

Management Guidelines – 13 to 18 years

<u>WHO</u>	<u>WHAT</u>
GP	<ul style="list-style-type: none"> • Listen to parents' concerns about their child • Listen to child's concerns if they are able to express them • Manage referrals to other specialists as appropriate • Consider whether there is any evidence of seizure activity which warrants further investigation • Refer family to AusDoCC for support
Paediatrician/ Developmental Paediatrician	<ul style="list-style-type: none"> • Monitor development and refer for further developmental assessments as necessary • Consider whether other diagnoses are appropriate such as autism, ADHD • Refer child for appropriate therapeutic interventions • Consider whether there is any evidence of seizure activity which warrants further investigation • Address any particular puberty-related issues • Refer family to AusDoCC for support
Paediatric Neurologist	<ul style="list-style-type: none"> • Manage neurological issues such as epilepsy • Refer family to AusDoCC for support
Geneticist	<ul style="list-style-type: none"> • Consider whether there is an underlying genetic cause for the child's ACC • Consider whether there are any familial links which justify review of other family members • Undertake microarray, targeted gene testing and WES • Refer family to AusDoCC for support
Other specialists Endocrinologist Urologist	<ul style="list-style-type: none"> • Manage related symptoms such as growth issues, incontinence
Ophthalmologist	<ul style="list-style-type: none"> • Is there evidence of any vision issues such as cortical visual impairment, nystagmus, strabismus etc
Occupational Therapist	<ul style="list-style-type: none"> • Provide therapeutic input to address fine motor skill difficulties, life skills such as toileting, feeding and dressing and sensory symptoms • Consider other related symptoms such as sensory processing disorder • Consider whether child would benefit from equipment such as bath seat, toilet frames and steps, specialised beds, any aids to assist with sensory needs • Refer family to AusDoCC for support

Speech Therapist	<ul style="list-style-type: none"> • Diagnose and treat speech delays and difficulties • Consider whether child would benefit from alternative assistive communication aids • Refer family to AusDoCC for support
Physiotherapist	<ul style="list-style-type: none"> • Provide therapeutic input to address gross motor function including symptoms of high or low muscle tone • Consider whether child would benefit from assistive equipment such as seating support, standing frame, walker, orthotics, wheelchair or other mobility aids • Refer family to AusDoCC for support
Orthotist	<ul style="list-style-type: none"> • Prescribe and manage any orthotic supports needed to assist walking and other motor function
Behavioural Psychologist / Psychiatrist-	<ul style="list-style-type: none"> • Provide strategies for child and family in the management of behavioural problems or anxiety • Focus on development of young adult's communication skills, and structured settings • Assist with young adult's adjustment to problems being experienced • Assist young adult to deal with emotional problems, image issues etc
Counsellor	<ul style="list-style-type: none"> • Provide the young adult with a safe place to talk without fear, providing reasoning and negotiation rather than directions • Assist the young adult to negotiate school stress and handle criticism, whilst controlling emotions.
Youth Mental Health / Support Worker	<ul style="list-style-type: none"> • Assist the young adult with issues such as self-doubt, depression, relationship drama, mental illness, self-harm, anxiety, sleep disorders, behaviour and the pressures of finding a career path • Provide treatment including medication and alternative behavior education.

Educational Management Guidelines – 13 to 18 years

<u>WHO</u>	<u>WHAT</u>
Principal/Educators	<ul style="list-style-type: none"> • Cooperation from High School to support your child’s needs in learning - NEP, special needs co-ordinator and honest correspondence with medical professionals and any health professionals the child has been referred to.
Special Needs Coordinator	<ul style="list-style-type: none"> • Establishing a system for extra help required in subjects, extra time for tests/exams, and have a safe place or timeout area arranged if needed. • Honestly about your child’s needs and ways they can work around any difficulties that may arise.
Sex/Alcohol / Drug Education	<ul style="list-style-type: none"> • Alcohol/drug/sex education more in depth than standard classes involving repetition and making sure your child has a firm grasp on actions and consequences
Vocational Training	<ul style="list-style-type: none"> • Help provided a smooth transition between school and university or the work force (whatever choice they make) • Possibly provide a buddy system or similar to establish routine and help blend in with society as far as need for punctuality etc
Independent living skills	<ul style="list-style-type: none"> • Educating your child on independent living skills • Teach functional skills, such as cooking basics, pay bills, leave phone messages, arrange social contacts, transportation, etc • Encourage to join social clubs where the child feels they fit • Help with teaching your child to drive and sit for a licence if it hasn’t been done already.

Compiled by AusDoCC members consisting of adults with a DCC, parents, partners and friends.

Reviewed by AusDoCC advisors including practitioners, researchers, clinicians, educators and allied health professionals.

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