

## **Chapter 6**

### **Breaking The News Of Diagnosis: Facilitating Adjustment And Acceptance**

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## Introduction

*Johnny has Autism. This is a life long developmental disability with no cure.*

*While autism may present differently at different ages, and Johnny may develop new skills, the gap between Johnny and a typically developing child will most likely increase with age. In addition, Johnny has an intellectual disability, which not uncommonly occurs with autism. This combination makes it likely that Johnny will need support class placements and even with that, it is unlikely that he will live independently as an adult.*

The time of diagnosis is described as a crisis event and an experience a family never forgets (Ptacek & Eberhardt, 1996). It is the critical time when parents are told that their special child is likely to have a life long disability with an unknown prognosis, and when they realise that their lives will be changed on a permanent basis. Families' memories of being told that their child has a disability are often very vivid and important many years later (Woolley, Stein, Forrest, & Baum, 1989). Parents report mixed emotional responses to receiving a diagnosis including: fear, confusion, isolation, loss, grief, shame, anger, despair, exhaustion, relief, hope, protectiveness, and love. It is suggested that the manner in which the bad news is presented, influences a family's ability to cope and adapt as well as their perception, acceptance and subsequent care of the child. This places a significant burden of care on the professional breaking the bad news to do this in as constructive and supportive a way as possible.

Fortunately, the debate has gone beyond whether or not professionals should inform a family about a diagnosis or a prognosis, but is rather focussed on *how* best to deliver the information and subsequently support the family. Ignoring parents or withholding prognostic information from them may lead to false hope and a sense of

anger, betrayal, and distrust. A central tenet of physician-parent communication is that parents need information to make treatment decisions for their child (Meert, et al., 2008).

How does one then balance the need to provide a clear diagnostic formulation and management plan, while not devastating parents who wish to hear the 'truth', but are likely to not be ready to accept it yet? Interestingly, but not surprisingly, the 'guidelines' on the 'how' have been formulated by observing experienced clinicians and gaining parental feedback. This is one opportunity to strengthen the strong partnership of mutual respect and collaboration in the care of the child and adolescent.

### **Models And Frameworks**

Descriptive academic terms have been ascribed to these clinical practices. For example, the 'Perspective-Display Series' (Maynard, 1991) is where professionals first invite clients to display their opinion on the problem, and then deliver the diagnostic findings as a confirmation of the clients' displayed perspective. In another strategy, termed the 'Incomplete Syllogism', the clinician presents a series of related, general, and particular premises that point to an implied diagnostic conclusion, allowing the recipients themselves to deduce the 'upshot' (Maynard, 1995). In a 'negotiating' stance, professionals were found to 'accommodate the distance between a professional's and a parent's point of view, modifying the label to conform to parental wishes, and modulating levels of optimism and pessimism' (Abrams & Goodman, 1998, p. 96). Some of the dilemmas and issues will be discussed to allow the reader to formulate an individual opinion and style. Current practice accepts that the 'Family centred care model' is one to strive towards. This encompasses exchanging complete and unbiased

information between families and professionals in a supportive manner, recognising and honouring cultural diversity, strengths and individuality within and across families, and recognising and respecting different methods of coping. (Shelton & Stepanek, 1994; 1995).

Bartolo (2002) discussed the dilemma of the delivery of bad news in terms of two poles of *realism vs. hopefulness*. While there is a need for a degree of realism, it could always be framed in the light of hopefulness. Without some hope it would be difficult for carers to be proactive and find a reason to invest the emotional and financial time and energy that is required in caring for a child with a disability to maximise their potential. The realism pole focused on the child's deficits, while the hopefulness focused on the parental coping process and supporting the child's progress. Realism focused on the honesty of the diagnosis and the limitation of the prognosis, while hopefulness focused on the compassion and the potential. The skill of the professional lies in the ability to be able to convey the information in the most hopeful and realistic way, constantly reflecting back on how the parents are feeling and whether the information conveyed is consistent with their perspective of their child.

