these difficulties the label 'learning disability'

seems to have lead to a situation where the young person was subsequently rejected from a Tier 4 inpatient facility for being "too autistic" to benefit from treatment! This would appear to contradict the advice from the NHS National Specialised Commissioning Group (NSCG) which includes 'neuropsychiatric and neurodevelopment services for children and adolescents including those with a duel diagnosis', as eligible for Tier 4 services.

Although the majority of the children and young people who were surveyed had a clinical diagnosis's consistent with autistic spectrum conditions it must be noted that the largest contribution to the diversity of needs displayed by the children and young people appeared to come as it does for most of the general population, from individual differences of temperament, experience and age.

The issue of self-injurious and other maladaptive behaviours were also described by various professions and reiterated by some of the children's parents. These behaviours included head banging, hand biting and suicidal ideations and actions which were articulated by some parents as being internally generated rather than the product of external stimuli. Other children were however displaying behavioural signs more linked to the situations which are discussed in the following section on challenging behaviour. What ever the cause, these behaviours were always an issue of serious concern to the parents and other professionals. Moreover the behaviours were in some instances generating secondary health problems such as bruising, bleeding and infection that were causing additional distress and anxiety for the families and other cares. Some families described how these behaviours were, albeit more rarely, vented and directed at the carers themselves through which escalating scenarios of violence produced significant management problems particularly when they were occurring in the confines of the home. A significant feature for policy makers and funders to note was that these particular children and young people were no longer living at home on a permanent basis or had been subject to costly in-patient care

# **Challenging Behaviour and Behavioural Problems**

It is now widely accepted (Department of Health 2001; Mansell 2007) that for people with learning disabilities behaviours that are all too easily judged as 'maladaptive', 'unwanted',' challenging' or 'antisocial' are often communicative mediums. The work of Caldwell (2007) suggests that where people have little or no control over their lives and / or have limited effective means of communication, then such behaviours are more appropriately understood as forms of expressive and communicative language. As such the behaviours described by some of the families who were interviewed alongside those of the professionals who were supporting the children and families, while very challenging for those who were trying to manage them, were not intentional or malicious. Rather the post holder worked with families and other professionals supporting them to conceptualise and understand these behaviours as responses to stress; powerlessness; frustration and even bullying.

The need for a multiagency behavioural intervention team for children and young people with learning disabilities was a recurring theme in the findings with a number of those who were interviewed wanting such a team to be colocated ('They could be based at Westbury Lodge' was mentioned more than once by the professionals) and multi-disciplinary with opportunities for ('weekly') allocation meetings. Alongside a location for the present post holder various professionals were proposed for this team including a clinical psychologist, social workers, advisory teacher, community learning disability nurses, speech and language therapists and family support service staff. Access to the Complex Difficulties Service and short break provision was also articulated as integral to this model. The findings from this study would suggest that in the absence of a dedicated CLDN team in Blackpool then a number of children and young people are receiving somewhat limited clinical intervention and support to manage and address their behaviours that are deemed challenging. There are clearly multiple reasons why children display such behaviours. The findings from Brylewski and Duggan (2004) suggest that prescribing medication for such behaviours has only a limited impact

(unless the behaviour is of course associated with an underlying psychiatric condition). Specialists in this area draw on applied behavioural interventions alongside supporting carers to manage the situation more confidently, consistently and assertively. While acknowledging the potential for diagnostic overlap, a number of the children and young people who have been referred to the post holder over the course of her employment, present with, in her clinical judgement, challenging behaviours rather than actual mental health problems. It is acknowledged that at the point of referral it is sometimes difficult to ascertain what is causing the actual behaviours. To achieve this has often demanded a lengthy assessment and analysis of need based on systematic observations over time. It is the post holders and author's contention that CLDN or behavioural support teams are more cost and operationally effective in achieving such assessments. Their role would be to then liaise and transfer 'appropriate' children and young people for CAMHS: LD mental health support.

# **Sleep Disturbance**

Sleep disturbance was another problem often described by the families; some of the young people had problems getting to sleep at an appropriate time or problems with night time waking. These were extremely wearing for the parents to cope with and had a huge impact on other children in the family. This seemed to create more problems for families than any other aspect of their child's needs. It may be area that local services want to focus on in any subsequent parent and carer training courses that they offer locally.

