# Information and resources for clinicians after a diagnostic assessment

The following are approaches to providing support and intervention for an individual and/or their parents or caregivers after a diagnosis of FASD has been made.

They are relevant for children, adolescents and adults. These approaches are also important to address patient needs even when the diagnostic assessment is inconclusive or FASD has been excluded.

#### 1. Explain the diagnosis:

Using a *non-judgemental approach* that recognises the range of emotions that might be experienced by individuals, parents or caregivers when a diagnosis of FASD is given, explain that making a diagnosis can:

- improve understanding of FASD
- improve understanding of the individual's difficulties while also identifying their strengths and help parents and carers adjust their expectations and provide support accordingly
- provide opportunities for individuals, parents and caregivers to express and/or process a possible range of emotions
- facilitate early intervention to improve a child's development, and
- identify individuals and/or their family members who are in need of assistance, eg referral to alcohol and other drug services.

#### 2. Provide individuals, parents and caregivers with:

- the reports of assessments from health professionals
- the outcomes of the assessments, eg diagnoses; provisional diagnoses; need for further assessment
- the details and implications of a FASD diagnosis (or non-diagnosis)
- some 'plain English' information about FASD and contact details for support organisations, and
- a contact number for a clinician who can respond to any questions that arise following diagnosis about the assessment and/or management plan.

# 3. Develop a management plan with individuals and/or their parents and caregivers so they:

- can identify their priorities and goals for inclusion in the management plan
- are aware of therapy options and family support mechanisms available as appropriate interventions put in place
- are empowered during future assessments, management and support
- · are aware of accessible parent, caregiver, family and personal networks in their community
- are aware of support organisations
- are aware of the need for referrals and further medical review and of potential waiting times for services, and
- receive a copy of the management plan.

### 4. Consider support and interventions:

#### Build therapeutic interventions around the individual's:

- strengths, interests and positive attitudes
- willingness to participate in family, school or institutional activities and routines, and
- engagement with their family, peers and/or caregivers.

#### Key approaches include:

- educating individuals, parents and caregivers about FASD and related impairments
- improving parent, caregiver and teacher understanding of interactions with the child, adolescent or adult living with FASD
- ensuring appropriate educational support and accommodations are implemented
- · targeting therapy programs towards supporting the individual's key functional difficulties
- medication (when indicated and appropriate), and
- advocating for the individual, eg in education, child protection or justice systems.

#### Challenges to address may include:

- challenges of daily life, eg caregiver fatigue, the need for routine and repetition
- emotional or behavioural problems for many individuals living with FASD, including aggression
- the family's need to access multiple health services, potentially with limited communication between different service providers
- service providers with limited knowledge about FASD
- the need for individuals, parents and caregivers living with FASD to educate teachers, health and other professionals about FASD
- the lack of recognition of a FASD diagnosis as a disability, providing a hurdle to obtaining funding for educational and other assistance, and
- a lack of recognition of coexisting mental, developmental or physical health conditions.

#### **Eight Magic Keys** (listed on page 3)

- These eight strategies underpin successful strategic interventions for students with FASD and are one example of an approach that can be taken.
- They are simple, functional strategies to use with young people with FASD and can be used by caregivers, teachers and health professionals.
- They were developed for use by the FASD Centre for Excellence, Substance Abuse and Mental Health Services Administration.

# 1 Concrete terms

Children living with FASD do well when parents/carers and educators talk in concrete terms. Refrain from using words with double meanings, idioms etc. The social emotional understanding of children living with FASD is often below their chronological age, therefore it helps to 'think younger' when providing assistance, giving instructions etc. It is also important not to make deficit judgements.

# 2 Consistency

Due to the difficulty that children with FASD experience in generalising learning from one situation to another, they do best in an environment with few changes. This includes consistency in language and routines. Educators and parents/carers should coordiante with each other to use the same words and/or gestures for key phrases. Communication books are effective ways of sharing what's happening and advising on language use and behaviours in classrooms and homes.

# 3 Repetition

Children with FASD have chronic short-term memory problems. They forget things they want to remember, as well as information that has to be learned and retained for a period of time. In order for them to commit something to long-term memory, it often needs to be repetitively retaught.

# 4 Routine

Stable routines and consistent visual cues that do not change from day to day make it easier for children with FASD to know that to expect next, and decrease their anxiety, enabling them to learn.

# 5 Simplicity

Remember to keep input short and sweet. Children with FASD are easily overstimulated, leading to 'shutdown', at which point they can take no more information. Break down tasks and always communicate the task in the positive: "we walk inside" instead of "don't run".

# 6 Specific language

Say exactly what you mean. Remember that children with FASD have difficulty with abstractions, generalisations and 'filling in the blanks' when given an instruction. Tell them step-by-step what to do. This will help them develop appropriate habit-forming patterns. Keep instructions concise and broken into achievable chunks.

# 7 Structure

Structure is the 'glue' that enables a child with FASD to make sense of the world. If this glue is taken away things fall apart. A child with FASD achieves and is successful because his or her world provides appropriate structure as a permanent foundation for learning.

# 8 Supervision

Due to their cognitive challenges, children with FASD bring a naivety to daily life situations. They need constant supervision, as with much younger children, to develop habit patterns of appropriate behaviour and ensure safety and well-being at all times.

## **FASD Scotland**

#### www.fasdscotland.com | Email: info@FASDscotland.com

FASD Scotland offers information and awareness about the lifelong risks of prenatal exposure to alcohol as well as support and advocacy to families caring for a child affected by FASD. It provides strategies for managing FASD and training for professionals involved with individuals affected by FASD. Through partnership with other agencies it aims to prevent FASD and reduce secondary disabilities.

#### National Organisation for Foetal Alcohol Syndrome - UK

NOFAS UK 022 China Works 100 Black Prince Road, Lambeth London SE1 7SJ

Helpline: 020 8458 5951

www.nofas-uk.org | Email: help@nofas-uk.org

The NOFAS-UK Helpline responds to enquiries from parents, family members, carers and others needing advice or referrals for children with FASD disabilities. NOFAS-UK organises events focused on wellbeing for families and carers of children with FASD and provides resources that help support those with FASD at home and in school.

