

# Contextual Statement



xué  
xué (shway) v. to learn

## Working with Parents/Carers of Children with Learning Difficulties and Disabilities (LDD)



*"I need the chance to develop my private life, my career and my relationships"*

[www.xueureka.co.uk](http://www.xueureka.co.uk)

Over the last decade considerable progress has been made in raising the consciousness, of all those who work with children and young people with difficulties and disabilities, of the need to address and meet their Human Rights. The UK government, criticised as recently as October 2008 by the United Nations Committee on the Rights of the Child, recognises there is still more to do and has raised the issue on their agenda. The Lamb Enquiry, established to report on how parental confidence in the special educational needs (SEN) system can be increased, is a recent example, as is government supported work relating to parent partnerships.

**Importantly, however, very little seems to have been said about the Human Rights of those who most closely support these young people . . . their parents/carers. When they do come into the frame it is usually allied to them being able to meet more effectively the needs of the children rather than related to their right to be autonomous individuals who are able to pursue their own needs and aspirations. This is in spite of our increasing understanding of the centrality of individual wellbeing to personal and social success in all areas of life. It is also surprising in the light of the increasingly person centred approach being required to be used with children and young people.**

The experience of **xué** consultants with parents/carers directly and, in particular in our work within and with Local Authorities and their partners, has confirmed the limited focus that there is on the personal needs of parents/carers. Parents/carers have told us

directly, (see Appendix 1), that caring for a child with disabilities can bring great joy but also presents enormous stresses, strains, complexities and challenges. Many of these relate directly to their caring role but a significant number are the result of the invisibility that they feel as individuals. While the difficulties relating to the former are being increasingly understood our hypothesis is that little attention is being given to the latter.

*"I'd like to develop skills so as to have a stronger presence so I can influence those who can help"*



We also have evidence that as public services become more aware and accountable for helping parents/carers to gain a better understanding of, and access to, services for their children they are likely to become more and more invisible in terms of their own needs. While Children's Trusts are now required to have a Parenting Strategy and there is an increasing recognition of the need to work with the whole family, the focus tends to be on the parents in relation to their children rather than on them as autonomous individuals with their own personal needs. This applies both in the traditional services areas such as SEN as well as in other areas such as social care, health and the justice system, as their work becomes more integrated into the Children's Services arena.

There continues to be important debate about the role of parents/carers and how essential it is for them to participate in all matters concerning their children. These conversations usually centre on matters such as . . . provision of information, access to better joined-up services for their children, 'parenting skills', the importance of short term breaks and finance. This sees the parent/carer primarily as an adjunct to their child and, while clearly highly relevant and important, does little to bolster their confidence or autonomy. It also completely overlooks how important personal and physical wellbeing are for the individual parent/carer if they are to have the necessary confidence and resilience to manage their situation positively and effectively and to become financially self supporting. All of these elements are clearly crucial for the whole family.

**Parents tell us that if they do not feel in control of their lives and are not able to be personally fulfilled, then it is more difficult for them to achieve what they wish for their children.**



*"It's difficult sustaining a positive self-image as parents, as a couple and as a family"*

This can result in feelings of frustration or resentment and, on occasions, parents trying to live their lives through their children. There is also the danger that if parents/carers are not in a position to be able to value their own

independence they will not value it for their children and will reinforce a culture of dependency both on the family and the state. We believe that to make a significant difference to the lives of parents/carers and their children, it is essential to work with parents/carers as clients in their own right. By supporting them to explore their own context, feelings, needs and aspirations, parents/carers are more likely to be able to make the decisions, and access the necessary skills, to achieve their own personal goals. By gaining the insights and skills to be self reflective, self determinant and self sufficient, their lives, as well as those of their children, are likely to be improved for the long as well as short and medium terms. Our experience also tells us that this is likely to mean that their use of universal, targeted and specialist resources will become more appropriate, timely and time limited.

Statistics to date highlight why parents and carers of children with LDD are likely to be high users of a range of services. They show, for example, that there are additional pressures for parents and carers of children with SEN, in particular with regards to family life and marriage. The lack of support for parents had led many reports to comment on the significant risk of family breakdown (Parliamentary hearings on services for disabled children, 2006; Disabled children and Child Poverty, 2007; Aiming high for disabled children: better support for families, 2007) as well as psychological trauma. Some of this trauma is a direct result of psychological and practical issues related to having a child who has learning difficulties or disabilities. However, our work and survey also suggests that the 'disappearance' of the adult as an individual with their own needs and aspirations is likely to have a significant effect. The high prevalence of family breakdown, in its different manifestations, also increases the likelihood of these young people going into care. Disabled children make up 10% of children in care but just 5% of all children nationally (Aiming high for disabled children: Better support for families May 2007).

