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# Teasing and bullying in children and young people with cleft lip and/or palate: A framework for formulation

Prepared for the Cleft Psychology Special Interest Group  
of the Craniofacial Society for Great Britain and Ireland

*by*

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*February 2010*

## Executive summary

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Orofacial clefts are the most common congenital condition, affecting around one in 650 babies. Clefts can range in severity and outcome after treatment can vary. Others' reactions to a baby's cleft, as well as problems with appearance, hearing and speech, can make a child more vulnerable to teasing or bullying at various life stages. The purpose of this paper is to link a range of theoretical frameworks to a lifespan formulation, and to provide a guide to enhancing clinical intervention where problems with teasing and bullying occur.

The main premise of the approach is that different frameworks come into focus at different stages in the life of the individual. Because of the nature of the condition, wider social and societal factors overlay the psychological impact, alongside the treatment pathway.

These different elements are represented in a series of diagrams in the paper. Each of these provides a different layer of the possible factors to be considered when formulating an intervention.

The main body of the text provides a framework based on life stages. Each life stage considers the key events, alongside the psychosocial issues which need to be considered at that stage; the relevant theoretical frameworks; and the type of intervention that may be appropriate. In order to facilitate the practitioner through the formulation, checklists are provided in the appendices, highlighting the main elements to consider at different life stages.

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# 1. A framework for formulation

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## Aim

We have been asked by the Cleft Psychology Special Interest Group (SIG) of the Craniofacial Society of Great Britain and Ireland to compile a document with regard to people with orofacial clefting (both visible and hidden) who experience teasing and bullying. The purpose of this paper is to link formulation with a range of theoretical frameworks, to produce a model to guide and enhance clinical intervention.

This publication is written primarily for psychologists. Over the last few years, there has been a number of publications, which have discussed teasing in terms of prevalence (Whitney & Smith, 1993; Hunt, 2007), issues relating to perpetrators and victims (Young Minds, 1994), and management (Smith, 2004). We acknowledge these more detailed publications relating to the specific therapeutic approaches and background research and we will refer to them.

While some children experience major problems for prolonged periods, some do not encounter teasing or bullying at all, and others do but only briefly and not necessarily more than children without a cleft. Further research is required to understand the contributing factors (Broder, 2001).

## Background

### Bullying

*The person who said: 'Sticks and stones may make break my bones but words can never hurt me', must have been deaf.* (Anon)

We are looking at teasing and bullying as one and the same thing in that it is the meaning of the event to the person who is teased which is critical. We shall use these terms interchangeably.

Bullying has been defined as 'the systematic abuse of power', which 'repeatedly and deliberately' (Arora, 1996, Smith & Sharp, 1994, p.2) harms others. Bullying may be perpetrated either individually or in groups (Hazler, 1996) and involves a negative interaction in which a dominant individual ('a bully') repeatedly exhibits behaviour intended to cause distress to a less dominant individual ('a victim') (Olweus, 1991; Reid et al., 2004).

Bullying behaviour differs from violence, fighting, play and general conflict along a number of dimensions: lack of reciprocity, repetition, intentionality and power imbalance between perpetrator and victim in order to achieve interpersonal dominance (Crick & Dodge, 1999; Marsh et al., 2001; Olweus, 1978).

### Types of Bullying

- Physical aggression, e.g. hitting.
- Verbal aggression, e.g. name calling or social exclusion.
- Indirect/relational aggression, where a third person or persons are used to harm

the victim, e.g. shunning, rumours, denigration through gossip.

- Cyberbullying – 34 per cent of 12–15 year olds had experienced cyberbullying involving mobile phones, e-mails or online networking sites such as ‘MySpace’ (*The Psychologist*, 2007 Nov; Li, 2006; see DCSF, 2007). The defining feature of cyberbullying is that the victim may not know who is bullying. This, coupled with high-tec graphics and the blurring of boundaries between reality and fantasy, can turn the bullying into a game where the results of the victimisation can be distanced from the perpetrators, allowing for name-calling and threats to be pushed to the extreme. This context has some similarities to the de-individuation process described in the Stanford Prison Experiment where students acting in role as prison guards could be induced to behave in extremely punitive ways (Haney et al., 1973; Haney & Zimbardo, 1998).

Genetic endowment influences which children become victims, bullies and bully-victims (Ball et al., 2008). These types of bullying or teasing all relate to malicious bullying or teasing, when the recipient perceives the behaviour they are experiencing negatively. Victims of bullying, particularly girls, may be at an increased risk of suicidal ideation and self-harm (Kim et al., 2005). Herba et al. (2008) reported a moderating influence of parental internalising disorder and feelings of rejection at home by victims of bullying who reported suicide ideation.

However, there are occasions when teasing, or perhaps banter, is positive, friendly and a form of play. Teasing can also be perceived as a form of endearment (Keltner et al., 2001).

### Who does it involve?

Research conducted on non cleft populations indicated four broad categories of people involved: bullies, victims, bully-victims and bystanders. Not all individuals who are teased or bullied will exhibit a victim profile. Just because there has been an incident of teasing/bullying it should not be assumed that a victim profile will be adopted. Research findings are often discrepant, suggesting the heterogeneity of the different groups. The table opposite summarises typical cognitions, emotions and behaviours displayed by the first three of these groups (Pelegriani, 1999; Toblin et al., 2005; Veenstra et al., 2005).

- **Bystanders**

Bullying is increasingly recognised as a group phenomenon, occurring away from adults but in the presence of peers. While peers may be present in 85–88 per cent of bullying episodes, bystanders seldom (11–19 per cent of the time) intervene to help the victim (Craig & Pepler, 1995, 1997; Eslea et al., 2004) and may even encourage the bully (Atlas & Pepler, 1998; Pepler, 2001; Greene, 2003). Peer group norms, more than adult norms, are all-important during adolescence and these norms may not only reinforce inaction by bystanders but also actively encourage an enthusiastic audience for interpersonal aggression.

Both victim and the bully may view passive onlookers as supportive of the bullying behaviour. Only a minority of children will directly express their disapproval of the bullying behaviour. In this way the child who is being bullied for their visible difference can feel that even their friends have joined the bullying circle and feel betrayed and mistrustful of friendships.



	Bullies	Victims	Bully/Victims
COGNITIONS	Aggression as acceptable means of attaining a goal Advanced theory of mind High self esteem, idealised self view	External locus of control Low self efficacy beliefs Low self-esteem Hostile attributions to peers Suicidal ideation Rejected by home	Low self esteem Hostile attributions to peers
EMOTIONS	Dysregulated  Aggressive Low arousal	Dysregulated Anxious Depressed Poor emotional regulation, quick to cry, less sense of humour	Dysregulated Anxious Depressed Angry  Irritable Higher levels of psychiatric disturbance e.g. ADD, Oppositional/Conduct disorder
BEHAVIOURS	Externalising Hyperactive Poor conduct High impulsivity  Less friendly  Dominating  Regular use of aggression	Passive Submissive Withdrawn Less effective at making and keeping friends Self harm	Impulsive Aggressive Hyperactive More physical in their bullying of others Lower assertiveness and prosocial behaviour  Higher academic failure

- **School**

School norms are closely linked to cultural norms. In Western society, the importance of individualism and causal attribution produce values such as ‘best to mind your own business’ and ‘you get what you deserve’, ‘bullying is harmless and part of growing up’. These values are pervasive, deeply rooted, slow to shift, inhibit helping behaviour and promote a tendency to blame the victim (Freeman & Mims, 2007).

Despite UK legislation that outlaws bullying in schools and requires every school to have an anti-bullying policy, any school can anticipate that there will be incidences of bullying, and staff attitudes and behaviours are key. Bullying can be reduced significantly by appropriate school policy and intervention (Smith & Sharp, 1994). Schools with less bullying are characterised by

positive disciplinary action, high academic standards and strong parental involvement (Xin, 2002).

The Department of Children Schools and Families – Cyberbullying Task Force (2007) document produced in consultation with Childnet outlines their campaign *Laugh at it and you are part of it*.

The school environment should be secure, one that expects appropriate behaviour, promotes tolerance, sensitivity to others' views, and cooperative interactions among its pupils. Olweus (1991,1993) built a school intervention programme around the following key principles:

- warmth, positive interest, involvement from adults;
- explicit rules;
- firm limits to unacceptable behaviour;
- non-hostile, non-physical sanctions;
- authoritative adults;
- active surveillance of pupils, in and out of school, e.g. supervision at breaks; and
- proactive fostering of peer relationships.

### **Gender Differences**

'Girls tend to perpetrate and are victimised by indirect verbal strategies such as group ostracising (often based on status related cliques) and rumour mongering, while boys tend to perpetrate and are victimised by direct strategies such as physical intimidation, name calling and extortion' (Crick & Bigbee, 1998).

## Introduction to the model

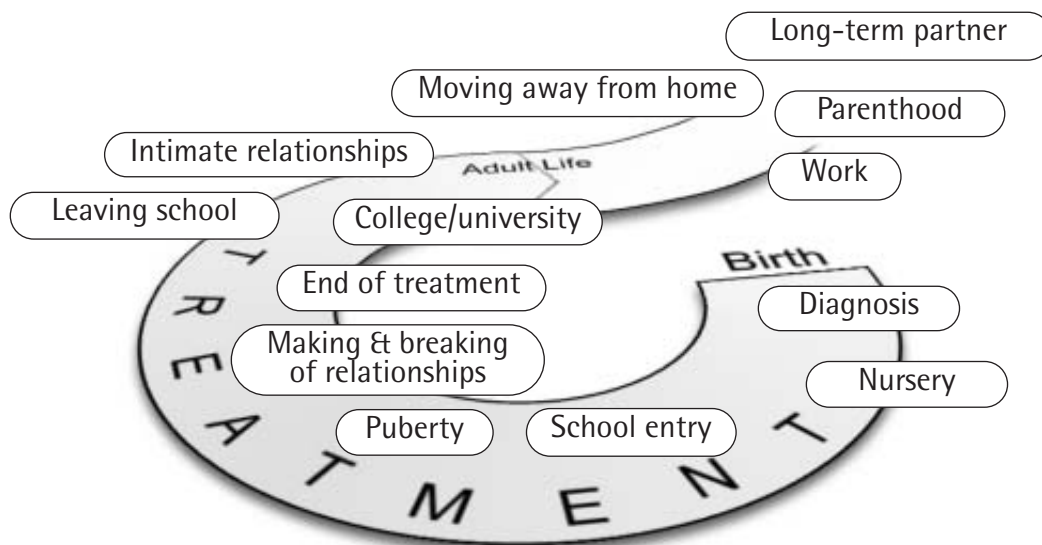
The model summarises the complexity of the phenomenology of teasing and represents a lifeline. It links theoretical frameworks to a context, to guide and enhance clinical assessment and intervention, at audit points and other significant times. The model has five facets, each of which will be discussed separately. A combination of these facets is presented at the end of this section. The model is **developmental**, in that children and young people will become increasingly aware of the impact of others' cognitions, perceptions of and beliefs about them, at different stages of their own cognitive, emotional and moral development. A useful review and analysis of the development of teasing is by Keltner et al. (2001).