# **Findings**

# Parental Perspectives: 'a light at the end of a dark tunnel'

These were the words used by one parent when commenting on the post holder's role. Another parent commented that despite having already fought long and hard to secure a diagnosis, the gap between diagnosis, appropriate intervention and support was "a distressing and horrendous experience." Once given a diagnosis parents commented that they needed "clear, unambiguous and sound advice" the preference was that this came from a single source. In addition the parents wanted to know what happens to their children when they are at school especially when professionals see their children at school. Families responding to the request for interviews placed a high significance on getting information about what is happening for disabled children in Blackpool. This emerged as empowering, placing them in control and better able to communicate with professionals about their specific needs. However few of the parents were able to articulate how the post holder's involvement in their lives had practically materialised. While welcomed this interaction was accompanied by a sense of 'being done to' rather than as a service that the parents were actually previously aware of or, indeed had ever formally requested.

Where families had had previous contact with CAMHS in Blackpool this was not viewed positively .One parent suggested that "They wanted us to have family therapy. I kept saying it wouldn't work. YYYY (name of child) has autism; it's much more complex than they seemed to be able to understand... In the end they said he was too difficult for them (CAMHS). I was just left with the problem; meanwhile our lives were a nightmare".

Through the interviews it became clear that parents (and professionals) need access to relevant information and advice to guide them in managing their children's behaviour. For some of the parents this needed to be more than courses and written material. As stated by one parent, "I wanted someone there in my home, someone to show me how to do it!" More over the need to do this in a very child centred way was articulated. Most families valued the

home based visiting service provided by the post holder. The service, its source of funding or indeed location emerged as much less important than seeing the post holder in a convenient place and time.

A major strength of the existing post holder was seen through her ability to proactively engage with children or young persons.

"I was impressed with the way that (xxxx) worked; she used activities using the child's preferred interests and toys. Unlike most of the others finally I had someone who understood about autism and things!"

Another parent stated,

"By being non-threatening and flexible she could get through to my daughter. She knows when to back off and when she has had enough. But by coming more than once a week she kept at it. I think they are making progress. She gives quality time to her. My daughter has benefited from the service; we like and trust (XXXX,)".

The more neutral professional label 'nurse' appeared to emerge less threatening than having social work involvement with the family, as such families seemed keener to engage with the services of the post holder. Professionals found this role to be complimentary to their own and beneficial in meeting their assessments of children's needs. It was never seen as a threat. As one social worker commented:

"She was a bit like super nanny with some parents which was really good, I couldn't just go in and do that, you know they don't like social workers going in and telling them how to bring up their children, but (XXXX) coming from a different background seemed to really make a difference."

While all of the families articulated satisfaction with the post holder's work with their child or family, this was sometimes tinged with some cynicism, in which they saw this involvement as part of their 'conveyer belt' experiences of receiving services for disabled children in Blackpool. This was summed up by one parent who stated

"You get passed from one to another, but no one tells you why and most of them don't know what the last one was doing" Another stated "It's just another face-hopefully she will stay as she is good and knows what she is talking about. Because she understands his problems she can reassure him and calm him down. I have lost count of how many people have seen YYYY".

"It is not helpful going from service to service, you feel judged and confused. We went into a downward spiral where our difficulties just got worse. It became harder to deal with more and more people involved and writing reports about us. In the end my child had to go away.... All this could have been prevented. Then I would still have my child with me today."

Where they were getting support, there was a concern that the interventions might stop abruptly, that it was going to be short term and "what then"?

Clearly and understandably families want seamless, well-coordinated services that provide continuity and consistency. In these interviews they particularly wanted to be able to build a trusting non-judgemental relationship with someone who had proven expertise in the area and particular insight into learning disability related issues.

