Amaze & Reaching Families FACT SHEET Updated July 2016

LEISURE

This fact sheet has been written by parent carers for parent carers



Like everyone else, disabled children and young people want to spend free time with friends doing things they enjoy. Although it may require a bit of thought and planning and quite possibly some additional support to make leisure activities work, it's well worth the effort. It will improve the whole family's quality of life.

The leisure basics

Encourage your child to harness their strengths or interests and try new things. It's hard to be sure what they'll enjoy if they haven't tried it!

Try to do some things as a family; it's easy to concentrate too much on your special child and get the balance wrong. If your child's needs make it hard to 'fit in' with ordinary family activities, joining up with other families who have children with similar needs to yours can help you feel more relaxed and confident about trying new things.

Be open to mainstream activities and 'special' ones; sometimes children and young people want to be like their non-disabled peers and distance themselves as much as possible from their differences or disabilities. At other times the same children may only feel confident alongside disabled peers.

Don't overdo it. Not every moment of your child's day has to be filled with something educational or therapeutic. Children need time and space just to be themselves and to daydream.

It's meant to be fun. It's easy to get hooked up on rules and protocols, structure and learning outcomes and these may be important, but if you ask children and young people what matters, they just want to have fun with friends.

Call ahead. If you're away from home, it's worth ringing disability organisations in the area you're visiting to find out what's going on. Contact big attractions before you visit - many offer concessions and special passes, so you avoid the queues.

Remember disabled young people really enjoy just 'hanging out' with mates at the shops, cafes, the park, the beach and clubs. You could find out about Direct Payments to help your teen organise their own support to enable them to do this. Or you could look out for local buddy schemes - see the 'Ask about' section below.

Choosing leisure activities

Ask your child what they want to do and avoid influencing their choices or encouraging them to do what adults think is best.

Ask other parents about safe places to go and fun things to do, especially when they have children with similar needs to yours.

Don't dismiss a club because parents are required to stay. Some of the best activities may be organised by other parents and volunteers who may not be able to take responsibility for supervising children going to the loo, for example. And these are often the places to meet other parents and exchange tips.





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You are likely to have many 'what happens if' and 'how will you' questions when visiting a new leisure activity. What will you do if my child cries? How will you respond if my child has a seizure? Of course you are itching to be reassured. But if you ask all your questions at the same time, it may knock a club's confidence about including your child. So just ask the really important ones.

Sometimes it's more useful to sit and see how a session runs. Written policies are fine, but what happens in practice is more important. Upsets that go unnoticed and grown-ups who seem more interested in their own news than the children's should ring alarm bells.

Making leisure activities work

Have five or so 'helpful things about your child' to hand that you can share with the leisure provider. You can write your list with your child, encouraging them to think about what's important to them. You might also make another list of more personal or medical information that's shared only on a 'need to know' basis.

Encourage your child to think about how they would like to be introduced and whether they'd like to do this themselves.

If you observe anything that worries you, discuss it. You shouldn't necessarily be worried by difficult or challenging situations; how they are managed is what matters.

Expect it to take some time for your child to settle and others to get to know them; accept there are bound to be hiccups along the way. Making friends and learning new skills takes practice and even old friends fall out sometimes. If things don't get off to a good start or hit a bad patch, take a deep breath and stay encouraging.

If you can't find the sort of leisure activity your child would like to do, you could set up your own club. Drawing on the energy and good will of other parents or disabled young people can help make it happen. You don't need to be a charity to attract funding, but it helps to have a constitution or 'some rules', a bank account and to be clear about what you want to do and the difference it will make.

Ask about

- Autism Sussex runs clubs and siblings clubs, go to www.autismsussex.org.uk or call 0345
- **Brooklands Park, Worthing** accessible playground with equipment opened by RADAR key and bike track for children with physical disabilities.
- **Compass Card** this is a free leisure discount card (administered by Amaze) for 0 to 25 year olds with significant additional needs who live or go to school in West Sussex, or who are looked after by social services in the county. Call: **0300 123 9186** or find out more at: www.amazebrighton.org.uk.
- **Core Assets** provides short breaks for children and young people via a one-to-one buddy to help them access local opportunities. Tel: **01903 753948** or email: **conor.chong@coreassets.com**.
- **Family Fund** you may be able to get help to pay for activities and short breaks. Go to: www.familyfund.org.uk or call: 01904 621115.
- **Family Information Service (FIS)** for information about leisure activities in West Sussex go to: www.familyinfoservice.westsussex.gov.uk, call: 01243 777807, or email: family.info.service@westsussex.gov.uk.





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- **Gig buddies** matches adults who have learning disabilities with volunteers with similar interests for gigs and events. Visit: www.gigbuddies.org.uk.
- Horsham Park, Horsham accessible swing opened by RADAR key.
- **Groups and clubs in West Sussex** include the Ashdown Club, Worthing: **01903 528607**; Kangaroos, Haywards Heath: **01444 459108**; PACSO, Chichester: **01243 533353**; Springboard Project, Crawley: **01293 531963**, Horsham: **01403 218888**.
- Local clubs and activities, parent support groups refer to our handbooks *Making Sense of It All* and *Making Sense of Adult Life*, which both contain directories of organisations and leisure activities running locally and nationally, as well as local groups where you can meet up with other families whose children have similar needs to your own. For further information, visit our website: www.reachingfamilies.org.uk.
- National Autistic Society (NAS), Worthing Branch runs a number of activities for children and families, including a Lego club. Call: 07766 525909.
- Sussex Association for Spina Bifida and Hydrocephalus (SASBAH) runs a number of services including social groups and activities. Tel: 01903 230782 or go to: www.sasbah.org.uk.
- **Short breaks** available for children and young people aged 0-18 years who live in West Sussex and have a disability and/or additional need. Children who receive middle or high care component of Disability Living Allowance (DLA) automatically qualify. For more information (and to also find out more about respite options) go to: www.westsussex.gov.uk/media/7940/short_breaks_directory_2016.pdf, email short.break.team@westsussex.gov.uk or call: 0330 222 2562.
- Worthing Kids & Dapper Snapper Worthing-based charity who have strong connections with families of children with Down syndrome. They run a number of projects and services including drop-ins for parents and children, a youth club and swim school. Visit: www.wkds.org, call: 07570 768893 or email: info@wkds.org for more information.
- Worthing Scope runs Super Scopers, a group for families of children with additional physical needs. Visit www.worthingscope.org.uk or contact their community liaison worker, Jo McCaffrey, tel: 01903 821437 or email: joanna@worthingscope.org.uk.

Further information and useful links

- Making Sense of it All and Making Sense of Adult Life (14+) Reaching Families' handbooks for parent carers of children and young people with SEND in West Sussex provide essential information on leisure and social lives, money matters, social care, health, employment and much more. Go to: www.reachingfamilies.org.uk.
- **Fact sheets** our companion fact sheet, *Short Breaks*, gives further advice on leisure activities. Our *Direct Payments* fact sheet explains how to use funding to arrange your own care. For more go to: www.reachingfamilies.org.uk/factsheets.htm.
- **Disabled Go** a national website with access information for many areas of the UK. Visit: www.disabledgo.com.
- **English Federation of Disability Sport** has information on sports opportunities for disabled children. Visit: **www.efds.co.uk** or call: **01509 227750**.
- West Sussex Local Offer go to https://westsussex.local-offer.org.