### Age and UK cleft-care audit points



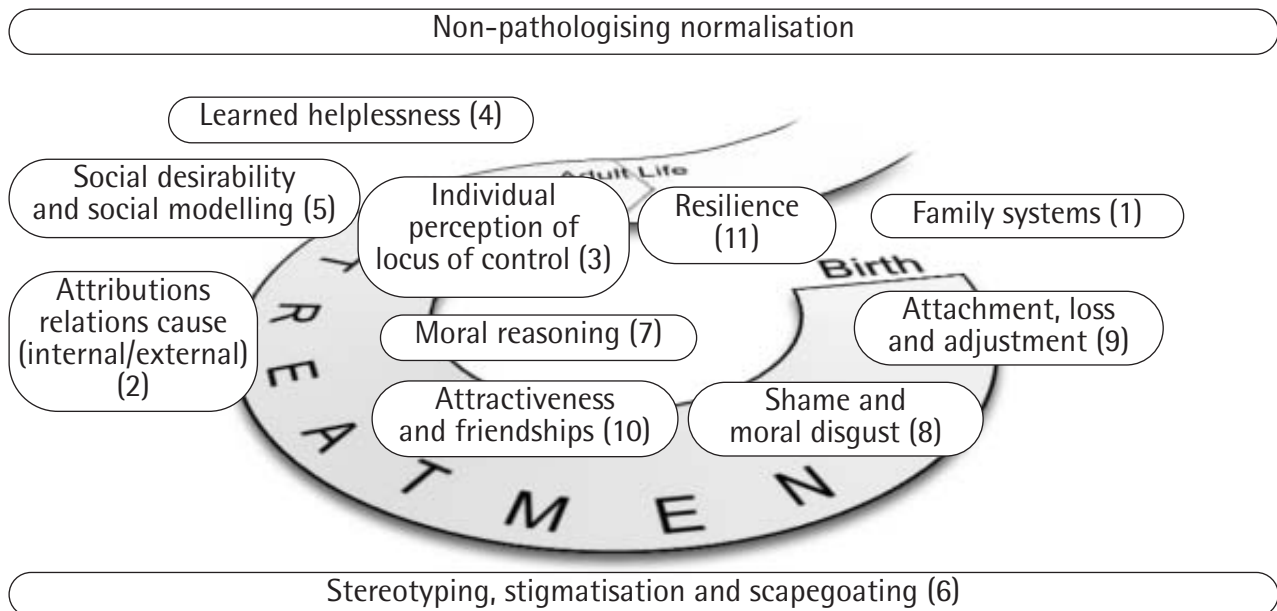
The nationally agreed **audits points** of the Cleft Psychology SIG are times when any issues may be regularly monitored and addressed. Parents and later children with clefts themselves may bring up either anxieties about possible teasing and social relationships in the future or describe present difficulties that they are experiencing.

### Major life events including treatment and tasks related to life stages



Incorporated into the model are **normal developmental events**, which all children will experience. There are also events **which specifically relate to people born with a cleft**, such as treatment episodes and the impact of ending treatment, which may affect self-image and relationships with others. At the various ‘hotspots’ (i.e. time of transition or extra vulnerability) at each of the life stages it is important to determine which, if any, issues are specifically cleft-related and which are phenomena of normal development and how they interact.

### Theoretical issues



The model poses a number of theoretical frameworks (which are not definitive) along the developmental progression or trajectory that could come into focus at different times in children’s development.

The major theoretical frameworks which will be referred to in the following document are summarised here with numerals as per the diagram above.

### General theories

- (1) **Family systems** (Haley & Hoffman, 1967; Minuchin, 1974; Palazzolli et al., 1978)  
How parents respond to their baby’s cleft and, later, how they respond to issues relating to teasing and deal with this may reflect their own experiences, and if, and how, they themselves coped with teasing when they were children. Alliances and the power *structure* within the family, as well as the family’s *strategies* to overcome problems may impact on how parents react to the child with a cleft. There may also be *trans-generational* issues that influence how parents react, and unwittingly they may model such patterns of response and communicate their underlying beliefs to their children. There may be issues relating to diagnosis, the role of grandparents, and family history and the ‘family story’.
- (2) **Attribution theory** (Kelley et al., 1980)  
Parents, and later children, and those in contact with them will continually make attributions about the meaning of what they observe and specifically events relating to the cleft. Attributions may be either internal (dispositional) or external (situational). With reference to coping with teasing it is the meaning and

attribution of success or failure that may be important. For instance, some may attribute good outcomes of their own efforts as result of internal factors, and bad outcomes as due to external factors. Conversely, in others good outcomes may be attributed to external factors and poor outcomes to internal factors. Neither extreme in attributional style (dispositional or situational) is appropriate at all times. Achievement or success may be attributed to effort, ability, level of task difficulty or luck, over which the individual has decreasing control over time. In helping families and children it can be useful to explore these factors.

(3) **Locus of control** (LOC) (Rotter, 1966)

Attributions also relate to issues about *locus of control*. There may be concerns about how much control parents and children have with regard to the medicalisation of cleft management by health services or about the control they have over teasing, in various situations. The extent to which children believe they have the ability to control what happens to them determines how they handle various situations. For instance, if they believe it is up to them (internal LOC) they are more likely to work at achieving a successful outcome, but after failure they lower their expectations of success. It is assumed that perceived locus of control develops from family, culture and past experiences. Consequently, family or trans-generational issues and the social and cultural contexts will be influential.

(4) **Learned helplessness** (Seligman, 1967)

Where children with clefts and their families perceive (rightly or wrongly) they have little or no control over the teasing they experience, despite past efforts, then learned helplessness may occur. For instance, in the case of a school being unable to contain teasing, and where this may continue or even escalate, children may give up trying to take any control or do anything when teasing occurs. Similarly parents may feel stripped of their agency to get the school to manage things better, and feel inadequate in supporting their child's efforts.

(5) **Social desirability and social modelling** (Bandura, 1986)

Families and, later, children with a cleft will both experience various reactions to the cleft including teasing which may reflect the bully's model of what is socially desirable. Parents and children may interpret these reactions in a way that affects their self-worth, or self-image. As parents of infants or younger children display their response to teasing or negative comments either through their actions or words, so their child with the cleft may learn how to respond on the basis of the social model displayed by their parents. In addition, Bandura (1997) suggests that perpetrators may morally disengage when they act unkindly. This model may, in part, explain the action of bystanders when teasing and bullying occur.

(6) **Stereotyping, stigmatisation and scapegoating** (Goffman, 1963)

*'The phenomenon whereby an individual with an attribute is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity.'* (Goffman, 1963)

The relevance of the concept of stigma to those with cleft may be central, and theoretically relates to (2) and (3) above. Falk (2001) has added that there is a value in stigmatising as it provides 'group solidarity by delineating outsiders from insiders'. These issues may be implicit in the way schools or perhaps parents deal with teasing of a child with a cleft.

(7) **Moral reasoning** (Kohlberg, 1984)

The issues relating to both social desirability and stigmatisation are relevant to Kohlberg's six stages of moral development:

- Pre-conventional: Obedience and punishment orientation  
Self-interest orientation
- Conventional: Interpersonal accord and conformity  
Authority and social-order maintenance
- Post-conventional: Social contract orientation  
Universal ethical principles

Children are essentially at the pre-conventional level, although adults may also be at this level of reasoning. Kohlberg (1984) proposes that adolescents and adults may move through the levels in order without skipping a level. In terms of dealing with bullying, understanding the moral stage of the perpetrator will help in managing the problem.

(8) **Shame and moral disgust**

Views on the consequences of being the target of stigma have changed over the past decades; rather than assuming the experience of being stigmatised leads to negative consequences to the personality, researchers now assume that people experience a set of psychological predicaments which they cope with using the same coping strategies as those used by non-stigmatised people when they are confronted with psychological challenges such as threats to self esteem (Crocker & Major, 1998).

At the moment of trauma, or loss of feeling secure, there will be feelings, thoughts and sensory experiences occurring all together in the situation, which has become dangerous or distressing. If appropriate support is promptly reinstated (the child is physically held, is able to tell her parent and recovers equanimity), the situation can run its course. When lack of support is perpetuated during development this can result in shame, humiliation and loss of a sense of well-being. Such experiences occur in every child's life to some degree. These incidents are likely to have greater developmental impact the more intense the experience and the younger the person who suffers from them (see, for example, Parlett & Hemming, 2002). Children who have a cleft are more likely to be subjected to these incidents for a variety of reasons, including surgical interventions and the reactions of other people to their diagnosis, possibly including family responses.

Current research on 'other – condemning' in the process of negative stereotyping looks at underlying emotions such as anger, contempt and disgust (Rozin et al., 1999; Haidt, 2003). Sociomoral disgust leads people to strip others of their dignity. While it can be an adaptive emotion, e.g. protecting physical well-being (by avoiding contaminated food) social moral disgust recruited into moral and symbolic contexts. Social psychological thinking links prejudice and bigotry to high levels of disgust, leading to hostility towards and ostracism of people classed as different from the norm (Taylor, 2007).

The bully can often use words and gestures which imply disgust and these can be difficult to endure, leading to feelings of shame in the victim. When people experience their physical bodies as in some way unattractive, undesirable and a source of a 'shamed self', they are at risk of psychological distress and disorders

(Gilbert & Miles, 2002); particularly in those with visible difference (Thompson & Kent, 2001).

### **Theories related to developmental stages**

(9) **Attachment, loss and adjustment** (Bowlby, 1969; Brazelton & Sparrow, 2007)

In their book *Touchpoints*, Brazelton and Sparrow describes 'cycles' of early bonding, where both the infant and the mother are locked into reciprocally stimulating behaviours, which provide the necessary input to the infant's developing brain, e.g. at around three to four months there is a 'hatching' when auditory and visual systems develop rapidly and the infant is beginning to have a greater ability to perceive a wider range environmental stimulation. This is best achieved in a secure attachment. As cleft operations usually occur at three and six months, this has the potential implication for this neurodevelopmental relationship as the baby's face is changing markedly. Murray et al. (2007) imply timing of lip repair has an effect on cognitive development at 18 months. The birth of a facially different child, even if predicted by antenatal scans, is a shock to the family system. Parents may experience a range of emotions including shock, grief, anxiety, confusion, depression, hurt, loss, inadequacy, disappointment, stigmatisation and resentment (Bull & Rumsey, 1988; Lansdown, 1981). Parents need to mourn the loss of the expected perfect child, the idea of what might have been (Solnit & Stark, 1982; Tomko, 1983) and deal with initial ambivalence towards the 'imperfect' baby they have, (Fajardo, 1987). Mothers may even experience the baby as a defective part of herself (Kohut, 1971). Facial difference can be a serious challenge to parents' feelings of self-worth and competence. A cleft is not easily hidden and is usually the only part on view when a newborn baby is taken out in public. Parents may occupy an uneasy position as buffer between their child and the outside world, seeking to protect their child from potential rejection, while having to confront their own feelings about facial difference. Extended family and friends are an important source of emotional and practical support to new parents and this can facilitate parental adjustment (Bradbury & Hewison, 1994). If the network of extended family and friends is able to contain its own anxieties and ambivalent feelings, the process of attachment between parents and baby may be enhanced (Fonagy et al., 1991; Fonagy et al., 2004) as it provides a model of coping that promotes parental resilience.