# **Views from the Professionals**

Amongst those social workers who have managed to have their 'complex cases' referred to the post holder there was a very positive response. This was particularly focused on the therapeutic skills that she utilized when working with children. The opportunity to observe the post holder engaging in direct work was seen as a window for professional skill development, promoting new (and possibly less threatening) ways of understanding the needs of the children and families and responding appropriately. "(XXXX) has given me skills and understanding, we have all benefited from her. (XXXX) was giving strategies to parents that I might not have thought about.... We took really good advice from her."

Working with (XXXX) has also enabled social workers to re-frame their original assessments of children's need." I think it's worked really well having someone on the team with those skills around severe disabilities, complex

difficulties and added mental health problems. It made me think about how I see things. I know about their communication now."

The social workers were acutely aware of the consequence of not having had this service in the past. "If that input had been early on, some of our children who are now looked after would never have got to this stage. I've seen the support that she gives and really that needs to be done early when the children are young, not when they are 12 and 13, really which is what we are trying to do now, were just patching it up not un-doing all those things they have learnt ...."

Professionals commented that the current arrangements for accessing the post holders services emerges as particularly problematic for professionals (and families), "It's confusing and takes too long..." There appears to be a real need to produce a referral pathway that is transparent and unambiguous. While there is information available regarding the eligibility criteria used by the CDT for accessing and introducing the post holder's services few of the professional were able to describe this. The perception at present is that no one seems to 'own' the post-holder- most of the respondents equated getting a referral to her, as only possible after gaining approval from the Service Manager for the CDS and then going through the CDT. As such the referral pathway arrangements emerge as particularly complex and misunderstood. One professional summed this up when they stated "If only there was a clear pathway in place for accessing this support for my families".

There are issues of 'ownership' and location of the post holder which require some clarification. The statement: "Having someone on the team who...." was used by all of the practitioners who were interviewed. This raises some interesting issues regarding 'ownership' and location of the post holder. Each team seemed to be suggesting that she 'belonged' in their designated area. When asked who they thought managed this post, the manager of the Complex Difficulties Service was consistently circled. With the exception of the actual post holder and CAMHS Service Manager, this post was never described by its 'correct' title of CAMHS: LD.

Most professionals were aware that the opportunity to refer was now closed. The criteria for referrals were more often discussed in terms of behavioural management problems rather than diagnosed mental health problems. In the absence of a specialist resource for those with challenging behavioural problems then this is not surprising. Regardless of who 'owns' it, generally the post holders work and associated support is thought to be highly skilled and providing a very beneficial specialist service.

Within weeks of taking up appointment the post holder had reached saturation and caseload capacity. "She is doing a great job with my child but she had to close new referrals because she is full...so what do we do now. It's hopeless..."

Clearly there remain, in the views of many professionals working in this area, high levels of unmet need. "We've got so many more children who need this service and she hasn't got the availability. It needs two people at least in that post for Child and Adolescent Mental Health Services for learning disability working full time, so it's like double her hours and she still would be full!" The Children with a Disability Team had compiled a list of children and young people who they wanted to be seen in anticipation of her taking up post. Interestingly they had not referred these children to CAMHS. The criteria for referral emerged as unclear as a result there were already a number of myths and misunderstanding about which children could be referred and why they might be rejected. The lives of most of the children and young people who were being seen were characterised by long standing professional involvement, being at risk of home or school breakdown or experiencing an associated crisis.

As highlighted a number of children and young people known to the professionals were seen as presenting complex behavioural problems, rather than mental health issues. However the lack of a specialist multi-agency service focused on working with children and young people who present behaviours that challenge services, leaves some professionals with few options other than a referral to the post holder. Although variously framed there was wide spread consensus amongst the professionals for the creation

of a local team that focussed on managing children's challenging behaviours and associated problems.

"We need a dedicated LD nursing service, like the one that works with adults with learning disabilities. Without this we are a sticking plaster service- never getting to the bottom of what are very complex problems and addressing these problems in a systematic way. Instead its crisis, crisis, crisis..."

Another emerging finding was around the need to work with the whole family, including the child "Dedicated family support workers attached to a specialist multi-agency children's team would really improve the ability to cope in so many of my most challenging families."

Another professional commented that:

"These children and young people need more than our support at school. It's at home where the real challenges emerge". There was a frequently articulated sentiment regarding the need for closer home – school interventions.

