

9. What parents and professionals say about supporting a child with a physical disability

In the early stages of this research project, the following issues were identified as important topic areas;

1. New diagnosis – coping, discussing with the child
2. Loss and grief
3. Positive support mechanisms
4. Making positive adjustments
5. The role of fathers
6. Positive parenting skills – behavior management skills
7. Negotiating major transitions associated with a condition e.g. loss of mobility, social isolation
8. Falling behind childhood development milestones
9. Frustration at being different, not being able to express this in healthy ways
10. Self esteem
11. Becoming aware of one's difference and being different from one's peers
12. Acting out issues
13. Anger management
14. Sexuality – what it means to be a boy or girl (self image)
15. Transition from child to adult
16. Planning for the future
17. Change in role i.e. from parent to full-time carer

Based on those issues, various key informants, (parents, and others working in the disability sector) were asked a series of three questions, which were:

- A. What do you see as the major psycho-social (emotional and social) issue for the target audience?
- B. Are there any particular things you have seen, or know of, that make it easier (or more difficult) for the family or child at the time of initial diagnosis?¹
- C. Are there any other subjects that you think should be covered, keeping in mind the project brief?

Although not detailed here, they were also asked “Are there any particular resources you know of or would recommend for the target audience, or me as researcher?”

While there is some overlap, and some items could fit into multiple categories, broadly speaking the responses of the *Key Informants* fall into the following categories.

1. Help and Support – The needs and ways of dealing with the additional caring and support needs of a Child with a Disability.

2. Communication Issues – Related to the need to deal productively with a range of health and other professionals, in relation to the care, treatment, educational and other needs of the child with a disability;

3. Grief Issues – Dealing with the ongoing grief related to having a child with a disability. This can include the guilt and grief of the parent, as well as dealing with the responses of others, in the child’s life. There is also the need, with some conditions, to deal with the child with a disability having a shorter life expectancy than a person without that disability.

4. Parenting Issues – Some of the additional issues related to having a child with additional care needs, and the implications of this on family dynamics, and finances, and the paid working, and caring responsibilities of the parents.

5. Sibling Issues – The implications for family dynamics, the roles and expectations of siblings of a child with a disability.

6. Sex, Drugs, and Rock and Roll – An acknowledgement that as a normal part of adolescence, issues around sexuality, drug use, (legal and illegal,) and independence from the family of origin will arise.

7. Personal, and Physical development and changes – Dealing with the psychosocial and physical development of those with a physical disability, and the differences compared to a child without a physical disability.

8. Education Issues – Primarily these relate to physical access and mobility issues of the child with a disability in an educational setting.

¹ In some later cases, (e.g. in school setting) and marked with * the question was amended to become “Are there any particular things you have seen, or know of, that make it easier (or more difficult) for the family or child in the setting in which you work?”

The following is a summary of the responses to these individual points.

1. Help and Support Issues

1. Finding a regular GP for the child with a disability, to deal with issues unrelated to the disability can be a problem, particularly for those cases where the child with a disability is non-mobile;
2. It is an advantage for parents to surround themselves with an accessible medical team (i.e. one of the advantages of networking with other parents with a child with a disability, the ability to find "good" Drs etc.);
3. Be prepared to pre-book/regularly schedule holidays/and or respite (without the child with a disability), as a normal part of the routine of raising a child with a disability;
4. Being aware of the support services, and funding sources is important;
5. The need to do extra paid work (e.g. overtime,) to assist in the financial side of running of the household, and help with the extra costs of raising a child with a disability will probably create further strains on the household, and interpersonal relationships;
6. Finance is an issue, in that the higher the income, the greater the ability to get additional services etc.
7. Community acceptance is not there yet, i.e. there is still stigma attached, potentially more so in some ethnic communities where there is the potential issue of a child with a disability being perceived as bringing "shame" onto the family, or extended family;
8. Dr's sometimes more interested in research, than day to day management;
9. For the question, "Does religion play any part in coping with the situation?" (in the context of a religious school) I was told it does with some families, but is very much a mixed response;
10. Guardianship, Legal wills, and Family Trusts, in that in some situations the child with a disability may have access to large sums of money, e.g. if parent's die suddenly/unexpectedly, or receive a payout related to the disability;
11. Maintaining interpersonal relationships (between parents of child with a disability and with others, in social and family network) including respite care, and related potential social isolation, if difficult to find appropriate babysitters;
12. Parent/peer support is not done well in WA, e.g. Perhaps it could be possible to set up a MSN (internet chat) group;
13. Need to be aware of the potential, or understanding/acceptance that it may be necessary to relinquish guardianship of a child with a disability, if the parent cannot cope;

