The Prader-Willi Syndrome Association UK

Impact Report

www.pwsa.co.uk

This report is based on an independent Outcomes Evaluation conducted by Insley Consulting Ltd. Names have been changed or quotes anonymised to protect the people with PWS involved, as well as their families. Some quotes have been edited slightly for readability. Case studies are based on interviews with parents who have engaged with PWSA UK. Photographs used beside case studies and quotes are not of the people with PWS and families featured.

Contents

Foreword

Over the last four decades, PWSA UK has helped thousands of people impacted by PWS.

I am delighted to introduce the first Impact Report of the Prader-Willi Syndrome Association UK – PWSA UK.

PWSA UK truly is a special organisation built on the need for support, services and advice for families living with Prader-Willi syndrome (PWS). As a charity and a membership organisation, it is ever more important that we can demonstrate the difference we are making through our services. It is equally important to ensure that we listen to our community and continually strive to improve and do ever better.

The Association was born out of the need to provide peer support and up to date information, at a time when people with PWS started to be diagnosed. We acknowledge those who were there at the start of the PWSA UK, who had the vision and energy to sow the seeds of this vital organisation that serves the PWS community in the UK.

In our day-to-day work, we see the difference that we make, but this report supports this with evidence that we are making a positive impact in the lives of the people we work with.

We are a community of members, family, professionals, carers, trustees, funders, staff, volunteers and supporters and we come together to help overcome the challenges of PWS.

Great progress has been made in medical and behavioural interventions to help improve outcomes for people living with PWS. But we know there is, however, still so much more to be done – in research, to understand PWS better and mitigate its impacts, and in supporting people with PWS to achieve a good quality of life.

This report is a moment to celebrate how far we have come – but it also gives us renewed energy to keep working to serve the PWS community, without a trace of complacency.

We remain committed to ensuring that we understand the needs of our community and seek their guidance and feedback, so we can ensure we are doing our very best for them today and for as long as we are needed.

Jackie Lodge
Chief Executive

PWSA UK in numbers in 2022-23

> *"PWSA UK provides a community of people who really understand where you're coming from, and what your challenges are. They walk shoulder to shoulder with you."*

84% of parents/carers feel better able to

MANAGE WORRIES

71% of parents/carers

FEEL LESS ALONE OR LONELY

We had **747 MEMBERS**

68% of parents/carers agree that we have helped them to

ACCESS BETTER SUPPORT from external organisations

87% of parents/carers think they have a

BETTER UNDERSTANDING OF THEIR RIGHTS AND ENTITLEMENTS

We delivered

70 EVENTS

with **1144 PEOPLE**

with PWS and their family members

Adults with PWS that we have supported

HAVE BETTER WELLBEING

than adults with a learning disability in general

16 OUT OF 18

ADULTS WITH PWS MADE NEW FRIENDS

with our help

We delivered **20 TRAINING SESSIONS TO 239 PROFESSIONALS**

94% of parents/carers feel they have a

BETTER UNDERSTANDING OF PWS

About the Prader-Willi Syndrome Association UK

The Prader-Willi Syndrome Association UK (PWSA UK) provides support to people affected by Prader-Willi Syndrome (PWS) and their families, to help them manage the complexities of the condition.

About Prader-Willi syndrome

PWS is a rare and complex genetic disorder that can affect anyone – male or female – from birth and throughout their lives, as there is no cure. Approximately one in 22,000 children are diagnosed with the condition. In the UK, it is estimated that there are about 2,000 people living with PWS.

Research (from Crinò et al., 2018, and others) shows that Prader-Willi Syndrome has an impact on every area of life.

On a physical level, it can cause overwhelming appetite and can lead to overeating, which in turn can lead to severe obesity and associated life-threatening illnesses such as diabetes and cardiovascular disease. According to the same study, babies with PWS can have difficulty feeding because of low muscle tone, and young people and adults may have short stature, difficulties with mobility and scoliosis. People with the condition can also have changes in their hormonal functioning and difficulty recognising and communicating pain – this means that a health issue can present in an unusual way and be overlooked, which may become life-threatening.