"We could do with someone who is available to intervene in their homes because we haven't got time to go into the homes as well because our role is to support the school you know"

Most professionals drew attention to the issue of unmet need. There are clear capacity issues, within weeks the post-holder had been inundated with referrals and soon reached the maximum capacity of her caseload. For the professionals this meant "we are left with a lot of unmet need"!

The post holder has two desks- one at CAMHS and another at Progress House, her co-location at Progress House emerged as a crucial dynamic in the joint approach to co-working and case management. One manager commented

"We are fortunate that she is located very near to our team and therefore we are able to get some face-to-face discussion going with referrals. It's been a great help to us her being here"

Although not specifically explored in this study most of the professionals were quick to point out that "Transition is still a major challenge and generates high levels of anxiety in many young people- we still aren't addressing this in a systematic way"

The need for clear referral pathways was further compounded by a lack of an agreed referral pro-forma. For all of the professionals who were interviewed (and indeed the post holder) there emerged a view of an unclear relationship between the various assessment systems that are being used e.g. CAF; LAC: SEN/IEP and the Care Programme Approach. This would appear to need clarification in order to avoid duplication of assessments. Work needs to be undertaken to produce a single recognised pathway and referral tool to be used for requesting support.

The research findings suggest that practitioners, especially social workers, appear to lack confidence in directly working with children and young people with additional mental health problems- their therapeutic role and skills emerged as underdeveloped. They were however very keen to develop such skills.

"Watching her work in this very child focussed way was a great opportunity. It has made me think about how I work with children and their families and my need to develop skills in direct work with the children on my case-load. I would really welcome some training on this".

# A teacher commented

"It's a different way of working and I think this different way of working brings out more in the child or.... even from myself. By listening to XXXX you are learning and getting a different perspective you know. It's challenging but good too. You know to look at a problem from someone else's perspective... well it helps you see things differently"

Given that the post holders role was largely conceptualised as being part of the CDT rather than the local CAMH Service then it is not surprising that when asked, the professionals were generally not aware of the local and government agenda around the emerging role of CAMHS as sources of support and intervention for children and young people with learning disabilities. On more than one occasion respondents commented "I didn't know we even could refer- I thought they didn't work with our (disabled) children."

Moreover, there was a high level of cynicism about the local CAMHS service and its response to children and young people with learning disabilities. While much of this may be unfounded and based on historic pre-conceptions and experiences, it remains very negative and potentially counter- productive to meeting the often complex needs of children and young people and when addressing the wider issues presented through their families and schools. This challenge was summed up by one respondent who articulated that while "Every Child Matters makes it clear that mental health and psychological well-being is everyone's job, but apart from XXXX (name of post holder), here it's no one's role".

Staff from all agencies consistently articulated a need for training and development programmes in understanding and managing the mental health problems presented by the children and young people who they were working with. However the recent NAS accredited training on 'Mental Health and Learning Disabilities' that had been provided was quite negatively rated. While positive about the presenters there was more criticism of the actual contents of this. Staff felt that they would benefit from a less basic course and one which adopted a 'real-time' case study approach. Through such a problem solving/ solution focussed structure then it was felt that a holistic multiagency approach would emerge alongside strategies that could be proactively used in managing some of the complexities that they often felt powerless to address. There was a real sense of staff who were deeply committed to their work and local services, who wanted "to do the absolute best for the children and young people on my case load, but without the skills to address these then I feel next to useless".

The professionals frequently articulated the need for joint working both as an opportunity for skill sharing and for creating seamless service provision. "The best thing about XXXX (post holder) is that she keeps me informed of what

she is doing, how often she is doing something and most importantly, why, is she is doing something". The professionals from education and children's social care services reiterated many of the positive sentiments that were articulated by the parents who responded. In their view the post holder is clearly providing and important service for children and young people in Blackpool with additional mental health needs. She is seen to be filling a much needed vacuum in existing provision. She was consistently praised as being highly personable; child-focussed and skilled in the work that she undertakes. There is awareness that she is however stretched to capacity. In the absence of a multiagency Community Learning Disability Team for Children and Young People with Learning Disabilities her time is also inevitably spent addressing referrals that are more about behavioural issues than mental health problems. In terms of 'best value' this may not represent efficiency and cost effectiveness for the commissioners.