(10) **Attractiveness and friendships**

Young children tend to prefer children who are attractive as potential friends and will attribute pro-social behaviours to them (Dion, 1973). Boyatzis et al. (1998) have also found that popularity is related to attractiveness. Consequently, being dissimilar in a way that may be seen as less physically attractive may affect children with clefts in their attempts to make friends. Failure to form friendships can lead to later social deficits, which are hard to remedy (Rubin et al., 1999). Consequently, if having a cleft negatively affects the formation of friendships, then a child with a cleft may carry these problems into their future. Peers may attribute negative meaning to physical difference and scarring, etc., so children with clefts may be stigmatised.

(11) **Resilience**

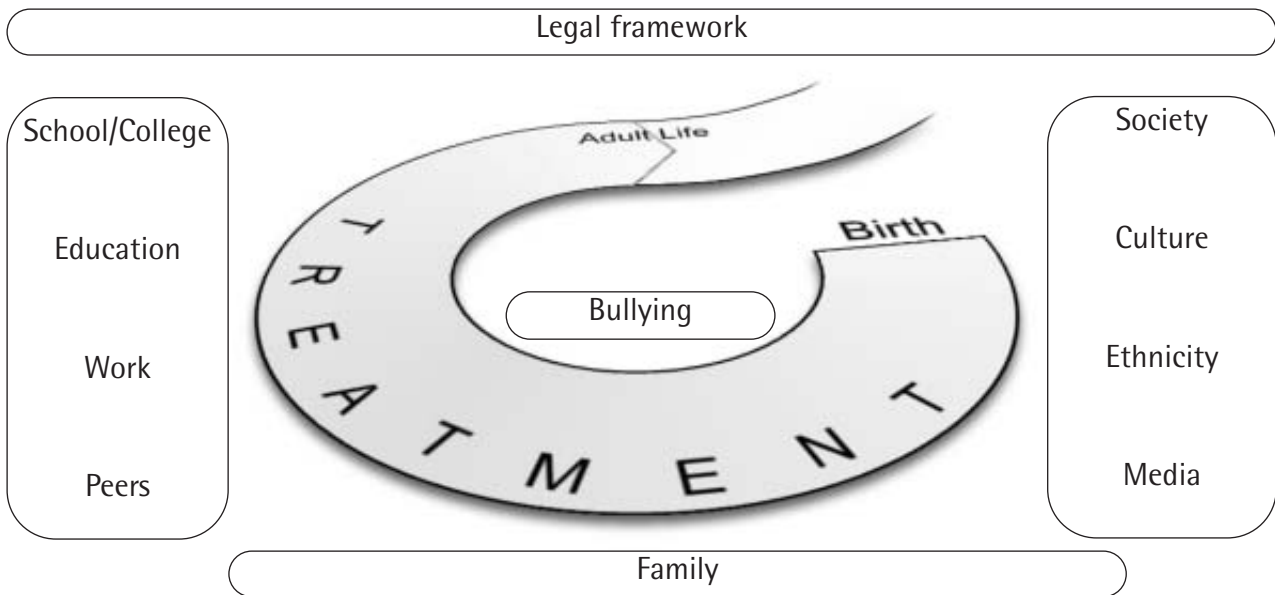
Resilience can be defined as successful adaptation to significant adversity, using protective factors to respond to change (Beardslee et al., 1998). It refers to a multi-dimensional, dynamic process with two critical conditions: 1) exposure to significant threat or severe adversity; and 2) the achievement of positive adaptation despite major assaults on the developmental process (Haggarty et al., 1994). There have been criticisms of the rigour of theory and research in this area, focused on ambiguities in definitions, operationalisations, instability of construct, difficulties of measurement, heterogeneity in risk experienced and competence of those judged as resilient; indeed the scientific value of the overall construct has been questioned. Has ‘resilience’ like ‘empowerment’ become a fashionable slogan with ‘a ring of virtue and unquestioned morality’? (Sarason & Sarason, 1993). Luthar et al. (2000) have written an interesting and useful appraisal of the area in which they conclude that resilience is a useful construct and ‘the continuation of scientific work in this area is of substantial value’, with their caveat that scientific rigour and precision must be improved. Resilience should not be used interchangeably with positive outcomes in general; the term should be reserved for the *process* of competence in adversity, not as a personality trait, and it is important to be specific by using terms such as ‘emotional resilience’, ‘behavioural resilience’ and ‘educational resilience’.

Protective factors – individual, family and community – affecting resilience are described in a later section of this document, under Early Adolescence. In the literature on cleft lip and palate, resilience is considered in a generalised way in the context of moving away from a pathologising, deficit model to develop a new craniofacial social science model based on health and success (Strauss, 2001; Broder, 2001). There is great scope for research on interventions to enhance individual emotional and behavioural resilience for victims of bullying.

A number of these issues may recur at each phase in development, particularly if they have not been resolved at an earlier stage. However, the majority of problems presenting in this population are not mental health issues, and the model is therefore **normalising**.



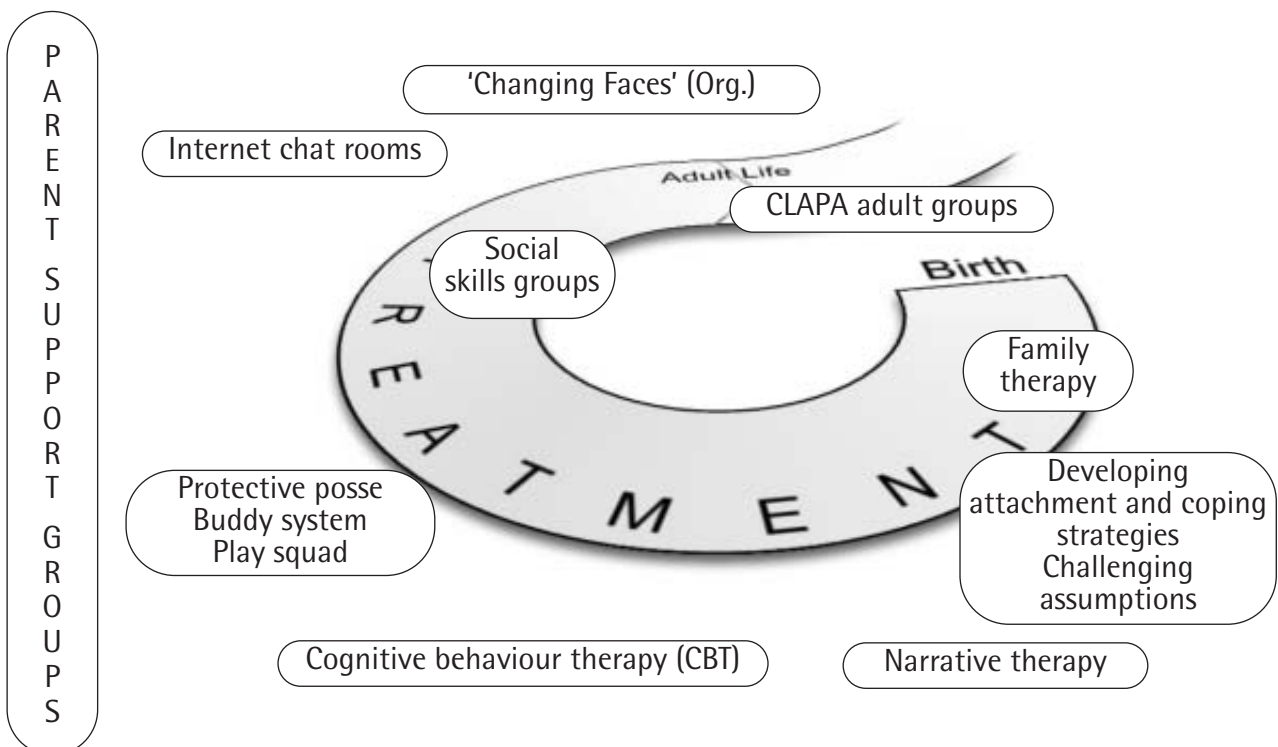
## Context



Teasing and bullying need to be seen within legal, social, educational and family frameworks. Fiddy and Hamilton (2004) provide a useful guide when parents need to know about the legal framework. Children will meet different beliefs and attitudes towards beauty from a very early age, reflecting society's and the media's promotion of perfection. The salience of appearance may differ in different families and in different cultures.

These contexts can be protective but can also contribute to the problem. Where teasing occurs at home it may be considered emotional abuse. Positive sibling relationships may moderate stressful events (Gass et al., 2007). The importance of cognitive difficulties may be of greater concern to some families than to others where physical appearance and beauty are seen as critical.

## Interventions



Support from the Cleft Lip and Palate Association (CLAPA) or Changing Faces as well as advice on legal issues from the Children's Law Society can augment therapeutic interventions.

Equally there are internet chat rooms, and internet advice on teasing and bullying (e.g. Kidscape) which young people may discover and use for themselves.

Functional analysis will indicate which are cleft-related and which are non-cleft-related issues, and the usual range of therapeutic interventions can be considered.

- **Cognitive behaviour therapy** (CBT) focuses on the relationship between the following: what we think, how we feel and what we do. The following list of underpinning statements come from a long line of research which is well described in Paul Stallard's book *Think Good – Feel Good* (2002).
  - Emotional responses can become conditioned to specific events.
  - Behaviour is affected by antecedents and consequences.
  - Consequences that increase the likelihood of a behaviour are reinforcers.
  - Altering antecedents and consequences can result in changes in behaviour.
  - Behaviour is influenced by cognitive events and processes.
  - Changing cognitive processes can lead to changes in behaviour.
  - Emotional affect is influenced by cognitions.
  - Irrational beliefs/schemas or negative cognitions are associated with negative affect.
  - Altering cognitive processes can lead to changes in affect.
  - Maladaptive cognitive schemas develop during childhood and may be associated with parenting styles.
- The schema-focused work of Young (2002) proposed that maladaptive cognitive schemas that are formed during childhood lead to self-defeating patterns of behaviour which are repeated through life. These maladaptive schemas are associated with certain parenting styles and they develop if the basic emotional needs of the child are not met. Evidence to support the presence of 15 primary schemas has been reported (Schmidt et al., 1995). Exploring the cognitive schemata of young people with a cleft and dealing with issues of learned helplessness, shame, loss of control, and possible misperceived intent can be useful (Stallard, 2002).
- **Family therapy** (Hoffman, 1981).

