

BREAKING THE NEWS

to disabled adults and parents of disabled children

Preface

Since its inception in 1987, the Kummissjoni Nazzjonali Persuni b'Dizabilita' (KNPD) (*National Commission Persons with Disability*) has maintained constant contact with disabled persons and their families. Over the years KNPD has noted that many disabled adults and family members of persons with disability express deep disappointment and sorrow about how the initial news about their own, or their child's impairment is imparted to them. The situation is the same both in the state and private sectors.

Whilst it is recognised that giving disagreeable news is difficult in itself and may even require specific training on the part of professionals, it is also recognised that such news may elicit very strong emotions in those receiving it. These strong, sometimes negative, emotions may, in a few instances, even be directed towards the person who is actually imparting the difficult news. Some accusations of insensitive behaviour on the part of health care professionals may be somewhat exaggerated, however, the fact remains that there exists a clear need for improving the standards of communication between professionals and non-professionals.

While on the one hand, the object of this exercise is not to apportion individual blame, on the other hand, one hopes that positive attitudes can be taught, learned and finally assimilated as part of the professional's general practice.

Bearing all this in mind and following similar documents published in the United Kingdom and elsewhere, KNPD is presenting the following guidelines for the attention of all the relevant authorities and health professionals. The present document is being put forward following a thorough consultation various stakeholders, that is, disabled persons, their families and organisations of professionals working in the sector. It must be stressed that this document is intended to present a number of guidelines and is not intended to be taken as a full-blown (and therefore legally binding) code of ethics.

KNPD will also take upon itself the responsibility to facilitate and provide support (within its own constraints) for the training of health care and other professionals in positive communication and the imparting of difficult news to disabled people, their families, and primary support providers.

Throughout, this document reflects a user-led approach, that is, the focus is on the needs of the disabled person, their family and primary support providers. When dealing with disabled children it is both the child and the parents who are directly involved. Therefore, whilst the child is, *always*, the centre of discussions, the document also provides due attention to the needs of parents and persons who, in the future, will be primary support providers.

Taking into account the comments made by disabled adults and parents (and primary support providers) regarding the issue of ‘breaking the news’, their requirements are twofold: “Give us HOPE and DIRECTION!”.

Firstly, they need some reassurance that all is not lost and that they reasonably hope for a future which holds the promise of an acceptable quality of life (for themselves if an adult or for their child, if they are parents).

Secondly, they also need to be directed towards the next steps that they have to take in order to begin forging that quality of life.

VALUING THE INDIVIDUAL: ADULT AND CHILD

1. The individual must always be regarded as central to the situation.
 - (a) In the case of diagnosis of a recently disabled adult it is essential that, as a general rule, the individual is present when their situation is being discussed. Furthermore, the language used should reflect respect and sensitivity to the person and their situation.
 - (b) In the case of diagnosis during the early months of childhood it is valuable for the baby to be present when being discussed, and responded to in a way that reflects that the child is valued, for example by using the child’s name.
2. In some circumstances either parents or professionals may feel that is not appropriate, advisable or practicable for the baby or child to be present. At such times, it is then all the more important that language and the manner of communicating should reflect respect for the absent child.
3. All discussions, whether about an adult, or a child should have a positive focus and be forward-looking.
4. Predictions about the subject’s future should be avoided as no one can claim to know the outcomes, or capabilities, of any individual.

RESPECTING DISABLED ADULTS AND PARENTS

5. Professionals should demonstrate compassion, respect, understanding and warmth towards disabled adults and parents.
6. Honesty (such as, fidelity to fact) on the part of professionals in sharing information with disabled adults and parents, and acknowledging the limitations of professionals’ knowledge, is essential if respect for disabled adults and/or parents is to be conveyed effectively. Any uncertainty should be shared. Such an

- approach is desirable in view of patient rights and in order to gain the confidence of parents and/or the disabled person.
7. Plain, comprehensible language, free from medical and other technical jargon and accessible to lay persons should be used in giving explanations that will help prepare the disabled adult, or parents, to handle the situation.
 - (a) Furthermore, the time and place chosen for communication should allow space for reflection and questioning, as recently disabled adults and parents need time to ask questions and explore the situation, a process which should also allow professionals to check whether the individual, and/ or the parents have fully understood what they have been told. .

INITIAL CONCERNS

8. If the individual has concerns, or if the parents are concerned about their child, then their concerns should be treated seriously and responded to quickly and honestly. All available information (including the availability of services) should be shared. The limitations of services should be acknowledged and alternatives suggested (where they exist).
9. If any member of the medical staff, or team, is the first to suspect a existence of an impairment, their concern should, as a matter of urgency, be thoroughly discussed with the senior member of the team (usually the consultant). It should be this senior member who then shares the information with the disabled individual and/ or parents and includes them in subsequent discussions and decisions.
10. Staff should be made aware of the danger of giving unconscious messages through body language and behaviour before the concern has been shared with disabled adults, or the parents. Details of how the individual, or parents, are told will depend on the stage at which diagnosis is made. This will reflected in the points that follow.

THE COMMUNICATION PROCESS: *how to tell (family circumstances vary enormously)*

11. Decisions as to how an adults, and/ or parents, are told about a newly acquired impairment are best made on the basis of the team's knowledge of the individual and each separate member of the family.
12. It is important to bear in mind that family circumstances and dynamics vary enormously, from traditional families to single parents, etc. Information sharing should also respect the character and personality of the disabled adult and/ or the parents of a disabled child.