# Service Responses: Blackpool Child and Adolescent Mental Health Services

All children and young people with both learning disabilities and a mental health disorder have access to appropriate Child and Adolescent Mental Health Services

(NSF (2007) Marker of Good Practice)

A significant focus of the research task has been to consider the existing role of Child and Adolescent Mental Health Services in meeting the needs of children and young people with learning difficulties in Blackpool, over and beyond the post holder's role. For the last 15 years the government has highlighted the need to improve mental health services for people with learning disabilities and as the literature review (Appendix 1) demonstrates the national landscape is peppered with research findings supporting this claim.

There is now a clear evidence base for promoting and meeting the mental health needs of children and young people with learning disabilities.

Nationally this responsibility has been formally devolved to local CAMH services. The NSF (Department of Health 2004) describes the need for a 'comprehensive CAMHS'. The respondents in this study consistently complained of dissatisfaction with the existing access arrangements to the local CAMHS team for disabled children. This was compounded by indicators of unmet needs and capacity issues. While the present post holder has gone some way to addressing this service challenge, it was also acknowledged that this role could be significantly extended. The interviews provide an impression, correct or otherwise, of a local CAMH service that both historically and presently does not engage in direct work with children and young people with learning disabilities.

This was articulated as a view of the CAMHS team where "their interventions are too sophisticated for our (disabled children) to access". Another professional suggested that

"Our children aren't seen to be clever enough to understand or benefit from their therapies. They just don't get our children, they see the label and then that's it. They aren't eligible. If they talked to us like (XXXX) does or the family then they could learn quite a lot about how to work with the child. It's like they only see the label, nothing else. It makes me angry but it's sad really because you know they are entitled to this service, but you try getting it here".

"I just can't understand why CAMHS won't see a child with a learning disability because as I say children with ASD have just those sorts of problems..., you know we can't just ignore them; a lot of them are very vulnerable children who need help from CAMHS"

These findings are entirely consistent with those found by Tom Madders in the recent study that he undertook for the National Autistic Society (2010). While the report produced by Madders as part of the 'You Need to Know' campaign is based on a much larger cohort of 450 parents, he found the CAMHS system was failing more than two thirds of children with autism. More than half of the parents surveyed also said that they did not think that mental health services knew how to communicate with their children.

Only one member of this team returned the postal questionnaire and none of the local CAMHS team was prepared to be interviewed for this study. Discussion generated from the only meeting held with the team suggested that there was significantly less local support for developing services for disabled children within the existing specialist Child and Adolescent Mental Health (Tier 3) Services. The impression was of a post that had been imposed on the team- neither within their remit or reflected in their skills mix. The team articulated capacity issues and a lack of knowledge and understanding about learning disabilities were clearly a real concern. There are important work force development issues to be addressed here. Relevant to this study the NSF (DH 2004) suggests that in relation to working with children and young people with learning disabilities local CAMHS services should include:

- Specialist staff training for staff working in Tiers 2-4
- Adequately resourced Tier 2 and 3 learning disability specialists
- Access to Tier 4 services for children and young people with learning disabilities

While there is clearly a demand for more training around learning disability, a more in-depth training needs analysis appears to be required to provide clearer details for training commissioners. Juxtaposed there is a need for individualised CPD learning opportunities. The impression emerging from my only meeting with the CAMHS team was that the post holder's services were largely seen as belonging out side of the remit of the existing CAMHS team. The comments articulated suggested that services for disabled children and young people did not emerge from an agenda around inclusion. Rather CAMHS staff articulated this as a need for more specialist input for disabled children but that this was not necessarily the domain of the existing CAMHS provision. Even when reminded of the Governments inclusion agenda, Public Service Agreement targets (HM Government 2007a), commissioning guidance (Department of Health 1998), and associated legislative requirements, there was a reluctance to engage in a discussion as to how this could be facilitated locally within existing resources. Despite the evidence that children and young people with learning disabilities are at particular risk then the idea of 'mainstreaming' children into the existing service seemed implausible. So much so that the researcher was forced to question the role the 'Disability Equality' duty (DDA 2005) within the organisation. This lack of service engagement and awareness seems extraordinary and also suggests a need for mandatory disability equality training for all staff employed in this area.