Where parents are directly or indirectly teasing/bullying their child or are failing to support them due to their own history of being bullied, then a systemic family approach may be needed. Parental experiences may perpetuate unhelpful coping skills. It can be useful to explore the alliances and power structures within the family, consider trans-generational issues which are 'passed on' to the next generation (e.g. the role of illness or the importance of beauty), through the drawing up family trees and the use of circular questioning in order to help the family function in a more supportive and positive manner.
- **Social interaction skills groups** (Kapp-Simon & Simon, 1991; Kish and Lansdown, 2000). These are described later in the document.

- **Narrative therapy** (White, M. 2005) and **Life Story Work** (Carroll, 1998, p 105)  
Narrative approaches see identity as largely shaped by narratives or stories, both personally and culturally. Identity problems can signify problem-saturated stories that dominate at the expense of preferred, alternative stories.
- **Work with schools** may include establishing a protective posse or buddy system as well as looking at the ethos towards teasing in a particular school and/or classroom.

## 2. Birth and early infancy

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### Antenatal Diagnosis

#### Key issues and events

- Prior to birth the expectations of parents can lay the foundations for later interactional patterns during early attachment between the child and the parents. It is important to consider whether or not the cleft was diagnosed antenatally, how the news was broken, the extent of the clefting and the impact therefore on feeding, and whether the cleft occurs in isolation or together with other physical differences, possibly in the context of a known genetic syndrome.
- Fifty per cent or more of babies with cleft lip and palate may be detected in prenatal scanning at 20 weeks with good scanning equipment and training. However, very few isolated cleft palates are detected because of the difficulty of seeing inside the mouth (Grandjcan et al., 1999). Detection during pregnancy can help tremendously with preparation while the parents are calm and have time to assimilate information. A surprise at the time of birth clearly leads to a lot of information having to be given in a short space of time and in the context of a very tired mother with possible post partum blues. However, early detection can lead to its own difficulties. The consultant neonatologist who makes the diagnosis will be likely to say something to the effect that it is likely to be an isolated problem, but that further complications cannot be ruled out. At this point, the parents can have no sense of containment about the scale of the problem their baby will have and will likely be beset by ‘what if’ type thoughts about other abnormalities and possible learning difficulties. They may momentarily discuss termination and then after birth, when they have a healthy much-loved child, spend years feeling guilty. Other parents may become fiercely protective, and come to the defence of their ‘special’ child no matter what. Others may take a religious view that God has given them this gift and chosen them to bring this child with distinctive looks into this world.

#### Primary psychological interventions

##### ■ Attachment difficulties

Integration of the Clinical Psychologist into the antenatal care pathway is important where therapy is indicated for parents who are struggling to attach to their baby and to let go of the hoped-for perfect baby. Support following a positive scan that indicates an oro-facial cleft is given by the clinical nurse specialist who remains involved through further diagnostic scanning. Referral to the clinical psychologist follows this process where necessary and requires the psychologist to work closely with this nurse and other members of staff in the antenatal care team. The areas to cover in clinical assessment and therapy would include:

- the parent’s perception of the unborn child;
- predictable concerns relating to post-birth issues, e.g. ‘will I be able to feed my child?’, self-blame, e.g. ‘did I eat something harmful?’;
- exploration of possible critical views of the extended family, e.g. ‘it is your fault you have got a handicapped child’;

- intergenerational transmission of attachment difficulties;
- discussion of fears of other neurological or medical difficulties; and
- discussion of termination issues (if relevant).

Intervention may be at the follow-up support level (e.g. through a specific procedure), parent infant therapy, couples therapy, individual therapy (e.g. for depression), assessment of specific mental health problems and referral to adult mental health.

## Birth

### Key issues and events

- The approach to birth may be clouded by trepidation rather than enthusiasm as parents wait to meet their child. In general, the birth of a child with a cleft lip and or palate is received well and with a certain relief if the isolated nature of the cleft is confirmed. However, although most cleft lips (with or without palate) are isolated, without further complications, the story is different for isolated cleft palates (that is without any lip involvement). The latter are more commonly associated with additional anomalies and can be just one feature of a broader syndromic pattern (as in 22q11 deletion syndrome). Parents who discover difficult news after birth and then hear an unfolding catalogue of associated problems require supportive intervention and good access to information as and when they need it.
- Parents may not react in the same way to their child with a cleft. When a supportive couple can accept their different reactions, discussion together may help the process of bonding with their child. An extended family which becomes part of the supportive discussion can take on the new information, be non-judgmental and provide practical support when needed and can also facilitate the bonding process. Problems may occur when there is disagreement on approaches, arguments over each other's reactions to the child, feelings of shame, blame or criticism. Interventions to encourage supportive communication and minimise misinformation at this stage go a long way to helping to optimise the initial bonding process.

### Primary psychological interventions

#### ■ Post natal attachment and post partum blues

Once the baby arrives there may be a clearer role for the clinical psychologist in supporting good attachment. The midwife will have scored the Edinburgh Depression Scale that the mother has filled out. A score above 15 is in the clinical range and the GP will have been informed that there are problems. A score above 21 will have been acted-on to alert services to the mother's mental health needs. The clinical psychologist on the cleft team may be involved in the assessment and support of mothers with high Edinburgh Depression scores. A CBT approach to help with depression and anxiety and problem solving approaches to helping with feelings of being overwhelmed will be helpful.

The quality of the maternal infant attachment may be assessed using techniques such as the following:

- **The Brazelton Neonatal Assessment Scale** (Brazelton & Nugent, 1995) is useful for infants up to three months and focuses on the largely instinctive and innate drives that define the behaviour of the infant.
- **Video-based feedback work** (Sameroff et al., 2004)  
Video-based feedback work such as video interactive guidance is helpful. There is a good evidence base to show that video feedback for parents to show them how they are handling and communicating to their infant provides them with here and now information about their relationship with their child. This method becomes a positive, objective and non-judgmental way for parents to enhance their relationship with their infant. Parents are encouraged to explore how their own infant relationship with their parents impacts on their current functioning. Helping a parent to appreciate that an infant has a mind separate from their own (mentalisation and promoting reflective function) is an important basis for good attachment.
- **The CARE-Index** (Crittenden, 2000)  
The 0–18 month scale looks at parental responsiveness to the infant’s vocal and visual cues. It takes into account that the infant’s individual characteristics vary and therefore the responses that the parents give need to be in tune with their child. There is a toddler scale for slightly older children. This work draws on Crittenden’s dynamic maturational model of attachment which sets a good framework for understanding the development of resiliency in the older child based on good early attachment foundations.

There is a good evidence base that positive early attachment leads to good outcomes for young people in their psychological adjustment. The National Service Framework for Children, Young People and Maternity Services (Children’s DoH, 2004) acknowledges this and supports the preventative model in the NHS.

## Post-birth

### Key issues and events

- Parents also react differently to the anticipation of the first repair surgery to the lip at three months. Some have greeted their baby’s arrival with all the pent up misgivings they have been harbouring for months and carry the sense of not having the perfect baby they wanted long into their child’s infancy. They feel left somehow personally lacking or to blame. They defend themselves against difficult feelings about the cleft by willing themselves through the first three months, needing only to wait until the problem is ‘fixed’. Early photos may not be taken or not displayed. Parents may choose to become isolated and feel no pleasure in taking their baby out in the pram, fearing negative comment. Relief that the operation is over may be marred by the reality of the visible scar. News that there may be hearing problems and that there may be speech problems down the line and their child may require further surgery will not be well received, since it is still their view that their child should have been perfect and can somehow be fixed. These parents are attached to their baby in a conditional kind

of way and still have to mourn the loss of the hoped-for perfect baby. As this baby grows up it may hear powerful comments like 'I couldn't take you out', 'I just cried when I saw you', 'we just didn't take any photos when you were born, but look at this lovely one of you at four months'. This child will likely think to itself 'there was something wrong with me', 'something about me was unlovable'. What is important in terms of the future is how this may affect their child's sense of self worth and ability to cope with teasing.

It is common, on the other hand, for well attached parents to fall so in love with their child's wide smile, that they dread the change that the 'correction' will bring and feel guilty on seeing their child after surgery because it was they who elected to change their baby's beautiful face. Parents may not recognise their baby after surgery, and feel they need to re-attach. These reactions, while powerful, are usually transitory.

At three months, parents and baby are getting to know each other better, and may have established a better sleeping pattern. It is into this context that surgery to the lip is performed. Feeding has hopefully become established, and as most cleft babies cannot form a complete airtight seal for suckling, the mother is using a breast pump or the right teats for the baby's special bottle. Parents are just sorting out their new roles and are feeling more relaxed about their daily routines. The baby has learned to smile and this reciprocal communication is rewarding all-round. Following surgery and while on the ward, the reciprocal communication may be disrupted, usual smiles and cuddles are more difficult. New parents who want to do everything 'right' with their child, suddenly do not have a way of responding to their child's needs, furthermore they are beset with feelings of guilt for having put their child through this risk and pain.

This period around three months is when a spurt in brain development in the visual and auditory cortex areas means that the baby can orientate outwards, to sights across the room and more distant sounds. This has been called a 'hatching', which acknowledges the early period of infancy as being focused on the attachment figure and then turning more to the outside world. Winnicott's (1988) notion of 'mirror roles' between the baby and the primary attachment figure is important; the baby learns about itself through interactive experiences with primary care givers. If the parent looks at the baby with disgust or sadness or anxiety the baby will internalise these feelings as part of him or herself. This theoretical work now has a basis in neurobiological research indicating that there are parts of the baby's brain, 'mirror neurones', which develop to form the early neuronal precursors necessary for gaining a sense of self (Rizzolatti & Sinigaglia, 2008).

At six to nine months the beginnings of stranger awareness start, where the baby who has been happy to be passed around, begins to react with anxiety to anyone other than its closest caregivers. It is into this context that palate surgery for the baby takes place. There is a brief period in which there is a disturbance and readjustment in the bonding process, with the baby separated from its parents in a strange environment full of unusual lighting, smells and sounds and exposure to pain.

Brazelton and Sparrow (2007) have described the reciprocal attachment patterns

that organise brain development and behaviour during the first months and years of life. The concept of ‘touchpoints’ is a useful term to describe the forces for change that drive a child’s development. They are driven by the predictable sequences of early brain development, especially in the first three years of life where there is rapid neuronal growth and also programmed cell death. Brazelton describes a process just before a surge of rapid growth in any line of development, where behaviour seems to regress and recently learned behaviours become disorganised or briefly lost. These predictable periods of regression may lead parents of a child with a cleft to become anxious that there may be additional difficulties, which are cleft-related. Brazelton’s work provides a useful framework for understanding parental worries about the cleft lip and palate, e.g. problems with feeding and concerns about surgery. This normalises the ups and downs in development, and may prevent parents forming negative attributions about their child or becoming chronically overprotective, both of which could eventually affect a child’s self-image and their vulnerability to teasing.