On a cognitive level, PWS can cause learning difficulties and people with the condition may also be autistic. The syndrome can affect mental health, meaning people with PWS are more likely to have mood disorders, like anxiety and depression. All these symptoms can lead to difficulties in socialising and challenging behaviours, and increased stress on family members.

Our sustained impact goal

We work to support people with PWS to live a healthy and fulfilling life and help their families access the support they so badly need, when and how they need it, whether they are in crisis or not.

In short, our aim is to help the PWS community to live life to the fullest!

Living with PWS

Living with a rare and complex condition like PWS, or supporting someone who does, is difficult and it can be hard to manage life without the right support in place.

Challenges people with PWS and their families can face include:

Lack of knowledge and information about the condition

Due to its rarity (Kowal et al., 2022). Most healthcare professionals may never have come across someone with PWS before. Therefore, understanding the condition is essential for people with PWS and their families, as it enables them to advocate for their health needs and manage the condition better. PWS can present very differently and its evolution is hard to predict, so there isn't a "one size fits all" approach.

> ***It's very important to understand PWS because nobody, no one else understands.***

Adult with PWS, focus group participant

Loneliness and isolation

Due to the lack of understanding of the condition, particularly the stigma around learning disability and neurodivergence. The need for routine and food management and the challenging behaviour that some children and young people with PWS present make it more difficult for families to leave their home and socialise. Because Prader-Willi syndrome is so rare, people affected by it and their families may never meet other people with the same experience, which is very isolating. People with PWS may also find it hard to interact with other people and make friends.

> ***It's a hugely isolating condition, partly because it's so rare. And because the specifics of it are so unique. So things like learning difficulties and challenging behaviour will encompass a lot of sort of genetic syndromes. But when you add in the very specific behavioural issues that we face, particularly around food, it is very isolating.***

Parent/carer of child with PWS interviewee

Financial Stress

That comes with living with a disability and the cost of living crisis, but also due to missed income – parents of people with PWS may have to give up work partly or completely so they can support their son/daughter with PWS, while people with PWS may not be able to work.

> ***Family-wise it completely changed our lives. I never fully went back to work, I either work part-time, job share or freelance. The only reason I could do that is because I get carer's allowance and benefits for my daughter – financially it had an impact.***

Parent/carer of young person with PWS, interviewee

Pressure on wellbeing, relationships and family life

Due to the learning difficulties, issues with socialising, mental health problems and challenging behaviours that PWS may cause as well as the difficulty to manage eating and exercise to prevent severe obesity and its associated health problems.

Families of people with PWS can experience life as a series of crises (Kowal et al., 2022). Additionally, a study by Whittington et al. (2022) showed that the restrictions of the Covid-19 pandemic may have had a negative impact on the mental health and behaviour of people with PWS.

> ***We can't do a lot with our son at the moment. We can't take him out because he's so unpredictable.***

Parent/carer of child with PWS, interviewee

Worrying about the future

As living independently is not possible for many people with PWS, so in adulthood, many need residential care – this, compounded by a lack of consistent services, can lead to worries about the future for both the person with PWS and their family.

> ***I fear for my son coping without me in the future.***

Parent/carer of adult with PWS, survey respondent

Difficulty in accessing services and professional support that fully meet their needs

Due to lack of knowledge and understanding of the condition of professionals in the health, education and social care sectors. People with PWS usually need different types of medical care, including endocrinology, dietetics, orthopaedics and physiotherapy, psychiatry and psychology. Families may also need additional support during times of transition (for example, going to school or moving to residential care) to access appropriate support services and funding. Lack of adequate services and support can have a negative impact on the mental and physical health of families of people with PWS (Kowal et al., 2022). Not accessing appropriate support can also directly affect the economic and employment situation of families of children with developmental disabilities like PWS (Vohra et al., 2013).