The comments that were expressed indicated that post-holders position was felt to have been imposed on to CAMHS with-out consultation or an analysis of existing demand. In spite of national directives and indicators suggesting the contrary, presently there does not appear to be a clear role for the post holder in the existing CAMHS team as her services are seemingly not seen

as part of the team's remit or expertise. The sense of children with learning disabilities being outside of the domain of mainstream CAMHS work is possibly best understood by the notion of 'therapeutic distain', a term that has been coined by Bender (1993). This provides a useful insight into how mainstream professionals rationalize their 'non-involvement' in the lives of people with learning disabilities. By seeing them differently and even negatively, the children are viewed as not able to benefit from their interventions. Using this analysis the 'problem' is located within the individual rather than the professional. This is not to suggest a conspiracy or even overt discrimination, rather there does appear to be a pressing need to address the way in which the mainstream service sees and responds to the needs of children and young people with mental health problems in Blackpool. While training will go some way to addressing this issue and indeed additional training was requested by some CAMHS staff, the need for a more fundamental cultural shift around inclusion also must be acknowledged. Without this the present situation is creating huge inequalities in access to effective mental health services in the town. Moreover as already outlined in Section 2 of this study, and reinforced by recent findings from Chaplin (2009), who suggests that such attitudes potentially reinforce some of the negativity and associated difficulties that have led to the creation of the mental health problems in the first place.

The lack of access to a suitably qualified and experienced consultant psychiatrist who has a particular brief for children and young people with learning disabilities is exacerbating this situation. This has been on occasions a particular challenge to the post holder as she has been engaged in' battles' to secure the appropriate clinical interventions for some of the children on her case load. Without this infrastructure then it is difficult to see how Blackpool CAMHS can meet government prescribed performance targets in this area.

Within CAMHS while the actual clinical work of the post holder was seen to be good, her co-location and role within the actual team emerged as much more precarious. This has led to a situation where despite the positive achievements of the post holder since taking up her job, she has experienced instability and turbulence in her role within the CAMHS team. If this continues on its current trajectory, it seems doubtful she will remain in this post in the long term. On the basis of these findings this would be a loss to local services.

#### Challenges Experienced by the Post Holder: the wisdom of hindsight!

The appointment of the post holder has brought significant gains to local services which have been outlined above. The willingness and skills of the post holder in adapting the ways she can work with individual children and their families emerges as a particular strength of her work and interventions. In the words of one respondent

"She adapts what she is doing and saying. It's focused on them and then she can pick up what's bothering them. She made me think about how I saw the problem. You know, as part of the autism. She made me realise it wasn't about the attachment or poor parenting, which is what we often see. It was about, I think I now understand, about how the learning disability was making the child feel"

Such an approach is not a fast fix process - it demands an ability to comprehensively assess, communicate across professional boundaries and a well developed skills repertoire. Working across agencies has brought additional challenges in relation to cross boundary management and admin systems. The IT infrastructures are frustratingly not compatible, forcing her to work, sometimes simultaneously, on two lap-tops! Inputting the same or very similar data twice to demonstrate compliance and accountability to duel management systems has generated discussion about efficiency savings.

Findings from the evaluation suggest that the objectives set for the post holder are largely being met with a high level of service satisfaction being reported by the families who responded and from the various meetings held with professionals. However the number of potential referrals and multitude of demands on her time is felt to significantly out weigh her capacity to respond in a timely and intensive manner- an approach that is consistent with best practice and individual job satisfaction. On taking up the post she quickly accumulated a waiting list which is now closed. Other professionals requesting her services commented on the high levels of unmet need and how this leads to behavioural and mental health problems escalating if they are not appropriately addressed. Moreover as a 'lone' post holder and the only CAMHS worker who is routinely involved with disabled children and

young people the needs of these children are not being met when she is off work for what ever reason. This has also led to a situation where the present post holder is very isolated.