### **Primary psychological interventions**

- Where there are early signs of rejection, sensitive intervention by a specialist nurse with back-up from a clinical psychologist should be available to help with attachment problems. Early signs of over-protectiveness or emphasis on the specialness of the child are likely to be less problematic but may also lead to distorted care giving and require some intervention.
- The Solihull Approach (e.g. Douglas, 2007) may be a useful framework of care provision where there are difficulties. This is an evidenced-based approach often delivered by health visitors and allied professionals aimed principally at 0–5-year-olds. Feeding, sleeping, toileting and behaviour problems are the primary presenting difficulties that are worked with using a theoretical approach that draws on three central ideas: containment within the relationship, reciprocity and behaviour modification.
- At three months when the cleft lip is repaired, post partum blues have subsided and if not, postnatal depression needs to be assessed. An irritable, difficult baby appears to increase the risk of depression in a new mother and the stress of feeding difficulties, hospital visits and surgery in this period is likely to produce both an irritable baby and a worried mother. It is likely that the mother, bracing herself for her baby’s operation, is likely to keep her feelings to herself. Fatigue, loss of appetite and insomnia can all be confused with recovery from labour combined perhaps with difficult or bad news. When these symptoms are added to persistent anxiety, irritability, emotional instability, crying and indifference to a new baby, postnatal depression needs to be taken seriously. This low mood is often accompanied by an over concern about an infant’s well-being, with worries that she, the mother, will harm the child or someone else will. Handing over the baby to the anaesthetist and surgeon is likely to be a huge ordeal for a depressed mother and supportive care through this process and follow-up will help.



## GUIDANCE BOX – Birth and early infancy

Consider

- Impact of diagnosis of cleft
- Attachment and bonding
- Parental mental health
- Parental relationship
- Parental knowledge of cleft
- Assumptions of future difficulties
- Impact of treatment
- Impact of any feeding difficulties
- Three-month audit

(See Appendix 1 for checklist)

### 3. Pre-school and nursery/school entry

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#### Key issues and events

##### ■ **Nursery/school entry**

Entry into preschool/nursery is a very important transition for any child both in terms of their cognitive development and education, and also with regard to the development of new social skills and early independence from the protective shield of their parents. Parents of children with clefts may find this stage particularly difficult. Cole and Cole (2001) describe this as a time when children's thinking 'wobbles back and forth between logic and magic, insight and ignorance, the reasoned and the unreasonable'. Events may be interpreted differently depending on the age and developmental level of any child. At this time parents begin to relinquish their control of their child and his/her environment for short but increasingly longer periods during the day.

- Nursery staff or teachers while having wide experience of children's development, may have little knowledge of children with clefts, and make assumptions that the child's cleft is the cause of cognitive, behavioural and social problems. Hearing difficulties associated with some clefts can lead to poor understanding and may be misinterpreted as poor attention, wilfulness or cognitive impairment.

##### ■ **Separation/attachment**

When parents take their child to nursery/school, and leave them for the first time, any problems related to separation and attachment (Bowlby, 1969), which have not been discussed or dealt with before, may come to the fore. A child's distress and crying will always upset parents, and it is possible that problems at this stage do not necessarily relate to the cleft *per se* although parents may fear this to be case. There may also be issues relating to parents' own experiences of going to school, which may be projected on to their beliefs of their child's experience. Parents may have concerns about their child with a cleft being seen as normal and fitting in, although parents may fear this generally. Emphasising the normalcy of these parents' fears can be helpful.

##### ■ **Social skills and empathy**

Socially children are learning to become integrated into a wider group, but also becoming aware of their own uniqueness. For the first time a child may be exposed to a number of children who are unknown as a group. Play with other children is a major source of learning and the basis of social development at this stage, and for children with clefts, it is the moment when the reality of parents' fears, anxieties and expectations about the social impact of their cleft is tested out. From two years onwards Dunn (1988) has found that children may tease rather than be physically aggressive. Three-year-olds can recognise emotions in others well, and those between three and four will comfort distressed friends more than those they do not have a relationship with. From two onwards they develop and use strategies to keep their emotions under control (closing eyes/covering ears). At this early age, children know they need to conform to be part of the group, i.e. importance of not being better than others (Leoni, 1964). Those preschool children who display

social emotional competence are liked more than those who do not.

### ■ **New friendships**

Up to and during this phase of a child's life, parents will have been choosing their children's friends, and although they will continue to be involved in the development of friendship skills, children will now begin choosing their friends and be exposed to acceptance and rejection by peers on their own.

### ■ **Self-awareness**

Children's self-awareness and identity may heighten at nursery/school entry through learning new roles in relation to peers, where both nurturance and conflict are necessary aspects of development. At the same time children with clefts may encounter questioning about and pointing at scarring, and other children may also find the child's speech sounds different and have difficulty in understanding him/her and comment on this. This experience and their ability to deal with it emotionally and cognitively will impact on their self-awareness and sense of agency. This may be the first time the child has to encounter this alone. Inadequacy in coping with these experiences may lead to a child with a cleft becoming socially excluded. Equally the child may appear to exclude others because he/she fails to respond through not hearing. These incidents may lead to negative attributions about a child, which can begin to impact on the child's sense of self-worth. Biederman et al.'s (1995) research suggests that in children between two and six, social anxiety was more likely to be found in children who tended to be behaviourally inhibited. However, Collett and Speltz (2006) have only found limited support for the supposition that young children with clefts are more at risk of social-emotional problems than unaffected peers. These authors suggest that early assessment can predict later psychosocial difficulties.

## **Primary psychological interventions**

### ■ **Supporting parents**

Helping to normalise parents' apprehension for their child when they separate for a few hours each day can be useful, as well as reassuring them that teasing and bullying are not inevitable. In addition, if issues relating to separation and attachment have not been addressed, then this can be the time to do so.

### ■ **Choosing and informing schools**

Giving parents the opportunity to discuss the issues in selecting a nursery or primary school and getting the ecology right for their child, and encouraging them to talk to staff in preparation for any issues they may have, can be helpful, as well as supporting them to inform schools in advance that time out of nursery/school for medical appointments may occur and how this may impact on learning. Issues relating to potential pointing and questions, and how to deal with this, can also be discussed, as well as preparing schools for a child who has unusual speech and some hearing difficulties. Such discussions may clarify ambiguities around the child's personality and false attributions of causality due to the cleft.

### ■ **Developmental assessment and statementing**

The above issues underline the usefulness of a three-year developmental check. This can either reassure families that their child is developing normally, or alert

them to concerns and support them in getting help for their child. This may involve formally instituting the process of getting a Statement of Special Educational Needs.

#### ■ **Behavioural interventions**

The five-year audit, which is standard for the cleft service, can be used as a way of assessing children's ability to make and maintain friends, and encourage good friendship skills. It is, therefore, strongly recommended that this is done as an interview with adequate time allocated, rather than within the confines of time requirements of other audit procedure in the clinic. Screening for anxiety relating to perceived competence and social acceptance (Harter & Pike, 1984), and seeking to reassure children may preclude future difficulties. Help with behaviour problems is important at this stage, as significantly difficult behaviour, particularly in boys, is predictive of pre-adolescent social problems and psychopathology (Messman et al., 2001) which may compound any issues relating to cleft. Dealing with anxieties or phobias relating to needles and hospital procedures may be needed, and reassuring children that coming to hospital should not necessarily be related to illness or death as is so often shown on television.

#### ■ **Systemic factors within the family**

If parent's experienced difficulties going to school it can be helpful to discuss this and how it may affect their handling of their child's anxiety about going to school.

## GUIDANCE BOX – Pre-school and nursery/school entry

### Consider

- What information about clefts has been given to nursery staff or teachers, particularly about fluctuating hearing
- Child's social and emotional competence
- Child's explanation of cleft
- Child's level of hearing
- Child's quality of speech
- Developmental check
- 18/24 month audit
- Early management of behaviour problems, particularly in boys
- Parental experience of school and teasing/bullying
- Family relationships and ethos
- Parental mental health
- Concerns about teasing

(See Appendix 2 for checklist)

## 4. Junior school and middle childhood

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### Key issues and events

#### ■ **Ongoing treatment**

Children with clefts may continue to be involved in the medical appointments and potential interventions during this time, and there may be a slow build-up to further surgery and future orthodontics. Although many know surprisingly little about their condition, fear of painful surgery, and a loss of agency and the medicalisation of their problems can cause widespread difficulties. In addition, as treatment and the associated professionals involved with service delivery change, the child will need to meet new members of the cleft team, and they may begin to become aware that their cleft and associated interventions are ongoing and will continue to adulthood. This may lead to feelings of difference, and powerlessness, which will contribute to create a negative self-image, and changed identity.

#### ■ **Cognitive development and education**

Prowess in school will relate to some extent to both achievement and physical identity, areas where children with clefts may be vulnerable. Although the presence of an isolated cleft lip and palate may not relate to cognitive ability, any cognitive difficulties or educational under-achievement emerging at this time may be attributed to the cleft whether or not this is the case. However, hearing difficulties with directly or indirectly associated speech and language problems (related or unrelated to the cleft) may affect children's attention and understanding in class. There may also be fluctuating hearing difficulties.

#### ■ **Group identity and play**

Between six and 12 years, children spend up to 40 per cent of their time with peers. Play and games are based on explicit rules and children develop the ability to comprehend and behave according to complex rules. At seven to eight years, rules are the essence of the game and need to be consistent and unchanging. Children develop social perspective taking, and become aware of the give and take in negotiating and playing games with social rules. From nine onwards, children treat rules with less awe.

With group identity becoming more important, children who look and sound different or who are not doing well in school may be excluded (Dion et al., 1972; Dion 1973) from play activities and groups and they may fail to hear or may misunderstand what other children are saying in games and play if they have associated hearing problems.

Children of this age tend to play in sexually segregated groups, although this is dependent on setting and a sizeable proportion do not conform to this pattern. This is a time when children need to learn the balance between competing and cooperating.

#### ■ **Friendships**

This is also the time when the development of affection, reciprocity and commitment in friendships become very important (Ladd, 1999). Forming relationships at this time is critical as a precursor to intimacy in older life. Hartup

(1992) describes the developmental functions of friendships as the context in which children develop basic social skills, and learn about themselves, others and the world. Friendships are also about companionship and fun, and as well as a means of learning models of intimate relationships (caring, helping, trusting). Gottman (1993) describes the themes of friendship as: common-ground activity; clear communication; exchange of information; reciprocity; learning about resolution of conflict; awareness of status; belonging and social acceptance (of which gossip is the cement).

Rubin et al. (1994) suggests that children pick friends who are similar (in age, sex, general skill level and have the same attitude to school). Poor peer relationships may also be related back to early attachment issues, and the importance the family gives to appearance. The ethos and culture of the school, and the school's acceptance that teasing is occurring and how they manage it, are critical.