Bartolo (2002) also described three major types of frameworks, that is, parent friendly frame, defocusing bad news, and hopeful formulation of the disability. The 'Parent Friendly' framework' incorporated empathising with parents, relating positively to the child, reassuring parents that they were already addressing the needs of the child, aligning parents through perspective-display-series frame and allowing parents time to seek clarification. He emphasised the need for professionals to present 'one story' to parents and not to disagree in front of them. This would be just as important in a multidisciplinary team as in private practice where families may see professionals in

different locations at different times. It would necessitate professionals discussing opinions prior to feeding back to parents to avoid confusion, particularly if one professional was aware the family have consulted with another who has specialist knowledge.

The 'Hopeful Formulation' frame focuses on stating the positive achievements first (e.g., 'This is what Johnny can do and demonstrated for us today'), hedging conclusions (e.g., 'This is a baseline from which to work from and we will monitor progress'), and focussing on relevant support strategies (e.g., 'What are we going to do about the situation' or the management plan). The defocusing frame avoided labelling the disability and focused on the child's individual improvement and special education provisions. This is considered a contentious point of view as many service and funding providers depend on a diagnosis to assess relevant services and financial support for the child. For example, on the one hand, a diagnosis of Rett Syndrome, clearly defines a high level of support required and a long term prognosis, while a diagnosis of Autism Spectrum Disorder (ASD) is less clearly defined and the prognosis much more variable.

There is little argument that labelling developmental disorders for research purposes is important and valuable, and that labels can be helpful to define the scope of support and describe the areas where an individual is having difficulty. However, there may be many more children who have very high functional needs, who do not clearly fit into any specific diagnostic category, and therefore may miss out on the necessary funding and support. This is a different argument that requires further discussion with governments and organisations to include a 'needs based' assessment as part of their funding criteria and not rely solely on labels. Furthermore there is often a perception that labels will lead to bullying and disadvantage a child socially and educationally.

Unknown long term consequences (e.g., obtaining life insurance/disability cover) may be an issue for some. It is therefore necessary that parents and professionals engage in a *process of negotiation* over the need to ascribe a label to a child and the meaning of such a diagnostic label.

Abrams and Goodman (1998) noted that professionals use *euphemisms* to soften and mask the truth. Terms such as ‘developmental delay’, ‘slow’, and ‘immature’ are less direct, concrete, graphic, and offensive than the term ‘mental retardation’. Secondly, professionals cover their own uncertainty and discomfort, and wish to mitigate the truth by hedging. Language that is indirect, vague, and uncertain serves both to manage professional uncertainty and to minimize the impact of the diagnosis. Hedges used to approximate a condition (e.g., sort of, kind of, a little bit), help shrink the distance between normative expectations and the abnormal condition of the child (Prince, Frader, & Bosk, 1982). To quote Abrams and Goodman (1998),

Professionals can preserve parental self esteem and allay distress through a process of negotiation. The concept of negotiation describes the socially constructed nature of encounters in which participants are able to forge a mutual understanding through language. Thus, the meaning of the encounter and the understanding of the information the parents maintain are interactionally and not individually based. The encounter is seen as a bargaining process in which each participant must adjust his or her line of action in terms of what they can expect to attain under the circumstances and in accord with how the others are developing their lines of action. The content of the information is not static and discrete, but fluid and continuous, subject to modulation, change, and adjustment to accommodate such contextual features as goodness of fit between

the child and the diagnostic category and parents' emotional needs. By fine-tuning the diagnostic feedback as conversation progresses, professionals and parents can keep the interpretation circulating around a mutually acceptable set-point (p. 88).

This view point rings true with balancing up and down the fine line between realism and hopefulness.

### **What Parents Want**

Reviewing the research describing parental experiences with diagnosis delivery, has identified a number of common factors that increase and decrease parental satisfaction. Parents have expressed similar preferences on how the interaction could be improved. Boyd (2007) noted that overwhelmingly parents wanted health care professionals to demonstrate empathy, sensitivity, and caring when delivering bad news. Parents find it helpful when they are allowed to show their feelings in a safe and non-judgemental environment. Parents should be allowed time to process the information and their feelings, and have the normalcy of the emotions they are experiencing acknowledged. A box of tissues in the consulting room never goes astray!

