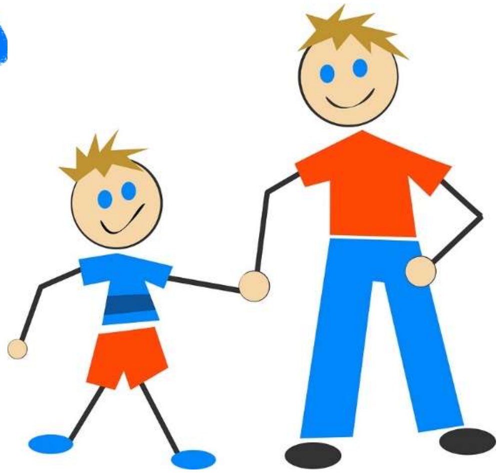
A Dad’s Journey

This toolkit is for Dads or male carers of a child with developmental disability or delay.

Here is some information and ideas about ***things that other Dads (from our Dads Group!) have found helpful to know about as part of their journey of parenting a child with additional needs.***



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With special thanks to the Dads from the Dads Group for their input and support with the development of this toolkit.

A Dad’s Journey

As a Dad whose child has a developmental disability or delay, you may feel that everything feels *‘new’* and *‘uncertain’* in the beginning. You may have lots of questions to ask, but equally may feel unsure where to start.

You may feel worried about starting off on the wrong foot, and feel worried about *‘getting it wrong’*, which might come from wanting to do your best for your child.

You may feel like there is a long road ahead, and you are unsure about the role you should take in your journey. You may feel lots of emotions and experience thoughts around wanting to *‘fix it’* or things like *‘am I needed?’*, *‘what’s going on?’*.

All of these thoughts and feelings are ones you might expect when your world feels different to how you imagined it, or how it did before.

A Dad’s Role

At some point in your journey, you may feel worried about the part you have to play in supporting your child or your family. It is important to acknowledge that some Dads might feel excluded from their role as a carer because of expectations from society that a Mum or a woman might be more ‘involved’ in this role. This can feel like a very difficult pressure and barrier to break down when you are wanting to do your best to be involved and care for your child. You may feel ‘shut out’ from this world and unsure what to do to feel on board.

Some of the things you might experience are:

- Professionals telephoning Mum/female carer as a default instead of you
- Not being addressed or invited into conversations in meetings or appointments
- Feeling like you don’t know any other Dads or male carers in the same position as you

It is vital to remember that the onus is on professionals to help change these ‘expectations’ that have been set up by society. If you feel comfortable, it might be helpful to let a professional know that this is a worry for you, however, we recognise how hard that is to do if you are in a positon of already feeling ‘on the outside’.

These feelings might come from the very early days in your child’s life where there may have been situations that you felt were gender-specific or exclusive to Mum. It is ok to feel this way.

“...problems of like breast feeding and not sleeping in the night, those are experiences that are unique to that gender. And in a way they're very sensitive issues that you just can't get involved in or relate to. So quite often you're blocked out or isolated.”

(Batchelor, Maguire & Shearn, 2020)

ACTIVITY

Write down 3 times where you may have felt stuck, excluded, or on the outside of your child’s care. Then, write down 3 times where you were proud of yourself for the role you played in your child’s care. This might help you acknowledge that even being thoughtful about some of these dynamics means you are a great Dad/carer!

Back to the Beginning – Diagnosis is not the Start

When your child receives a diagnosis of developmental delay or difficulty, it can feel like a really destabilising time. It may feel like the life or the future you have imagined for your child will feel slightly different. You may feel a wealth of different feelings that can feel hard to sit with. Examples of these might be…

These are all very expected feelings. It can be important to hold in mind that a diagnosis or a label might not mean this is the ‘start’ of your journey for you or your child. It is likely that you will have been doing lots already to notice, understand, and respond to their individual needs. Try to hold on to this and remember that a label for your child’s needs does not change their needs or who they are as a person.

Top Tips from Dads

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Your journey might take lots of time and energy. If you have a partner, it's can be helpful to support each other to ensure you both have time for yourselves. It doesn't have to be anything big, it might just be a meaningful separate space from everyday life to maintain your own identity.

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Connect with others who either share your experiences or understand your experiences really well. This might help things to feel like less of a weight on your shoulders.

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Try to find ways to be involved in your child's medical, health or emotional care in whichever ways feel comfortable and possible. Good communication with people involved in your child's care might help with feelings of exclusion. This might feel uncomfortable at first! Is there anyone who can support you with this?

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Think about strategies that can help you to sit with uncertainty. There may not always be answers to everything which can feel difficult, so supporting yourself and others to feel comfortable with this can be powerful. It's ok to not know what to do.

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Where possible, have lots of open communication with other family members. This might involve supporting people to "get it". Being on the same page with strategies and approaches can mean you are working with each other, rather than against.

Connecting with Others

Connecting with others who are in a similar situation to you can be a helpful way to share experiences. This can help with feelings of being 'alone' when going through something challenging. Below is some information about the **Dads Group** that runs within **Serennu Children's Centre**. Groups in North and West Gwent are also in development and will be on varying Saturdays!

For fathers / grandfathers / male carers of children with a disability or developmental difficulty

The 2nd Saturday every month:

10am-12pm

Come for a chat and breakfast with other Dads at the Serennu Children's Centre!

"There's groups that I can attend with my children for my children but the dad's group is the only place where I can get an adult male perspective on living and functioning as a dad and partner, and the struggles that adding ASD into the mix brings with it. In short it's the only place I would say that I'm emotionally open and feel comfortable in asking for emotional support and advice".

