

## A BRIEF GUIDE FOR PARENTS of HEART KIDS DURING INFANT AND SCHOOL YEARS

The following information is provided to the parents and caregivers (parents) of children with congenital heart defects (HK Children). Most of the HK children lead normal lives but find physical activities very difficult. Things many of us take for granted such as running outside or even walking up stairs, can be very difficult or not possible for these children.

The lack of energy and mobility when HK Children are infants means that parents need to spend time to stimulate their development by encouraging activities such as artwork, plasticine, music, computing and key board skills. Such activities may require '*one on one*' attention, but are a great alternative to mind dulling television and videos!

Their first days at kindergarten may require parents to be present to remind staff of their physical needs and limitations (if any). Depending on the medical condition and the energy levels of the HK Child, parents may need to be available for their child during their times at kindergarten and school.

As HK Children reach school age, it is worthwhile that the kindergarten teacher speaks to a school staff member about future special needs and development opportunities during the primary school years.

As the HK Child progresses through school, some parents will need to become an advocate for appropriate physical, and curricular development of their HK child. Some options are as follows:

Negotiated Education Plan NE Plan (formerly known as a Negotiated Curriculum Plan) are used when planning curriculum for a range of other students including: children & students with learning difficulties, gifted learners, home schooling, distance education, and some with behavioural needs. A NEPlan can be developed with a key staff member of the school, and it is necessary to be part of a review assessment at least once a term. There are two categories:

1. *Child with learning difficulties*
2. *Child with life threatening illness* (reduced energy and/or mobility)

The NE Plan can be as simple as reduced contact hours, less homework or can mean that special emphasis on passive subjects and activities. A NE Plan can be tailored to suit the needs of the HK Child.

If you think your HK child might need a NE Plan then arrange an interview with your child's teacher to discuss your concerns prior to a request professional

support. If your child is assessed or verified as having a disability then support services can be arranged.

Further information can be accessed at your local preschool or school, Family and Youth Services- children's services Ph 82267000, South Australian Student & Professional Services 82261774; or the following District Education Offices: North 82568111, South 82073700, East 83668800, Riverland 85952323, Yorke 8821 2555.

(Source: South Australian Department for Training, Education and Employment- NEP pamphlet)

Choosing suitable subjects and activities: There are opportunities for HK children throughout life to use and develop their fine motor skills. Passive activities such as music, art, computing, lateral thinking activities (i.e. chess, board games) can assist in stimulating the development and creating self esteem of the HK child.

Activities such as swimming can assist with aerobic exercise of the heart, following approval of the cardiologist of course! The Education Department provides funding for children on a **Negotiated Education Plan** to attend specialised swimming lessons (Contact your District Education Office-Special Needs or Disability Coordinator see phone numbers mentioned above). Please note though that parents are responsible for transporting the HK Child to the venue and it must be within school hours.

However, it is most important that a Child or teenagers confidence remains high.

Here are a number of ways to boost a child's confidence:

- Lots of hugs and kisses when to babies and when they are young;
- Tell children you love them;
- Smile and talk from the very start;
- Give praise for things achieved like making beds, cleaning shoes, cleaning teeth;
- Avoid nagging;
- Discipline children by removing them from the situation;
- Share daily activities (preparing meals, share stories);
- Stay calm and be fair remember, you are the adult and your child's teacher!
- Reinforce and encourage your child's good behaviour. Use praise or a special game or time with your child;
- Spend time with your child. Play, enjoy fun times or read together;
- When children misbehave let them know they are OK its their behaviour is not okay;
- Take time to listen to children and really hear what they are saying and want to share with you;

- Encourage children to develop their own strategies for achieving things and help them review their effectiveness- resist the temptation to provide your adult solutions all the time;
- Encourage children to see " mistakes" and "awkward moments" as a natural way of learning;
- Children feel valued and important when family and friends watch them participate in school or weekend sports or hobbies;
- Take an active part in your child's schooling & help out at school where possible;
- Teach children personal safety principles especially saying "No" to unpleasant or harassment situations. They must learn to trust their feelings, recognise that they own their own bodies and that they don't have to keep secrets which frighten or hurt them;
- Teenagers are more likely to respect your views if you respect theirs;
- Respect your child's privacy- they need their own space and time to themselves;
- Let your children know you are always there to provide comfort and support;
- Make it clear that you want to be involved. If you find that you are not often involved you may want to work really hard at it;
- Don't impose your thoughts- if you think your teenager has odd views, remember that imposing your own attitudes could make things worse;
- Lastly, laugh with your children not at them.

(Source in part includes NAPCAN Australia brochure - [www.napcan.org.au](http://www.napcan.org.au))