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## 4. CURRICULUM

### PARENT INTERVIEWS

1. **Emotions Experienced by Parents of Disabled Children: (Dr Ronald McKeith)**
  - Two Biological Reactions:
    - Protection of the helpless
    - Revulsion at the abnormal
  - Two Feelings of Inadequacy:
    - Inadequacy re reproduction
    - Inadequacy re rearing
2. **Feelings of bereavement:**
  - Anger
  - Grief
  - Adjustment
  - Shock
  - Guilt
  - Embarrassment
3. **Parent Self-Help / Support Groups**
  - Research has identified specific approaches and in particular the need for early identification and intervention.
  - It is now apparent that Parent Power has become the most effective way to effect implementation.
  - Parents have to be proactive to lobby for appropriate education and resources.
  - Legislation globally has given more power to parents.
  - In Europe and the UK in particular parents have now realised the possibilities e.g. the mass demonstration in London, meeting with the Prime Minister and the Autism Bill passing through Parliament in 2009.
  - In South Africa it is proving difficult to mobilise parents of learners with autism once their children are in a specialised facility.
  - In meeting parents of children who have not been able to access schooling it was observed that there were feelings of helplessness, depression and resignation. Parents often seem to be looking to professionals to fight their corner.
  - This is also the case with parents of adults with autism.
  - There is a need for NPO's to bring parents together and to lobby government and agencies to become involved.
  - Professionals can help by encouraging parents to raise the profile of autism e.g. World Autism Day (WAD).
4. **Three Requests from Parents to Professionals**
  - Please LISTEN to us. Parents have an instinctive feeling about their child and also an accurate idea of the child's level of functioning.
  - PLEASE, PLEASE use teamwork so that we do not have to tell our story over and over again.
  - Please let us know ALL the services available so that we can make an informed choice.
5. **What can Educators do to help?**
  - Communicate
  - Home visits
  - Telephone calls
  - Home school diaries
  - Meetings
  - Set priorities jointly
  - Have realistic expectations
  - Exchange information
  - Undertake joint training
  - Daily diary or log:

- Summarise the whole day or give a copy of the schedule.
- Share one thing learned and that can be reported in a positive way so that it furthers knowledge about the child.
- Describe any problems in class and *relate to the barriers to learning i.e. educate about an area of difficulty*. Withholding information leads to lack of trust and angry reactions from parents at a later stage.
- Ask questions at the end so that parents can give feedback about the child at home. They are the experts on their own child!

## 6. Conclusion

- Remember: Professionals go 'off duty' which parents can rarely do