Rubin et al. (1999) categorise children in peer relationships as:

- **Popular** – These children have good skills at initiating and maintaining positive relationships, and are good at compromising and negotiating.
- **Rejected** – Children who are actively disliked as their aggression/shyness leads to loneliness and distress. They over-estimate their own social skills and competence, and underestimate how much they are disliked. They are prone to misinterpret accidental injury as deliberate. Once rejected they gain a reputation.
- **Neglected** – Less sociable than peers, but they improve their status over the school year, and become more compliant and liked by staff. They are not particularly distressed by lack of social success.
- **Controversial** – These children combine characteristics of popular and rejected categories and compensate for aggression by joking around. Similarly to neglected children, they are not particularly distressed by lack of social success.
- **Victimised** – Not totally rejected by whole group, but 'harmed' by limited minority.
- **Bullies.**

## ■ **Teasing**

Around seven to eight years is the time when teasing and bullying may reach their peak (although this may be an artefact of studies which tend to start their cohorts at this age), and children with clefts may be particularly vulnerable. They are negotiating the difficult task of differentiating friendly banter from teasing, and negative connotations may be attributed to incidents when teasing has not been the intention, or unkind comments are too easily forgiven. Where peers, school and/or parents do not support children at this time, then patterns of learned helplessness could emerge.

Teasing may show itself in overt bullying incidents, the continuous 'drip-drip' method of daily minor incidents, or exclusion from groups. Around nine years of age there can be backstabbing and undermining comments among girls (Wolke et al., 2000). There may also be issues which relate not only to perpetrators but bystanders who are assumed to condone the bullying by the victim. Schools can be encouraged to intervene with a child's peer group to empower the bystander

group, by giving them licence to intervene and by role-playing the necessary language and behaviour, so that they can intervene in a protective and pro-social way. In addition, there is now the issue of cyber-bullying through internet chat rooms or children being bombarded with nasty and frightening text messages. When children feel they are being teased, parental support to intervene on their behalf is crucial. However, it is possible that the child is also being teased at home by siblings or indeed by one or both parents. Parents therefore may not necessarily intervene, as they should. Some parents may have the attitude that teasing is part of growing up and do not feel it is important to intervene themselves, and let children 'tough it out'. Possibly advice about fighting back constructively can be given. In addition, if parents themselves have been teased or bullied when they were at school, they may have negative memories of their own experiences of teasing and feel equally powerless to do anything now for their child and may not intervene as they should. Failure to deal with issues of being excluded from groups, teasing and bullying at this stage can have long-term effects on children's self-image and adolescent and adult relationships. Bullying which has led to extreme fear and threat to integrity of the child may lead to the development of post traumatic stress reactions or a full post traumatic clinical disorder.

#### ■ **Transition to secondary school**

At the end of this stage, children experience the major transition to secondary school, where the protective primary school environment of being in one class all day, with a class teacher who knows the child well, changes. Secondary schools with their multiple buildings, and possible split sites, which require routinely moving around to different classrooms, can appear daunting to any child. Harter et al. (1992) have found that the changing emphases in educational environment may have complicated academic outcomes, depending on the individual resources of the child, and in perceived competence and anxiety of children without clefts. If a child with a cleft moves to secondary school with few of their friends, where there is a need to start new friendships, etc., any previous problems may come to the fore.

## **Primary psychological interventions**

#### ■ **Cognitive assessment**

Assessing intellectual development and language skills if there are concerns, either to set fears aside or to facilitate suitable support in the classroom and if necessary involving SENCOs, alerting the educational authority, etc., and supporting Statementing.

#### ■ **Information and empowerment**

Giving children information about their condition (if they do not already have this) thus empowering them with the knowledge to explain how they look and sound different to others.

#### ■ **Cognitive behaviour therapy**

The cognitive model suggests how cognitive distortions may develop in a child with a cleft lip. The following example relates to sensitivity to bullying:

- Core belief: 'there is something about me that's wrong- there is something unlovable about me'.

- Important events activate core beliefs: ‘Dad left mum – If I had been more lovable I could have stopped him going.’
- Core beliefs trigger cognitive assumptions: ‘People won’t like me the way I am, that’s why they pick on me about my lip.’
- Assumptions produce automatic thoughts: ‘If I say anything in the class people will look at me and see that I am different, they may point this out – they may say something critical.’
- Automatic thoughts generate automatic responses and emotional responses such as feeling anxious or inhibited which consequently affect behaviour so the child appears disinterested and distant.
- Somatic: breathing is shallow when fearing critical comment, higher tension levels lead to higher adrenaline and irritability.

#### ■ **Social skills training**

Social skills training for children with social phobia using an integrated CBT model has been found to be effective immediately post treatment and after six to 12 months in children without clefts (Beidel & Turner, 2000; Spence et al., 2000), and may be a useful adjunct to individual CBT. Parental involvement with the programme has been found to enhance treatment (Spence et al., 2000).

#### ■ **‘Tool kit’ of behavioural strategies**

Proposing and teaching children a tool kit of behavioural strategies to deal with teasing directly (Lovegrove & Rumsey, 2005).

#### ■ **Transition groups**

Running transition groups for children in the final year of primary school, with parallel parent groups, can help in allowing children (and their parents) to discuss their anxieties, and shares ways of overcoming their concerns (Maddern & Owen, 2004).

#### ■ **Empowering parents**

Working with parents to empower them to intervene on their child’s behalf by addressing their own issues and giving them information about the legal aspects of the school’s teasing policy, if the school were not to intervene satisfactorily. This may involve making the school’s anti-bullying policy explicit to the parents and child, and finding a safe person the child can communicate with in school.

#### ■ **Supporting and advising schools**

- Working with the whole school to heighten awareness of teasing and bullying in and out of the classroom.
- Agree strategies with staff about what a child should do if they are bullied.
- Encourage a ‘buddy’ system to support the child.
- Normalising teasing, i.e. teasing is not necessarily cleft-related and defining what bullying is and the importance of believing the child’s perception.

Comprehensive whole school programmes to deal with teasing and bullying have been shown to be effective (Olweus, 1993), although replications of this type of intervention have been less consistent (Hunt, 2007). Interventions in primary schools have been more effective than in secondary schools (Smith, 2004). Hunt’s (2007) follow-up study of short-term interventions in Australian schools showed that attitudes towards bullying and incidents of bullying did not change permanently. She concluded that complex long-term approaches were necessary.



## GUIDANCE BOX – Junior school and middle childhood

### Consider

- Child's knowledge of their condition and treatment programme
- Child's hearing level
- Impact of cleft on self-image
- Cognitive assessment and academic attainment
- Ability to play games with complex social roles
- Friendship types
- Monitor incidents of teasing/bullying
- Early ostracism and rejection
- Post traumatic stress reactions
- Parental experience of school and teasing/bullying
- Parental response to teasing/bullying
- School ethos and policy on teasing/bullying
- Early preparation for the transfer to secondary school
- Child's core beliefs about cleft
- Five and 10 year audits
- Child's 'tool kit' of strategies

(See Appendix 3 for checklist)

## 5. Adolescence

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### Key issues and events

- Adolescence is commonly viewed as an inevitably stormy and crises-ridden period as a result of simultaneous changes in physical, cognitive, social, affectional and sexual spheres but research indicates that adolescence is better regarded as a period of transition, demanding new forms of adjustment. The young person is certainly confronted with new issues, potential problems and unfamiliar tasks but has also been shown to be a competent decision maker (Olbrich, 1990; Colman & Hendry, 1990). The rapid rate of change can potentially make it a stressful time for all adolescents and difficult behaviours and emotions need to be negotiated and accommodated by friends and family as well as by professionals on the cleft team.
- The concept of developmental tasks is an old one, deriving from the work of Havinghurst (1948, 1953). These were defined as problems that arise at certain periods of an individual's life. Tasks arise from different sources:
  - physical maturation;
  - cultural pressures;
  - societal expectations; and
  - individual values and aspirations.
- Thus tasks can differ between cultures and social strata; they are interdependent such that coping with one task gives rise to another. Successful achievement of a task leads to happiness and increased probability of success with future tasks. Failure causes unhappiness, societal disapproval and difficulty with later developmental tasks. At adolescence the tasks include:
  - 1) accepting physical makeup and acquiring masculine and feminine roles;
  - 2) developing appropriate relationships with peers of both sexes;
  - 3) becoming emotionally independent of parents and other adults;
  - 4) achieving assurance that one will be economically independent;
  - 5) determining and preparing for a career and entering into a job market;
  - 6) developing cognitive skills and concepts necessary for social competence;
  - 7) understanding and achieving socially responsible behaviour;
  - 8) preparing for partnership/marriage and family; and
  - 9) acquiring values and ethical systems of belief that form the basis of one's behaviour and become a basis for ideology
- In today's Western society, with prolonged education and a volatile job market, tasks 3) and 4) may well extend into adulthood and it seems more appropriate to speak of emotional and economic inter-dependence, rather than independence.
- What distinguishes adolescence from previous stages is the increasing importance of the peer group in the successful negotiation of developmental tasks, i.e. success is not a function of individual personality and coping strategies but interpersonal activities and social relationships. The peer group, in providing recreational outlets, age mates to share developmental tasks and a context to try out behaviours, acts as a laboratory to try out different roles and set standards as young adults (Sherif & Sherif, 1964). Adolescents need to identify with peers as well as

family in order to establish a wider range of contacts. Peers are crucial as normative and comparative points for adolescence (Hurrelmann & Hamilton, 1996), and coping with developmental tasks depends heavily on adolescents' identification with peers as well as family.

- The type of peer group (formal or informal) appears to be much less important than the relationship with the group members; the support received from peers is related to the degree of identification with and closeness of relationship to the group. If the adolescent feels close to the group and if the group accepts him/her, then the group provides the context in which he/she has personal ties with others and can achieve a personal sense of worth and can accomplish things as an individual. (Sherif & Sherif, 1965). The group (together with family) influences the resolution of stressful events and maturation rather than a mere change of individual mood or behaviour.
- Similarly the peer group is important in the development of individual identity and self-image, which reflects, in large part, the relationship with the reference group and the yardsticks it provides. Role models are particularly important at this time. The adolescent at the margins of the group may have more problems with self-esteem than the adolescent at the centre of the group.
- While family influences remain important, particularly in terms of providing guidance, skills and training and a forum to discuss future related issues, the continuity of ego identity from day to day depends on the stability of ties with members of the group and their shared norms and reference points, (Hurrelmann & Hamilton, 1996). In pre-adolescence, activities are primarily focused on home, its environs and the school classroom where there is a high degree of parental presence and control. During adolescence, there is less supervision and control by adults and more involvement with peers who operate in a wider and generally less nurturing school, geographical and social environment. There may well be conflicting demands and expectations – a mismatch between parental ideas, individual interests, peer attitudes and the reality of school and community environments.

## **The adolescent with a cleft lip and/or palate**

The additional challenges derive from the impact of facial difference/functional difficulties and consequent treatment on social relationships and integration into peer groups.

### ■ **Appearance**

Appearance is central to social experience and social interaction (Harris, 1997). Adolescents rate appearance as the most valued characteristic (Prokhorov et al., 1993) and negative self-evaluation in relation to attractiveness is very common in adolescents unaffected by a cleft (Lovegrove & Rumsey, 2005) so appearance-related concerns may predominate in this age group. Lovegrove's research (Lovegrove & Rumsey, 2005) suggests that 44 per cent of secondary school pupils feel that 'looking good' contributes significantly to social confidence and this figure rises to 78 per cent by the age of 18 years. The power given to the peer group can heighten consciousness of being on display to others' attentions, either

favourable or critical. There is evidence that teasing is associated with body dissatisfaction, though this is not necessarily related to 'objective' ratings of attractiveness (Thompson & Van den Berg, 2002; Wardle & Collins, 1998, cited in Rumsey and Harcourt, 2005).