There is a need to ensure this service is resourced to meet the supervision needs of its staff. Initially the post holder's isolation was compounded by the absence of arrangements for clinical supervision. This has subsequently been addressed leaving the post holder feeling much more supported in her clinical decision making. Interestingly this clinical supervision is commissioned from out side of the CAMHS team.

The job description for this post is all embracing and effectively knows no boundaries. Initially in the absence of a clearly defined referral pathway there were a number of inappropriate referrals for the post holder's services with individual children e.g. children with specific learning difficulties as opposed to the more complex needs associated with ASC's, learning disability and severe cognitive impairment. This had led to a situation where there is now some confusion regarding the post holders brief. By becoming involved with children and their families she has found herself in situations where she is identified as the 'lead professional, key worker or case holder. Rather her view of the role is that she should be seen as a "co-professional" albeit a highly specialist one, who is specifically commissioned to undertake agreed work focussed on the child or young person's learning disability and mental health needs. To ensure service efficiency this role possibly needs to be time- constrained and be undertaken through close liaison with the actual commissioner.

At another level there would appear to be an associated need to determine if she is to act as a 'care-coordinator' and focus on direct work with children, young people and their families; undertake therapeutic intervention; a coworking role or primarily take on a consultative role. Presently her role emerges as a combination of all of these. It must be noted that she is left as a relatively powerless 'care coordinator' – she has limited access to using support services as these are usually commissioned or managed by other agencies. From within CAMHS there emerges an impression of other

specialists not co-working with her through skill sharing and related arrangements. For example, when working around sexual abuse and associated child traumas, she was not able to access therapeutic interventions from specialist CAMHS workers to support her work in these complex areas.

The post holder was set the additional responsibility of a training role. This has proved very difficult to meet, to date she has only been involved with one course, co-delivered with the Service Manager for the CDS. Other training is however now planned to take place with Clinical Psychology Services in the autumn. To date her primary role has been focussed on direct work with children, young people and their families alongside a consultative role within local services. She has recognised that for a number of young people social skills training in a group situation would best address their needs and related social isolation. Her view is that the capacity to engage in such an approach, which demands the space to commit over time, has been undermined by her wider clinical responsibilities and one-to-one work with children and their families.

This along with other indicators of unmet and growing need suggest that overall there is a clear need to strengthen and develop this valuable position. As a lone worker the post holder's position is very precarious. Various options are suggested:

- Increase the number of specialist workers in this area.
- Knowledge transfer: use the post holder to build workforce capacity by focussing on her training role through which she could increase the awareness of the mental health needs of disabled children in the locality and promote intervention strategies to meet these needs
- Use the post holder to act as a 'consultant' to local staff.

## Case Load Analysis (Sept 2009- June 2010)

(The figures are based on the post holder's records)

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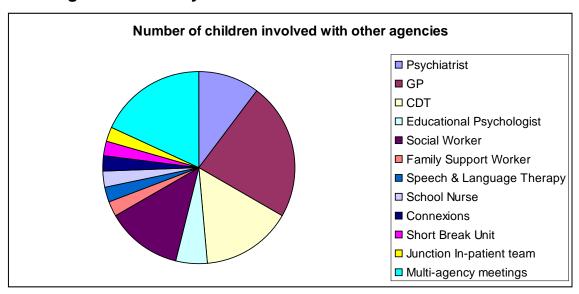
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Case Load		
Case Load of 9	<ul><li>1 child</li><li>8 young people 12+</li></ul>	2 cases identified as due to be closed
Mean Age	■ 13 years	Youngest child = 5,  Oldest Young Person = 16
Gender	<ul><li>7 Boys</li><li>2 Girls</li></ul>	
Legal Status	2 children 'Looked After'	Details of their CA 1989 status not specified
Referral Patterns	<ul><li>Complex Difficulties = 8</li><li>CAMHS = 1</li></ul>	