> ***When my son was 18 months, they did some blood tests and they came back saying it was PWS ... The paediatrician at the hospital didn't know much about the condition. When my son was born, he had a dislocated elbow and hips, and that took over the PWS. It was only later that they investigated that.***

Parent/carer of adult with PWS, interviewee

Why we exist

Our vision is to overcome the challenges of PWS.

Our mission is to ensure that every member of the community has access to high quality care and support, so they can live the healthiest and most fulfilling lives possible.

To support our community, we:

- Provide advice, support and services to people who live with Prader-Willi syndrome and their families.
- Raise awareness about the condition, especially among professionals in the health, education and social care sectors, and provide support to them so they can better work with people with PWS.
- Support research efforts into PWS and its impacts.

The Association was founded over 40 years ago, by parents of children with PWS, at a time when there was very little information and understanding of PWS and very little support.

As the quality of medical care has evolved, people with PWS today are living longer, and PWSA UK has grown and developed to respond to the changing needs of the PWS community.

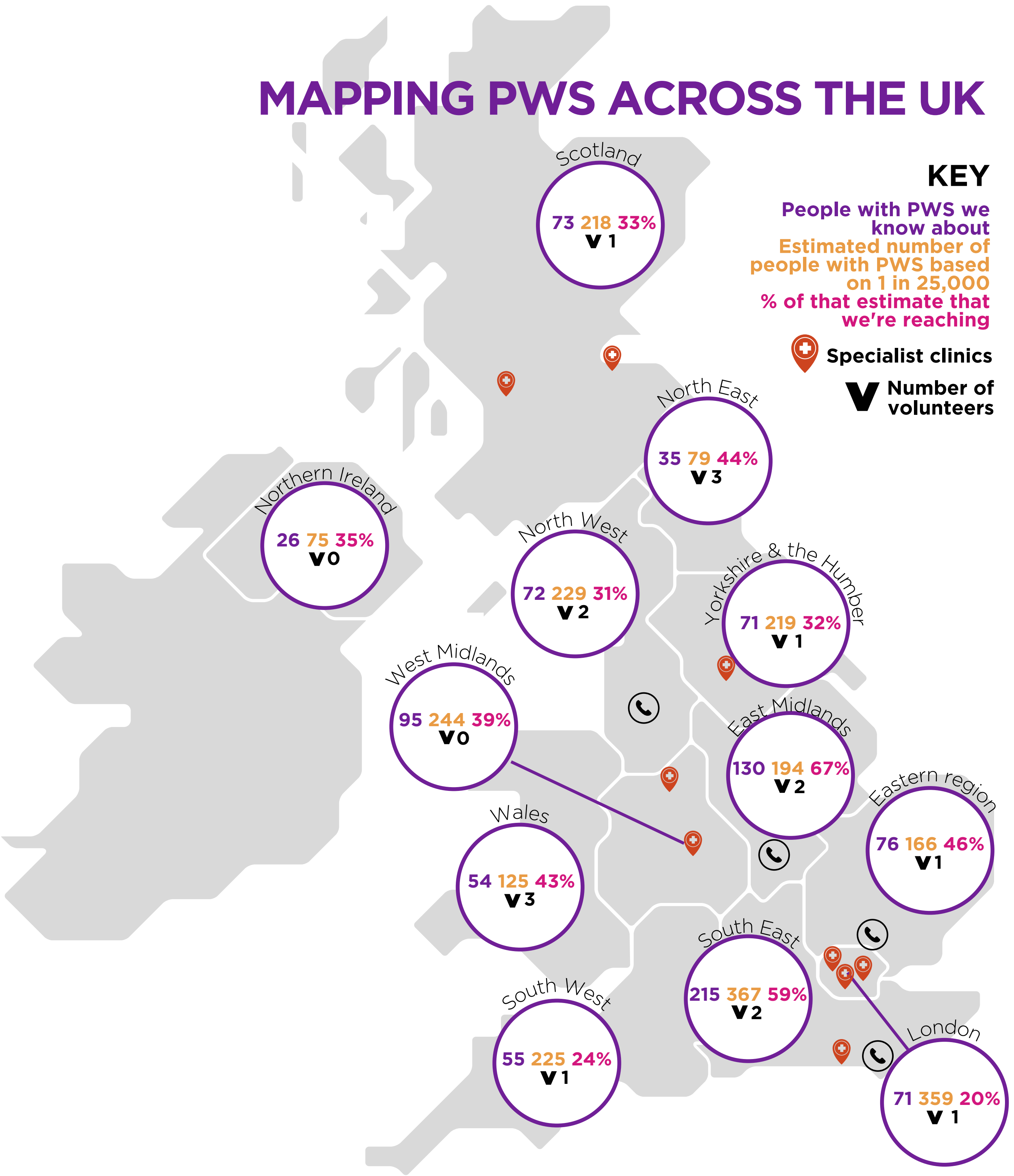
> “ ***Having the support from the PWSA UK is very much like having an extended family giving me a ‘psychological hug’, providing reassurance and guidance all along the way, as they completely understand the challenges of having a child with PWS. I don't feel alone.*** ”
>
> Parent/carer of child with PWS, written testimony