In the context of the medical treatment and the cleft clinic, there may be an assumption that it is the cleft that is causing concern or dissatisfaction with appearance, an assumption that may well be unfounded. Evidence from clinical audit, undertaken in UK national cleft centres, suggests that 15-year-olds with a cleft have the same, if not higher, levels of satisfaction with facial appearance as their unaffected peers. Emerson and Rumsey (2004), in an unpublished study quoted in Rumsey and Harcourt, 2005 (p. 96) also showed that 15-year-olds with a cleft were as satisfied with their appearance and friendships as their unaffected peers. Conversely, severity of facial difference is not related to psychological outcome (Shute et al., 2007) and therefore whatever the personal judgement of the clinician, it is important to routinely ask the young person how he/she feels about their appearance, any experience of bullying or teasing and any perception of a connection between the two.

### ■ Relationships

Making friends and integrating into new and extended peer groups requires social competence and self-assertion and can be problematic for any shy adolescent. The challenge to adolescents with a cleft is potentially all the greater. Research evidence is contradictory: an American study by Kapp-Simon and McGuire (1997) (cited in the *Psychology of Appearance* by Rumsey & Harcourt, 2005) suggested that adolescents with craniofacial conditions initiated and received fewer social approaches compared to those without a facial difference. A UK study on adolescents with a cleft by Emerson and Rumsey (2004) failed to replicate this, which may reflect the differences in the two cohorts (the participants in the UK Emerson and Rumsey study had a cleft while the US study by Kapp-Simon and McGuire used participants with a wide range of craniofacial conditions). Social competence can be defined as the ability to elicit positive social responses and avoid negative responses in a range of social contexts (Mash & Terdal, 1997), i.e. feeling socially accepted and having good friends. A study by Shute et al. (2007) tested a specific model of factors predicting social competence in young adolescents with cleft and other craniofacial anomalies and found that feelings of self worth, as a lone variable, predicted social competence, and was closely associated with fear of negative evaluation from others. Social avoidance and distress predicted social competence and was mediated by peer support, while another aspect of social anxiety – fear of negative evaluation – predicted social competence and was mediated by parental support.

By late adolescence, many young people are psychologically ready for an active sexual life and are establishing informal or long-term partnerships. In the fumbling and tumbling of adolescent exploration, the mouth is significant and can be an additional aspect of self to consider. Perceptions of society-defined acceptability and choosing a mate on the grounds of attractiveness become important.

## ■ **Shame**

Shame can be a major and disruptive emotion of early adolescence, related to self-image and emerging sexuality. Strong feelings of ridicule, humiliation, embarrassment and disgust are not uncommon, against which defence mechanisms are built and inappropriate behaviour may result (Geldard & Geldard, 2004). Such feelings may be difficult to discuss, especially where discussion of the cleft lip/palate has become strained and difficult, or even taboo.

## ■ **Identity formation**

In Erikson's model (1963), the search for identity involves the formulation of a meaningful self-concept, incorporating and linking the past, present and future. It also requires the adolescent to assess his/her personal assets and liabilities and how they are to be used. Erikson viewed devotion and fidelity to people and principles as characteristic of this period.

Waterman (1992) suggests a strong link between ego identity and effective psychological functioning while Adams and Marshal (1996) state that identity formation, a continuing process, can be altered through heightened self-awareness and that there are sensitive points along the life cycle.

The importance of feelings of control is magnified during adolescence and is central to identity formation, maintaining identity integration (Erikson, 1963) and the harnessing of sexual impulses (Blos, 1962). These factors are all significant for those adolescents who are facing repeated clinic appointments for future treatment, including surgical intervention to change appearances and/or functioning.

Establishing personal identity as a member of a minority ethnic or cultural group can involve internalising any negative views held by the majority as well as the personal meaning of membership in that minority group. The search for ethnic identity can be positive and emotionally charged as the adolescent negotiates a path between his/her own views, those of their parents, their peer groups and broader society (Geldard & Geldard, 2004). For some adolescents with cleft, the issue of 'difference from others', in terms of facial appearance and/or distinctive speech and genetic factors may carry similar emotional charge. Adults with a cleft who can provide positive roles models can have significant influence at this stage.

## ■ **Gaining independence**

Adolescents most commonly want to be thought of as independent and have their views respected. The process of gradual separation from parents can be affected by disrupted attachment relationships as a result of a cleft, as well as the effect of high parental involvement in treatment decisions and potential over-protectiveness. It may be a challenge for adolescents with a cleft to formulate their own views of their self-image and consider treatment options for surgical revisions, while also incorporating their parents' views into the decision-making equation. The adolescent might find it hard to refuse further treatment in the face of parental pressure to rectify an obvious difference and a medical team who may be seen by the adolescent as an authoritarian parental figure. Conversely, an adolescent may be desperate for further surgical treatment, particularly if they feel stigmatised by their appearance but encounter parental opposition and medical reluctance. Clearly, perception of control in decision-making is highly linked with

independence issues and there may be struggles where parents hold their own strong views on treatment decisions or are strongly protective. Coming to regular clinic appointments highlights the 'cleft identity' to the young person and may tie them to their parents in an unwanted or unhelpful way. Where this creates problems, it is important for the young person to have a forum to discuss issues confidentially and the psychologist is well placed to provide this.

#### ■ **Resilience**

For the individual this is associated with:

- secure attachments and relationships;
- good self-esteem and perceived self-efficacy;
- strong sociability;
- good intellectual functioning;
- feelings of optimism;
- goal oriented behaviour;
- good problem-solving skills; and
- fewer adverse experiences.

This is within a context of family resilience including:

- warm, nurturant parenting;
- consistent, authoritative parenting;
- close parental monitoring;
- high parental expectations; and
- positive extended social network;

and, within the wider community, affording:

- supportive schooling;
- involvement with pro-social organisations; and
- attachment to adults involved with social activities (Broder, 2001; Healey, 2007; Tiet et al., 1998).

#### ■ **Protective factors**

In terms of bullying and teasing, protective factors include:

- authoritative, not authoritarian, parents (Baldry & Farrington, 1998);
- having a friendship group (Hodges et al., 1997);
- being friendly and pro-social (Tani et al., 2003); and
- emotional regulation, i.e. not rewarding a bully with a display of emotion (Mahady Wilton et al., 2000).

#### ■ **Vulnerability factors** include:

- authoritarian and (for boys only) over-protective parents (Baldry & Farrington, 1998);
- social isolation (Hodges et al., 1997);
- aggression-permitting beliefs and hostile attributions (Schwartz et al., 1998);
- emotional dysregulation (Mahady Wilton et al., 2000); and
- low socio-economic status (Wolke et al., 2001).

## Primary psychological interventions

### ■ Working with schools

Proactive, preventative interventions can be key in facilitating the transition to secondary school, particularly where there is a fear of future bullying and teasing and/or where bullying and teasing have already occurred in the primary school. The psychologist can be a useful go-between between family, primary and secondary school in setting up practical measures to ease integration, e.g. extra visits by the adolescent to the secondary school before entry, explaining the psychological impact of facial difference to year/form heads and arranging for the adolescent to have a key staff member responsible for dealing with specific acts of teasing or bullying, etc.

### ■ Social skills

Social skills training incorporating role-play can be effective in increasing self-awareness and empathy, which in turn has a positive impact on peer acceptance and popularity (Kapp-Simon & Simon, 1991). Interventions, group or individual, aimed at extending the repertoire of strategies are based on:

- creating a positive self-image;
- enhancing self-image;
- improving self-control in awkward situations;
- enhancing perception of available social support; and
- increasing initiative taking in social situations.

Such social-skills training addresses problem-solving, body language – particularly making eye contact and conversational skills (Kapp-Simon & Simon, 1991; Bradbury, 1996; Kish & Lansdown, 2000; Maddern & Owen, 2004). These interventions can be augmented by cognitive-behavioural techniques to challenge false beliefs about what others are thinking as well as helping to develop active coping strategies to defuse bullying, e.g. Lovegrove and Rumsey's (2005) *Ten Tools*, involving self-motto and body language, explanations, assertive conversation, distraction and armour plating, humour, friends as reinforcers, and appearance.

### ■ Individual psychological interventions

The research database on the efficacy of psychosocial interventions remains limited in terms of rigorous methodology and suggests randomised controlled trials are long overdue (Collett & Speltz, 2007). In the meantime, the clinician can perhaps harness aspects of research findings to enhance interventions for individuals, e.g. in the Shute et al. (2007) study of social competence, different aspects of social anxiety and their mediators were identified using questionnaires. More extensive use of questionnaires in individual therapy could, for example, help identify the degree of perceived parental and social support and focus interventions accordingly. Similarly, Rubin's categories of children in peer relationships (1999) – 'popular', 'rejected', 'neglected', 'controversial', 'victimised' and 'bullied' – could be equally helpful when applied to an individual intervention aimed at enhancing social interactions.

#### ● *Cognitive Behaviour Therapy*

CBT is an evidence-based effective approach for working with social anxiety, obsessional thinking and low mood and can also be useful when working with

parents who may want to discuss their adolescent's concerns with appearance, interest in boy/girl friends and challenges around independence and autonomy.

Beck (1976) identified a cognitive triad that powerfully reinforces low mood. The triad of 'negative view of self, negative view of the world and negative view of the future' starts to become apparent. For most children with a cleft, this stays at the level of difficult but normal adolescent struggles. However, it is easy to see how for some it can lead to low mood that requires some supportive intervention. Schema focused therapy provides a good framework for an assessment of an adolescent's core assumptions (Young, 2002).

- **Narrative therapy**

Narrative therapy techniques (White, 2005) can be effective in helping the young person fit difficulties and decisions into a narrative account, to illustrate the bigger picture of increasing independence within the family and forming friendships and hence broaden the adolescent's self-perception to create a more holistic view, which emphasises strengths and competencies. Incorporating motivational interviewing and work on self-belief can also help the young person work towards a positive imagine future.

Adolescence is necessarily a time of egocentricity and a feeling of uniqueness, which can contribute to the conviction of not being understood. Working with adolescents may require greater creativity and a more proactive approach from the therapist to achieve engagement. Individual face-to-face therapy may be rejected with the adolescent preferring telephone contact, written information or on-line chat rooms. For individual therapy, Geldard and Geldard (2004) suggest that each therapy session has to be relatively complete in itself as subsequent sessions may be rejected.