Parents appreciate having time to talk and ask questions without feeling rushed, but this is a difficult atmosphere to create when there is a busy waiting room. Gestures such as requesting not to be interrupted, not taking phone calls or answering mobile phones impart a feeling of concern and that the professional is listening to the parental concerns. Parents also value privacy. Bad news should always be delivered in a location that is private, comfortable, and quiet with attention paid to minimising interruptions and distractions. Families strongly agree that bad news about their child should be

delivered in person, with both parents, and preferably the child, present. This provides support for both parents, and also removes the burden of one parent having to impart the bad news to the other, and being in a position not to be able to answer questions effectively. It also allows the parents to begin the grieving process at the same time.

It is always best that the news be delivered by the professional that the parents have come to know and trust. It may be that the information and diagnosis is conveyed by the experienced consultant, rather than a junior member of staff who may themselves feel insecure or uncomfortable in such a difficult situation. When receiving bad news, parents prefer that the health care professionals attending the meeting are known to them. It is important that all the relevant information is collected prior to the meeting and is readily available. If the bad news is conveyed in a 'team', there should be consistency and agreement about what information each professional will present.

Parents appreciate the timely provision of current, accurate and straightforward information about their child's diagnosis, prognosis, treatment, care, and future expectations. The news should be presented in language that is easy to understand and jargon-free. A professional interpreter should be available for translating the information for when families are not fluent in the language of the individuals delivering the news. It is preferable to provide written information on the day so that parents are able to have something tangible to read and reflect on after the meeting. This written information should include additional sources of information for families including support groups that can offer emotional support and practical advice. Parents value an individualised approach where their cultural and unique needs and aspirations are respected. Guidelines that have been published include the delivery of news about



Down syndrome to parents (Cunningham, Morgan, & McGucken, 1984). This ‘model service’ outlined in Table 6.1.

*[Insert Table 6.1 here]*

### **Professional Training And Guidelines**

Research has indicated that parental dissatisfaction with disclosure remains high (Skotko, 2005 ). It cannot solely be relied on that disclosure is an innate skill of professionals and that experience, sound knowledge about the chronic disorder, empathy, and sensitivity is sufficient. There is a need to teach medical students and registrars basic skills and principles to increase their confidence in delivering bad news in a manner that parents feel comfortable and confident that their child is receiving the best treatment. A study by Horwitz and Ellis (2007) in the UK noted that most registrars did report receiving training in delivering bad news and their perceived level of confidence in this skill was high. However, this form of self assessment is often inaccurate, with weaker students and often male students frequently overestimating their skills while stronger students and often females, underrate themselves. Multi-source feedback has therefore become the preferred method in the UK.

Many methods of teaching how to disclose diagnostic information have been applied in clinical practice. One method is the use of interactional skills training having an impact on clinician’s skill in communicating with patients. This training however should be delivered at undergraduate and postgraduate levels to ensure skills maintenance (Perkins & Sanson-Fisher, 1996). However, teaching communication skills is only one aspect to be addressed. The challenge is far broader than the clinician to

child and family interaction, as in disability, the diagnostic assessment often occurs in multiple settings with multiple professionals and agencies. Therefore, there is a need to develop guidelines that negotiate the boundaries between assessments and agencies to facilitate the process for children and their families.

Providing specific training and guidelines have been found to be welcomed by professionals and parents in the field of disability. Such an example is the '*Informing families of their child's disability: National best practice guidelines*' (National Federation of Voluntary Bodies, 2007) that were developed in Ireland as part of the Informing Families Project. The practice guidelines were initiated in response to feedback from parents that the news of their child's disability had been conveyed insensitively or in inappropriate environments, and that the experience of being told the news had caused additional distress at the time of disclosure. Similarly, feedback from professionals to delivering the news indicated that they felt there was an absence of training and clear guidance available to support those undertaking the sensitive and challenging task of giving families the news that their child has a disability.

An important finding of the Informing Families Project was that a broad range of professional disciplines were involved from mainstream health settings and disability specific services. This meant that clear planning and ownership of tasks within the disclosure and support process, interdisciplinary training, and a structured cross sectoral approach to the dissemination of the best practice was necessary. Parents and professionals indicated a clear need for continuity of care to be provided within service settings (e.g., where more than one medical or social care team were involved in providing the diagnosis), across settings (e.g., where families are discharged from hospital settings into the community), or when waiting referral to early services. Parents

and professionals identified a need to provide continuity of care and a coordinated team approach to avoid the

- Distressing vacuum following discharge and before reaching early services, and
- Mixed messages that were often received when internal teams did not communicate effectively.