About the Prader-Willi Syndrome Association UK

Continued

We provide support to **people of all ages** – from parents whose newborn baby has just been diagnosed with PWS, through to adults with PWS who get in touch with us for the first time to get help with applying for benefits.

MAPPING PWS ACROSS THE UK



Who we support

We work with people that are diagnosed with Prader-Willi syndrome (or who suspect they might be) and their families across the UK.

Our membership

We are a membership organisation, but support anyone that has PWS or cares for someone who does, regardless of whether they are members.

Our membership scheme is free of charge and open to anyone 16-years-old or over who shares our mission, vision, and values.

As a member of PWSA UK, you will be joining an organisation that has supported the PWS community for over forty years, and you will have the opportunity to:

- Join a thriving community.
- Attend our community events.
- Network with people with PWS, their families and others from the PWS community.
- Get direct access to our online community (including peer support groups) – a vibrant forum of like-minded people who share experiences and advice.
- Stay up to date with our online Members Newsletter bringing you PWS news and updates.
- Attend our Annual General Meeting.
- Elect our board of trustees.
- Use your lived experience of PWS to influence our strategy and work.

There were 747 members in total in 2022-23
including **323** who have PWS themselves

We also work with professionals in the health, education and social care sectors, by providing information and guidance on their interaction with people with PWS, as well as training.

What we do

We deliver a variety of activities and services:

Helpline

Available through telephone and email, to anyone who needs support in a crisis, mediation with services, information about the condition and approaches to managing its challenges, or emotional support. This is available to people with PWS, their families and also professionals.

Advocacy and support

Tailored one-to-one support to people with PWS and their families, from helping to fill out benefit claims and attending meetings with professionals on families' behalf, all the way to assisting with behavioural issues and supporting a move into residential care.

Information hub

Online library with various publications about PWS, its impact and ways to manage its manifestations in various areas of life – from health and education to finances and relationships. PWSA UK keeps abreast of relevant changes in legislation (e.g. on the rights and entitlements of people with disabilities), as well as new developments in research (e.g. information about new therapeutic approaches).

Conferences and information events

An annual National Conference and online webinars to share information that is relevant for the PWS community.

Peer support network

A UK-wide network that enables parents and carers of people with PWS to help each other, through meeting online and in-person, as well as interacting with Facebook groups. The network is run with the help of our volunteers.

Community events

A programme of events all over the UK throughout the year, including days out and weekends, that provide a safe and relaxed environment for people with PWS and their families to meet other people and have fun.

Training and support for professionals

We raise awareness of PWS among healthcare professionals, to support with early diagnosis, and train staff working directly with people with PWS (e.g. social workers).

Research support

We support research on PWS, its impact and how to best manage it, by connecting the PWS community with opportunities to participate in medical trials and studies and collaborating closely with the Foundation for Prader-Willi Research UK (FPWR UK).