## GUIDANCE BOX – Adolescence

Consider

- Impact of diagnosis of cleft
- Attachment and bonding
- Parental mental health
- Parental relationship
- Parental knowledge of cleft
- Assumptions of future difficulties
- Impact of treatment
- Impact of any feeding difficulties
- Three-month audit

(See Appendix 4 for checklist)



## 6. Transition to adulthood

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### Key issues and events

Working with young adults may require great creativity and a more proactive approach from the therapist to achieve engagement. As with early adolescence, each session may have to be relatively complete in itself.

#### ■ **The challenge of transition**

The late adolescent age group make the transition from childhood to adulthood having to deal with biological, psychological, social and educational challenges at a time when they are expected to be taking on much more individual responsibility. The high levels of change can make it a stressful time for all young people and difficult behaviours and emotions need to be negotiated by friends and family as well as professionals on the cleft team who may have to accommodate to it.

#### ■ **Graduating from treatment**

There has often been a long period of waiting for orthognatic surgery and lip and nose revision, which culminates in the period in which the young person stops growing, and this time can be a watershed. Expectations for transformation may not be met. Conversely the degree of change may be overwhelming.

By age 16 to 18 (depending on hospital policy) young people will move on from care under a paediatric service to care in an adult service. Parents who have been used to carrying the burden of care for their child can find it difficult handing over responsibility to their teenager. Parents who desperately want their child's life to be 'unaffected' by the cleft may find it difficult when an adolescent is reluctant to undergo further treatment despite their visible difference. This can set up a difficult dynamic between the young person, the cleft team and the parents, with the cleft team offering treatment but being careful to take the wishes of the teenager, rather than the wishes of the parents, fully into account. Of course, alternatively, some parents, having seen the pain that their child has gone through with surgery, do not support their child's aspirations for a more perfect cosmetic outcome.

Many young people long for treatment to be over so that they can get on with the business of moving away to college, settling in employment and finding a longer-term partner. However, the challenges of going into new situations can lead to an increased self-consciousness for anyone, and for someone who feels different in some way this can be additionally problematic. Not all individuals with a cleft will find this an issue, and for those who have adjusted well in the past, there may be few problems. Their cleft may not be something they are conscious of day to day and equally, others may also not notice it. There can be practical problems in timing however, as the last few revisional procedures may need to be juggled to fit in with, for example, the practicalities of exams, or moving between home and university, or college and work.

#### ■ **Genetic implications for long-term relationships**

When contemplating a family themselves, young adults may become more

concerned about the genetic basis of their cleft condition and how this may be passed on to a future child. As the age approaches for starting a family, this issue can become very significant. Some people dread the prospect of a child of theirs having a cleft (and perhaps suffering teasing as they did). Others feel well-equipped to cope with supporting their child, as they 'know what it's like'. It is possible that these considerations have some impact on the age at which people marry and have children. Peter and Chinsky (1974) suggest that people with a cleft lip and palate marry later than their non-cleft peers. Entering into a long-term relationship can have a significant effect on self-esteem for young adults, whether or not they have a cleft, and the move to living as a couple has its own impact on self worth and self acceptance.

#### ■ **Self-worth**

Current understanding of the impact of having a cleft suggests that self worth is a significant factor in how people cope, but the origin and development of self worth is no more obvious in people with a cleft than in people generally. The usual suspects of family and social milieu are significant. However, for a small number of adults their cleft is a very salient feature, which does have a significant impact on how they feel about themselves and how they imagine others perceive them.

## **Primary psychological interventions**

#### ■ **Coping strategies/social skills**

Social skills training may be helpful, role-playing responses to those who are using teasing or intimidating language. It is also helpful to role-play positive self-statements and the assertive language that may be necessary in seeking support from others. Some adults will not have had a very positive experience of living with a cleft. Where there is a combination of poor outcomes in terms of speech/hearing/appearance, poor family support and/or a history of chaotic family background, the adult is inevitably going to find the challenges of having a cleft more difficult to manage. Sometimes a long family history of inappropriate coping strategies is brought to the fore by a life event such as a divorce or the birth of a child with a cleft. It can be slow work to counsel people in this situation and teaching new skills can be a tentative process. However, some adults are excited by the prospect of making changes and rise to the challenge. The use of group sessions can be effective where there is already a willingness and confidence to move on.

#### ■ **Information, CBT and challenging unhelpful beliefs**

Alongside general social skills work, CBT can be effective in working with adults going through transitions. Normalising the process of change and the grief/loss reactions or anxieties that accompany change can be helpful. Standard CBT approaches can be effective in helping people to reframe their thinking by challenging unhelpful thoughts.

#### ■ **Longer term person-centred/psychotherapeutic work on self worth**

Individual case histories can illuminate the long-term effectiveness of working in relational depth with clients. A case illustration follows. A young adult came to the psychology service as she had become very tearful after an unexpected referral to

the cleft surgeon by the GP. She had made a routine visit due to feeling ‘bunged up’. The referral coincided with an incident in a queue, which brought back memories of severe teasing as a teenager. The therapeutic process took some months, ranging from using CBT, narrative therapy, discussing dreams, and working with regression. Such longer-term work is rarely needed, but where it is indicated it can heal deep wounds in self esteem and open up hope of a more positive future. When clients come to the psychology team for this type of work, there is a need to be aware of the wider context of the person’s story, in terms of the attitudes they may have faced in society and their own family, and their previous experiences of contact with the cleft service.

## GUIDANCE BOX – Transition to adulthood

### Consider

- Evaluation of mood and stresses
- Mental health issues
- Expectations of and decisions about treatment
- Relationship with hospital system and graduation from treatment
- Self-worth and core identity
- Social skills and peer support systems
- Fear of (further) bullying in work place
- Long-term relationships, future families and genetics
- Imagined future
- 20-year audit

(See Appendix 5 for checklist)

## 7. Guidelines for future research

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- Critiques of the research literature on bullying and teasing have highlighted the challenges to future research, citing the need for clearer and more consistent definitions of teasing and bullying, in order to facilitate comparisons across studies, cultures and countries.
- Similarly, this literature comments on the need for psychometrically sound measures, which are used consistently across studies.
- Any research needs to describe the heterogeneity of the group to the reader in order to help in meta-analysis, i.e. in terms of whether their difference is visually and/or hearing/speech.
- There is a need to examine differential effects, e.g. function of gender, ethnicity, cultural group, socio-economic status and type of school. Specific information on type of school and school ethos is lacking in the research base other than confirming prevalence of significant peer harassment across a wide range of school contexts.
- There is a need to take a more differentiated and developmental perspective in bullies, victims, bully victims and bystanders. The continuity of bullying and victimisation over time and across different school settings as well as changes in status for an individual student are salient factors in understanding risk.
- In assessing effectiveness of interventions for bullying, future studies should consider inclusion of protective factors – individual/family and community – using focused, operationalised definitions of resilience ie emotional, behavioural, educational resilience, etc.
- The focus needs to move beyond individual and specific programmes to include systemic change including culture and climate of school. Schools over-rely on the use of negative consequences and social control techniques. There is a need to further develop social and emotional learning skills in the school and home and develop safe and caring environments with a sense of belonging and community, backed by relevant policies and system supports.
- There is a need to examine whether early interventions with parents of children with clefts make a difference to children's self-esteem later in childhood and adulthood. This could be done by investigating services where there has been a long-established team approach and those services in areas where there is no such multi-disciplinary team.
- Longitudinal research is important to establish the long-term impact of teasing in children with and without clefts and assess whether are different trajectories with different outcomes.

## 8. Concluding comments

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There is no single formulation to protect the individual who has a cleft from feeling vulnerable to teasing and bullying at any stage in their life. Teasing and bullying may or may not be more prevalent for these individuals – the data is not conclusive, though our clinical experience indicates that teasing and bullying are a major anticipatory concern for many parents and some children.

Each family and individual will make their own journey through the cycle of treatment and involvement with the cleft team. The task for the psychologist in bringing a non-pathologising, normalising perspective is to separate out the specific and specialised issues around having a diagnosed congenital, inheritable condition from the ‘ordinary’ demands and problems of everyday life. For children and young people with a cleft, the additional risk factors include:

- attachment patterns;
- pre-school anxieties in parents and/or child;
- absence of close friendship group;
- poor quality friendships;
- early tendency to withdraw;
- being labelled as physically or behaviourally different;
- somatisation of anxieties;
- low socio-economic status;
- instability of parental relationships;
- parental mental health issues;
- transient life style;
- frequent changes of school; and
- poor cognitive ability

Incorporating the theories described previously may help to improve the effectiveness of our interventions, for example, by systematic attention to the transgenerational issues that create a family’s beliefs system and ‘story’ and affect how parents react to the cleft, to internal and external attribution errors, to increase individual and family’s locus of control, decrease learned helplessness, reduce stereotyping and stigmatising by school and community, reduce any sense of shame and assist the school in dealing with bullies through an understanding of the level of moral reasoning attained.

For maximal effect we need to integrate our hospital based assessments and interventions with what is happening at school and in the community and this joining of systems is the biggest challenge.

# Appendix 1

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## Suggested checklist – Birth and early infancy

### Consider

Impact of diagnosis of cleft	
Attachment and bonding	
Parental mental health	
Parental relationship	
Parental knowledge of cleft	
Assumptions of future difficulties	
Impact of treatment	
Impact of any feeding difficulties	

## Appendix 2

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### Suggested checklist – Pre-school and nursery/school entry

#### Consider

What information about clefts has been given to nursery staff or teachers, particularly about fluctuating hearing	
Child's social and emotional competence	
Child's explanation of cleft	
Child's level of hearing	
Child's quality of speech	
Developmental check	
Five-year audit	
Early management of behaviour problems, particularly in boys	
Parental experience of school and teasing/bullying	
Family relationships and ethos	
Parental mental health	
Concerns about teasing	

## Appendix 3

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### Suggested checklist – Junior school and middle childhood

#### Consider

Child's knowledge of their condition and treatment programme	
Child's hearing level	
Impact of cleft on self-image	
Cognitive assessment and academic attainment	
Ability to play games with complex social roles	
Friendship types	
Monitor incidents of teasing/bullying	
Early ostracism and rejection	
Post traumatic stress reactions	
Parental experience of school and teasing/bullying	
Parental response to teasing/bullying	
School ethos and policy on teasing/bullying	
Early preparation for the transfer to secondary school	
Child's core beliefs about cleft	
Child's 'tool kit' of strategies	



## Appendix 4

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### Suggested checklist – Adolescence

#### Consider

Satisfaction with physical appearance and any associated bullying/teasing	
Satisfaction with speech quality	
Understanding and explanation of cleft	
View of proposed treatment	
Peer support and friendships	
Level of social skills	
Social avoidance and shame	
Low mood, suicidal ideation and self-harm	
Concerns about intimate relationships	
Resilience, protective and vulnerability factors	
Adolescent/parent relationship	

## Appendix 5

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### Suggested checklist – Transition to adulthood

#### Consider

Evaluation of mood and stresses	
Mental health issues	
Expectations of and decisions about treatment	
Relationship with hospital system and graduation from treatment	
Self-worth and core identity	
Social skills and peer support systems	
Fear of (further) bullying in work place	
Long-term relationships, future families and genetics	
Imagined future	

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