There are also huge financial implications for many parents and carers which lead to a greater likelihood of both financial and social poverty. Parents and carers whose children



*"I need help to sort out my feelings of inadequacy in failing to meet my child's needs"*

had an Limiting Longstanding Condition (LLSC) were far more likely than average to comment that they could not find a job with the right hours (14 per cent compared with 8 per cent).

Importantly, access to appropriate childcare and the cost of childcare were of greater concern to parents of children with long-term conditions (and in particular to those with children whose condition limited their activities) than to parents of children with no such health problems (Health, Disability, Caring and Employment, 2007). These families are also 4 times more likely to be in debt than those without children with SEN (Disabled Children and Child Poverty, 2007).

While such data, quite rightly, has raised the profile of this key group and led to an increase in service provision, this has tended to be more of the same. For example, there has been a requirement for local authorities to ensure there is access to more short breaks provision for these children and young people, earlier and increased access to specialist services and improved planning for transition to adulthood. However, there is still limited evidence of there being any cognisance of personal implications for parents and carers, particularly of their physical and psychological health, until there is obvious breakdown.

**xué's focus is always on the individual as a whole, taking into account their emotional, psychological, economic, physical, social and spiritual needs as well as those relating to their external and more social environment. Our experience indicates that an individual's self belief will be increased by providing support for them to become more autonomous and insightful. This enables them to be both more in control of all areas of their life and able to meet their own aspirations.**

Our experience suggests that this usually means working at a deep level at some point during the process, looking at areas such as values and beliefs as well as feelings such as powerlessness, resentment, anger, grief, loss and bereavement. This provides a solid foundation for identifying how to meet more tangible needs such as the building of new relationships, developing new interests and skills, opening up new work and leisure opportunities and becoming more independent financially.

In response to what parent/carers have told us **xué** has developed a coaching model for supporting them to identify and better secure their own wellbeing. This model is informed by our own belief that this can only be achieved by addressing all aspects of wellbeing as described above – the social, physical, emotional, psychological, economic and spiritual. The model provides a framework within which parents/carers can be assisted to achieve autonomy and fulfilment and then have access to a means of developing the skills and knowledge they need to move forward.



The starting point, 1:1 coaching, facilitates self reflection and the gaining of the personal insights and understanding necessary to move forward. By using a range of tools, techniques and approaches tailored to the individual's needs, the trained coach enables parents/carers to identify their strengths as well as any self limiting assumptions or other barriers standing in the way of them taking back control of their life. Armed with this information they will then be able to shape a personal programme that addresses their specific needs. This 'support' programme, for example, may include . . . training to develop new skills, opportunities to engage in relevant activities such as work experience, access to a range of specialist information, further coaching or therapeutic support.

The model is cyclical, so recognising that learning is not linear but a constant voyage of discovery that opens new doors as a person's confidence and belief in their ability to succeed is demonstrated and reinforced. In reality the model, therefore, is one that could apply to any individual in whatever circumstances. However, while the central focus is the **Key Aspects of Wellbeing** that lead to personal autonomy and raised aspirations – the social, psychological, economic, physical, emotional and spiritual - it also recognises some of the specific needs of parents/carers. These are identified in the **4 Key Service Areas** that our research indicates

need to be easily available for parents/carers to meet their varying developmental and practical needs. These relate to:

1. Skills development (work and life skills)
2. Information, advice and guidance
3. Experiential opportunities – for example in social or work contexts
4. Therapy - e.g. access to counselling or psychotherapy

In our conversations with parents/carers to date we have been supported by a number of non-maintained and maintained schools that work with children, particularly those with autistic spectrum disorder, as well as by other organisations that operate in the Children's Services context, such as NASS. In addition we have developed close working relationships with a range of other organisations interested in supporting our work at both strategic and operational levels. This includes local authorities, health authorities, Job Centre Plus, the Third Sector, and both further and higher education including Sheffield Hallam University.

We are now keen to use the expertise and experience within our team to work directly with parent/carers as clients, as well as with those who work with them, to demonstrate that by supporting parents/carers to identify and meet their own needs they will become more resilient, autonomous and personally fulfilled. Also we believe that by developing the confidence and skills they need to become less dependent on others, parents/carers will have a greater influence on the lives of all those they come into contact with, including their children. In addition, they are also more likely to be able to influence the shaping of service provision and use these external resources more appropriately.

In order to take this work forward we are currently:

- working directly with some individual parents to test out the coaching model that has been developed
- working with a group of multi-professionals, including voluntary sector providers, who work with parents to inform a training programme that can be rolled out to a wider audience.

Our medium and longer term aim is to establish a business model which will secure this work in the future. We are, therefore, actively seeking funds to support this aim.

**Sue Harrison**

Please see the attached Appendix 1 for a summary of what parents told us in the survey we undertook at the beginning of this year.

Q: Would your life as a parent/carer be made easier if your own needs were understood and developed?

A: *"Yes, I need time and space to develop my own creative pursuits and to have a fulfilling career with some financial security"*