13. The professional breaking the news must also remember that, in some instances, the varying cultural needs of families with different ethnic backgrounds need to be carefully and sensitively taken into account and accommodated.

Who should be present?

14. An adult who has recently acquired an impairment; they may prefer to have someone else present when the news is broken. On the other hand some may request to attend the interview on their own. In either case, their wishes should be fully respected.
15. With regard to parents:
 - (a) both of them have a right to know and generally they should be told together. Indeed, in most cases they generally prefer to be told together.
 - (b) However, this cannot be taken for granted. For example, a child may live with only one parent. For this or many other reasons the parent being told may need the support of a friend or relative, rather than the other parent.
 - (c) Arrangements should take these possibilities into account. There will be occasions when sharing the concern with only one accompanied parent cannot be avoided. In these circumstances it is particularly important that professional support should include ensuring that arrangements are made that take into account the parent's needs for support and practical help immediately following the discussions (for example, how will the parent get home?).
 - (d) When only one parent has been told separately, arrangements need to be made for one of the professional team to tell the other parent as quickly as possible, preferably with the consent of the parent who already knows.

Which staff members should be involved?

16. The disabled adult and/or parent(s)' vulnerability and right to privacy should be respected by keeping the number of people involved at the time told to a minimum.
17. Preferably, the professional giving the news (usually, but not always, the consultant) should be known to the individual and/or parents. One other member of staff should also be present, once again someone already known to the individual and/or parents – who would also be available to talk to them more fully at a later stage.
 - (a) The disabled adult and/or parents should be given the opportunity to consult expert opinion.
 - (b) If they wish to seek a second opinion this decision should be respected.

18. The individual/ family's general practitioner should be informed of the situation immediately, and provided with the notes of the disclosure meeting and whatever other information is necessary. The disabled individual and/or parents should be informed of the advantages of such a move and their consent sought *before* any such action is taken.

Respecting the persons' reactions to the news

19. It should be expected that the reactions of individuals vary enormously and cannot always be predicted.
20. Professionals should respect individual reactions and attempt to be aware of them and respond to them appropriately and supportively.
21. Some individuals may require immediate support from a team member as they may be in a state of shock and not wish to be left alone. Naturally, those whose reaction requires medical attention should receive it immediately.
22. Others may want to be left alone for a while, and will need to be given space. Such messages should be respected. In these circumstances it is known to be valuable that, before going home, people should be given yet another opportunity to speak to one of the professional team.
23. Follow- up contact (preferably with the same team member) should always be made immediately upon the disabled adult, or the parents' return home.
 - (a) Community support services should be made known to them immediately and early contact with community teams planned and followed up.

The need for privacy

24. One can never over-emphasise the need for privacy. Learning about one's own, or one's child's disability is a hugely traumatic experience and cannot be accomplished in inappropriate environments.
 - (a) Privacy and freedom from distractions, such as, telephone calls (fixed line and mobile), pagers, people walking into a room, generally noisy environments --- all these things need be taken into consideration.
25. It is advisable to find ways and means of imparting difficult news in private.
 - (a) However, if a mother has recently given birth and is still in the maternity unit, she should not be separated from her baby without discussion with the mother in each case. It is important that her wishes are respected.

Written information

26. Recently disabled adults and/or parents should be given legibly written (or preferably typewritten) notes immediately after the meeting to clarify what was said for future reference.
 - (a) These should be available in the language appropriate to the parents.
 - (b) A third person, preferably part of the professional team and already present (not some one extra) should take accurate notes.
 - (c) In order to respect confidentiality and to avoid undue anxiety, disabled adults and/or parents should be informed in advance that this will be done.
27. Useful contact numbers should be given so that the disabled adult and/or parents can make further inquiries as necessary.

PRACTICAL HELP AND INFORMATION

28. The individual's information needs will vary. They should be made aware that they may be eligible for various benefits and services, and advised where they can find out more relevant information, regarding:
 - social services
 - education
 - employment
 - peer support (disability-related NGOs)
 - other relevant services provided by the state and NGOs
29. Pamphlets should be made available, providing information about the impairment and about where to find practical help, for example, the variety and availability of services, benefits and support groups.
30. Furthermore, long-term informal support arrangements should be made, for example, by giving support, where required and requested, during the process of informing the rest of the family (especially siblings in the case of a disabled child) and friends.
31. Collaboration between professionals and voluntary support organisations, or NGOs, will help considerably in helping these families cope with their situation
32. Adults who have recently acquired an impairment, or parents of children who have done so, should --- as a matter of priority --- be put in touch with relevant voluntary organisations. Generally, individuals who have recently experienced such traumas, value the help they have received by NGOs.
 - (a) Unfortunately, many report that this information was not given to them, or that they only found out about it by chance.

- (b) Close collaboration between professionals and voluntary organisations should ensure that recently disabled adults and/or parents benefit fully from the help available through the voluntary sector.
33. While English is the language of instruction in Malta, particularly at university level, professionals are well advised to remember that Maltese remains the first language of the majority of the people they will be dealing with. On the other hand, in Malta there is a not inconsiderable number of people whose first language is English.
- (a) Therefore, throughout these procedures it is absolutely crucial for the professional to take into account the language needs of the people they are dealing with and to address them in their preferred language. If the professional cannot do so, then appropriate arrangements should be made for the news to be imparted to the person(s) in their preferred language.

Ed. Joseph M. Camilleri

References:

Scope (1994): *Right from the Start*. A report.