14. Resources (both human and physical) for those from a Non-English speaking background can be extremely difficult, if not impossible to find;
15. Social Networks very important, in that a family can be coping equally, well (rich and poor) if they have the same levels and types of support;
16. The need to look at and create a supportive environment within the family, community, and educational settings for the child with a disability;
17. There can be a problem, or particular need for respite for carers of adolescent males, who may be angry and or violent;
18. Transition from child to adult, can mean reduction in types/availability of services, e.g. school to non-school services;
19. There is the risk of isolation if there is a perceived (or real) need to keep the child at home;

2. Communication Issues

1. Assertiveness/powerlessness or lack of control and communication issues, can be an issue, in particular with medical professions, and the need to develop appropriate communication skills for interacting with these service providers/health professionals;
2. Be prepared to take somebody else along with you as an advocate who is not so directly involved;
3. Dr's "bedside manner" [my term] can sometimes make a number of differences, (keeping in mind their "gatekeeper" role), e.g. their attitude to (and or knowledge, or lack of, about,) a particular type of intervention, or service provider;
4. For separated families, there is a need to find way's of sharing information between the parent's, as sometimes, as part of the grief related to the breakdown of the relationship is the belief (rightly or wrongly) that information is sometimes used as a "bargaining tool" or "reward", between the separated parents;
5. Information overload, can be a problem in particular in relation to Duchenne Muscular Dystrophy, but there is the "double-edged sword" of wanting/needing as much info as possible, at the time of diagnosis;
6. Other's expectations e.g. Teacher's, Occupational Therapists;
7. Parent's may forget or "not take in" info due to information overload;
8. Parent's may need advocacy skills, in the medical/hospital setting, as otherwise the interaction may become a "battle of wills" or adversarial;
9. Parent's should try to avoid self-censorship, when interacting with the medical/care team, and remember that doctors are not "Gods";

10. Parents should feel comfortable about taking a “Shopping list” of questions, on visits to the health professionals;
11. Some insight into positive and negative attitudes/beliefs of those directly or indirectly involved may be of help.

3. Grief Issues

1. The time of initial diagnosis, can be a time of huge stress, that can “shatter” the family;
2. Whether or not the parents have had previous contact with a person with a disability will impact on how it affects them;
3. Adjustment (for parents) to issues re looking for “cure” rather than “maintenance” ;
4. Advisable to have an “automatic” appointment (at the time of initial diagnosis,) with a counsellor, to assist with coping/adjusting to the news;
5. Attitude to diagnosis, (in particular in the case of DMD) i.e. looking at death versus life will have an impact;
6. Grief – because sometimes it can take up to 6 years to get a diagnosis, also the constant change for the worse (with degenerative conditions);
7. In the case of degenerative conditions, the need to make the most of the time available, and set achievable goals;
8. Issues related to being a single parent, (apparently a high incidence of this);
9. Lots of Dad’s “cut and run”;
10. Need to be aware of help and support for parents, children (including classmates) and families and schools in relation to early death (i.e. for degenerative conditions);
11. Need to look at the child with a disability and others in the school community and grief, related to the loss of function;
12. Anecdotal reports that it is not uncommon for families to separate shortly after a house has been built/modified for wheelchair access;
13. The implied sense of responsibility behind looking for the “cause” of the disability;