The number of requests for support is increasing, as is the complexity of the issues presented to us

PWSA UK supported people with PWS, their families and professionals with

1,070

issues
in 2022-23 (4% more than in 2021-22)
and took

2,682

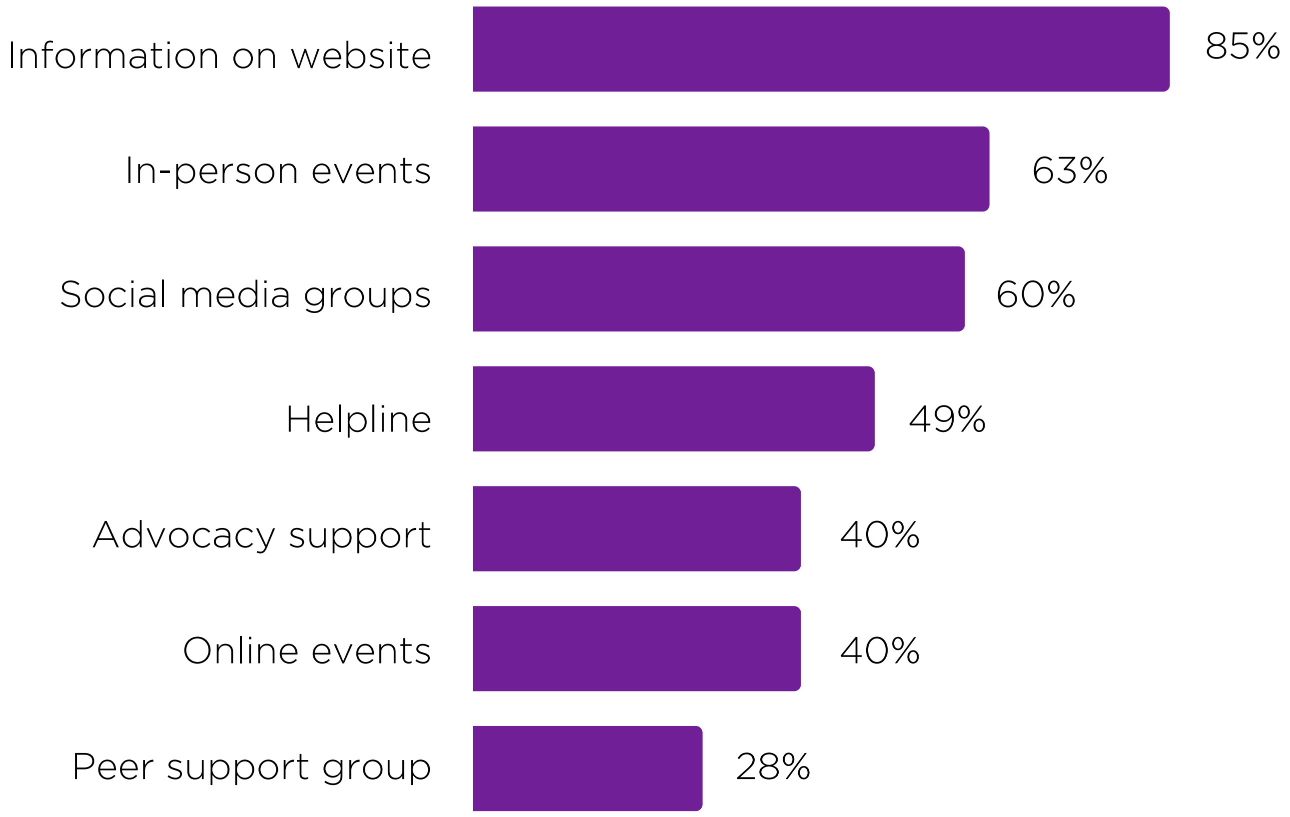
actions (calls, letters, meetings)
to support their resolution
(16% more than in 2021-22)