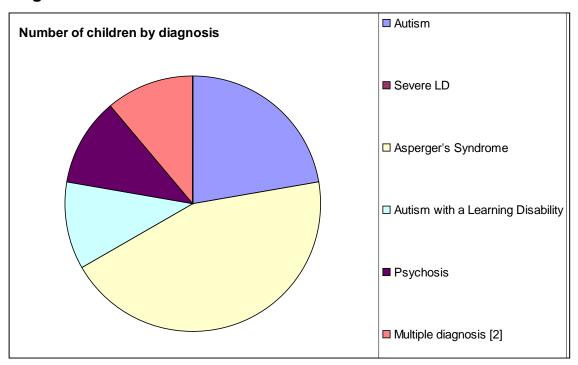
### Other Agencies actively involved



### **Presenting problems**

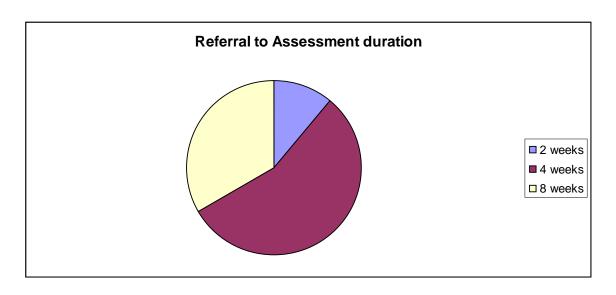
These were variously listed as: General behavioural and conduct problems; self harm; suicidal ideation; emotional distress; low self esteem and acute psychosis

## Diagnosis<sup>1</sup>



#### Previous CAMHS involvement/ referral: 2

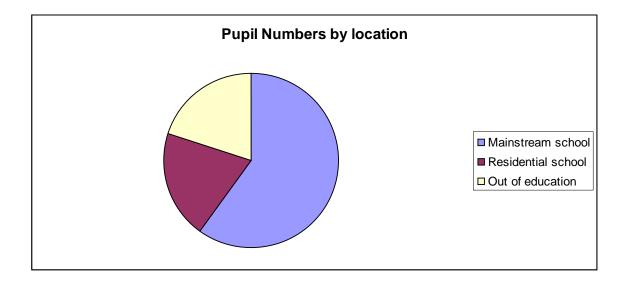
Average length of time between referral and assessment: 4 weeks



<sup>&</sup>lt;sup>1</sup> Some of the children have duel/multiple diagnosis

2 Asperger's Syndrome, OCD, Tourettes Syndrome, Pathological Demand Avoidance and Motor Dis-coordination

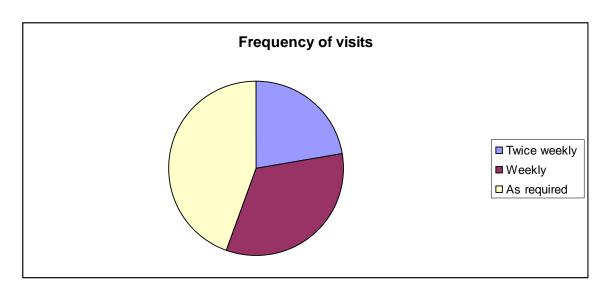
### **Education**



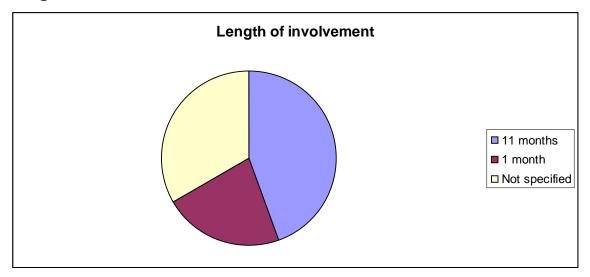
#### **Assessment**

CAF in place = 4

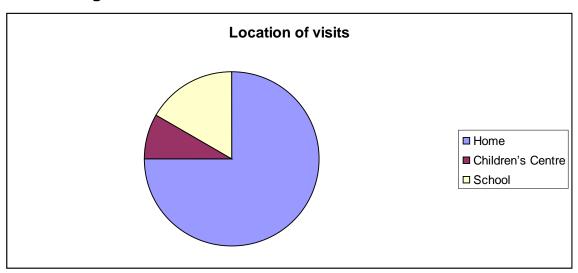
### Frequency of visits



# Length of involvement



## **Visit Settings**



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