4. Parenting Issues

1. All children including child with a disability have a right to; a.) Make mistakes, and; b.) Be teased;

2. Condition specific training for parent's e.g. a.) How to manage condition; b.) Implications of doing/not doing particular exercises/interventions; c.) Expected side-effects of particular drugs;
3. Guilt re use of/need for respite care, and constant "visitors" to home, and perceived need (by parents) to have clean and tidy home;
4. Learned helplessness of the child with a disability can be a problem;
5. Parent's can forget to teach child with a disability life skills;
6. Seek to pre-empt / avoid behavioural problems by use of appropriate parenting techniques, skills, and or training, e.g. the "Triple P Parenting program" modified for child with a disability;

5. Sibling Issues

1. Family "behind the 8-ball", due to financial costs of raising a child with a disability, will have implications for how the family uses it's financial resources, i.e. disproportionately on the child with a child with a disability;
2. Family can't (normally) be a 2 income family , as parents/carers, constantly going to Dr's etc;
3. Mother (being most likely carer) can be/feel less fulfilled due to full time carer role, rather than returning to workforce;
4. Sibling Issues – a.) Attention diverted to the child with a disability; b.) Perception that Mum loves child with a disability, more, better, can result in anger;
5. Sometimes siblings of a child with a disability can be inappropriately expected, (implicitly, or explicitly) to take on duties and roles they are not ready for, or it is not reasonable to expect of them, e.g. physical lifting of a child with a disability, or physical or emotional support of siblings or parent/s, or de facto parenting of younger siblings²;
6. Sometimes teachers can expect siblings of child with a disability to be the same as the child with a disability, i.e. do not take into account individual differences;

6. Sex, Drugs and Rock and Roll

1. Do not ignore the sexual health, and sex education of the child with a disability, particularly for adolescents; as this relates to development of self;
2. Need for both child with a disability and parent's to develop relationships outside home;

² For sibling issues and support see www.siblingsaustralia.org.au

3. Sometimes parents can be too “nurturing”;
4. Be aware of the issue of drugs, (both prescribed and illicit, i.e. IV drugs) and alcohol, for child with a disability;
5. For parents “letting go” can be an issue i.e. the usual dependence-independence issues of adolescence, can be complicated by the disability, e.g. personal hygiene, and mobility issues;
6. The need to empower the family and child with a disability to make decisions;

7. Personal and Physical Development and Changes

1. Manipulation by the child with a disability, (their ability to “see a sucker at 100 paces”) can also be a problem;
2. Child with a disability becomes centre of attention, doesn’t always recognise this and may become egocentric, and resulting in lack of compassion for siblings, and impairs social/emotional development. i.e. does not become responsible, compassionate, and looking outside self.
3. The process is different for spinal injury patients vs congenital disabilities.

8. Education Issues

1. Preparation for life after high school, i.e. education, training, paid work or other activities (also a parenting issue);
2. “Breaking into” a new school can be problematic/difficult;
3. At secondary school age, self image and body image can be major issues;
4. For sports carnival’s, a parallel carnival for child with a disability is run by a Phys-ed rather than a Special Ed person;
5. In educational setting, unstructured situations e.g. small group discussions, create less problems*;
6. In response to my question, about educational settings, “Are there any particular Girl Issues?” It was noted that the circle of friends reduces, and the child with a disability may want to be in a school, where they are not the only child with a disability;
7. In settings like school camps, and other excursions, there can be hidden barriers to access, that can best be prevented, by a thorough, “walk-through” of the venue, or excursion destination beforehand*;
8. In the school setting, the issue of how degenerative conditions are dealt with, depends on the teacher, as much as anything, which may well be affected by the response of the primary carer;

9. School subjects where there is “equipment” of some kind, (e.g. science, art, home economics,) can result in problems, which can be reduced by planning well in advance*;
10. Secondary school children with a disability don’t like modified sports and may go to the library instead;
11. Off-site school excursions can be difficult, due to being unable to get a taxi to arrive on time, if available, and alternatives, like hiring a bus with a wheelchair hoist, can be difficult.
12. If thinking about private schooling, be prepared to plan well ahead (e.g. for someone planning to go to a private high school, need to start planning in yr.6) to allow time for any building modification etc. in case it is needed.