The central aims of the Informing Families Project were to develop evidence-based national best practice guidelines, and education and training on appropriate procedures to inform families of their child's disability. The guiding principles included,

- Family centred disclosure;
- Respect for child and family;
- Sensitive and empathetic communication;
- Appropriate, accurate information;
- Positive realistic messages and hope;
- Team approach and planning; and
- Focussed and supported implementation of best practice.

### **Follow-up Support**

Long term follow up and support is an important component of care to facilitate the individual and family adjustment to living with a disability (Bailey, Armstrong, Kemper, Skinner, & Warren, 2009). Families require a written plan of action and a 'road map' as to how they proceed to address the medical, physical intervention, educational, emotional, financial, and community supports. Most often this is provided in a comprehensive written report at the conclusion of the diagnostic and assessment

process which includes a date for a follow up appointment to discuss the report and any other issues that may arise. Ongoing support includes,

- Providing ongoing access to accurate and understandable information;
- Facilitating support from professionals and other parents;
- Active surveillance of child health development and behaviour;
- General and targeted interventions mutually determined by parents and professionals;
- Scheduled visits at times of known increased stress e.g., transition periods to high school, adult services.

A contact person, or 'case worker' should be identified who parents are able to contact if further information or support is required. Parents and carers deserve evidenced based information and practical support to allow empowerment to adjust to living life with their child's chronic disorder, and fulfil their hopes and the dreams for their child.

## **Summary**

In order to summarise this chapter, the following is a review of the introduction paragraph incorporating best practice in delivering bad news to parents about their child with a disability:

*We have enjoyed meeting you and getting to know Johnny today. We were really pleased that he managed to settle in this unfamiliar environment and was able to enjoy some of the toys and activities that were presented to him today. We do share your concerns regarding his development, particularly your concern about his delayed language and play skills. Based on the information you have provided, the reports from his therapists, and our observations and testing*

*today, Johnny's development is different to that of other children his age. The combination of difficulties in the area of communication with others, in the way he is socialising and preferring his own company, and finds comfort in familiarity and routine, is consistent with what we see in the Autism Spectrum Disorders. Johnny would meet the DSM-IV criteria for a diagnosis of Autistic Disorder. All individuals on the spectrum have impairments in communication, socialisation and behaviour, but they are all also very individual and unique, with their own set of skills and personalities. There were a number of encouraging features that Johnny displayed today. He did show interest in some of the activities we presented to him, allowed us to direct some of his play and did not tantrum too much when we removed his trains. This suggests that with time and perseverance he will engage in therapy with his speech pathologist and special educator. Even though Johnny took very little notice and did not initiate with us, he is very aware that you are his parents and frequently approached you for assistance which is also very encouraging. The Griffiths Mental Development Scales today has documented a moderate global developmental delay. This is the term that we will be using in his report as it is required in order for him to access appropriate services. This assessment should be viewed as a baseline of Johnny's skills and we know that he has at least demonstrated these skills, but it is not at this point in time indicative of his potential. This will become much clearer with time. We will continue to monitor Johnny's development very closely and continually review the most appropriate support, intervention and educational placements best suited for him. Anita will continue to assist you to navigate your way through the maze of public and private*

*services until we have established the best service providers for Johnny, but please do not hesitate to contact us if you need any further assistance.*

**Table 6.1*****Model Service For Delivering News About Down Syndrome To Parents*****Procedure For 'Model Service'**

- Consultant paediatrician and 'specialist health visitor' to convey diagnosis
- Disclosure given as soon as possible
- Discussion takes place with both parents together
- Interview located in a private place with no other professionals present
- Infant is present
- Parents given news directly
- Parents given as much time as they wish to ask questions
- The specialist health-visitor sees parents again as soon as they want
- Parents provided a private place immediately after the interview
- Follow-up interview arranged 24 hours after the disclosure

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Adapted from Cunningham, Morgan, & McGucken (1984).