"The Dads group has been a life line, discussing issues, realising that you're not alone, helping one another and providing support. Although some of the Dads have children with more complex issues it is the understanding of what it is to be a Dad with children who have additional needs. Talking about issues and getting a perspective, it is only 2 hours a month but we also try meet outside the group - creating friendships and understanding, something that is sometimes hard to do"

"They just get it. I fit in by being myself and there is a sense of connectedness after being in the same bad place. It is cathartic and helpful emotional processing"

"Meeting people who have survived this journey for longer than you is extremely comforting. It shows you what life can look like on the other side. Even though it has been challenging, they are all still laughing. It's so powerful and the experiences I have had in the group have been pure magic.

Stories from Dads

“One thing that has felt really challenging about my journey, and something I didn’t necessarily know I would need to prepare for, was having to go toe-to-toe with people you wouldn’t expect to need to. It’s not their fault, but I had to do a lot of teaching people I love about my child’s needs and advocating for them to avoid wider family rifts. The way I was parented and the way that I parent are worlds apart. I had no template for how to parent a child with additional needs. It felt hard to come to terms with the fact that my path in life and the expectations I had were not the same as my parents. Overcoming this has made me feel proud, and seeing shifts in other people’s mentality towards my child because of it fills me with pride. I had the power to help it not be an issue.”

“Throughout this experience I have really had to learn how to be emotionally ready, and how I prefer to process things so that they don’t impact my relationships with my family. For me, I used my ‘alone time’ during my commute home from work to process the stress I had experienced that day to avoid it impacting other parts of my life. Some people prefer to process alone or through talking to someone like a family member, but it can be helpful to know what works for you and that you explain this to others. Things were always stressful and challenging, particularly when supporting my child through challenging behaviours, but having my processing time helped me feel like I had some control over helping life to feel less challenging”

For me and my partner, one of the things that we have had to work hard at is bonding over difficulty and functioning as a team together. We realised that our relationship had taken a hit and so we ‘rolled up our sleeves’ whilst focussing a lot on talking, communicating and repairing. Being on the same page as each other has been so successful for us.

Breaking the Cycle

As a Dad, it can be powerful in itself to notice and understand the difficult feelings and worries you might be experiencing. You might also be wondering how to *'move forward'* and change how things currently feel. This might include wanting to become more involved but being unsure how. It's important to be kind to yourself and acknowledge that there may be things that make this feel harder, like what is mentioned above in 'A Dad's Journey'. There may be other things that make this feel challenging too – like taking time off work. We hope the below resource will help to build your confidence to start to think about your role and experiences as a Dad / male carer of a child with developmental disability or delay.

"You are just as important" was a key message from our Dads Group attendees.

Here is a link and QR code to a fantastic resource from Contact – on information for Dads of disabled children. (You can also type this in on Google!). It includes information on the following:

- Relationships
- Dealing with employers
- Thinking about finances
- When you don't live with your child
- Useful organisations

Hover your smartphone camera over this image!

SCAN ME

fathers.pdf (contact.org.uk)

Top Tip

Our **'Building Resilience'** toolkit is available for all parents and carers, to think about your own wellbeing needs and the importance of looking after yourself as a caregiver of a child with additional needs. To receive this, please contact us using the details on the last page of the toolkit.

Useful Resources

Self-help Apps

Self-help apps can be a useful and viable way of support. The NHS have published apps on thei digital library, some focussed on helping you relax include:

Calm	Chill Panda	Headspace	Mindfulness	Woebot

Useful Websites

The following websites may offer some useful resources and information regarding building resilience, learning disabilities, and mental health support.

- https://www.nhs.uk/apps-library/category/mental-health/
- https://www.mind.org.uk/media/17944275/peer-support-toolkit-final.pdf
- https://www.mind.org.uk/
- https://www.psycom.net/dealing-with-change

Further Support

Children's Centre Psychology Team: If you require further support please use the contact details overleaf to contact the team in your designated Children's Centre.

GP: If you are concerned about yourself or a member of the family you can access support from your local GP.

Charities: Charity organisations such as Mind Cymru, Samaritans and Young Minds may also be able to provide you with support with emotional wellbeing.

Mind Cymru	02920 395 123
Samaritans	116 125
Young Minds	0808 802 5544

Local Support Groups: Groups are a great way to meet new people and to talk about shared experiences. Here are the links to some we are aware of in the local area:

https://www.facebook.com/SparrowsAln/ http://www.valleydaffodils.co.uk/

https://www.magicparents.co.uk/ http://www.buildingbridgesproject.org.uk/

https://hopegb.co.uk/ https://dads-can.co.uk/

https://www.asdinfowales.co.uk/newport-autism-support-group/

Contact

This toolkit was created by the **Children's Centre Psychology** team at Aneurin Bevan University Health Board (ABUHB).

Your feedback in important to us! If you would like to tell us what you thought about this self-help toolkit, please get in touch with us using the contact details below to speak to a member of the team at your local children's centre. We would love to hear from you.

Additionally, if you need any help or support with using or accessing these resources, please do not hesitate to contact to contact us with the below details.

Serennu Children's Centre 01633 748023	**Nevill Hall Children's Centre** 01873 732713

Caerphilly Children's Centre
02920 867447

Please contact the team if you would be interested in any of our other toolkits on the following topics –

Understanding and Managing Behaviour

Building Resilience

Supporting Siblings

Friendships

Promoting Sleep

Managing Anxiety