We supported

40

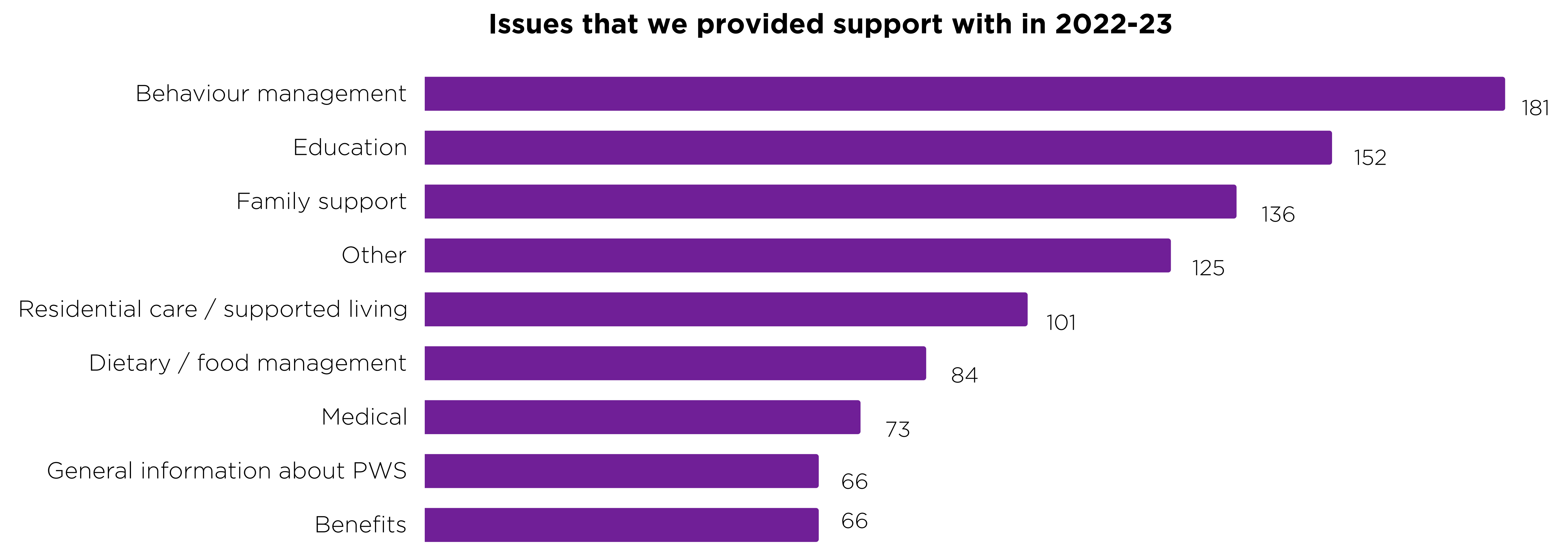
newly diagnosed people

PWSA services accessed by survey respondents in 2022-23



(86 survey respondents)

Our most used service is our online information hub



800 issues recorded by PWSA UK in 2022-23

In 2022-23, we delivered

70 events with 144 attendees, including:

30 community and social events

35 webinars and information events

5 peer support group sessions

22

volunteers fundraised and helped us run peer support group sessions and community events

The photograph used here is not the person mentioned in the testimony.

> “The association was invaluable in providing support to us and enabling my daughter to receive the very best possible start.”

TESTIMONY:
How PWSA UK has helped me and my family in our journey over the years

My amazing daughter has PWS and is now unbelievably 23 years of age.

It’s a little blurry now. She was approximately seven weeks old when the prognosis came through – it was recognised early on that she had some genetic condition. When she was diagnosed with PWS, we were simply offered an A4 photocopied sheet with an extremely alarming article – not to mention inaccurate. That was all we received before we were discharged. We were now on our own.

We felt so isolated and in shock with the magnitude of the situation, it was so daunting. At this time, the only real source of information was the library.

Then somehow, we discovered PWSA UK. Our contact started off with friendly and supportive phone calls and within seven months we plucked up enough courage to attend our first conference in Derby.

The association was invaluable in providing support to us and enabling my daughter to receive the very best possible start.

The best example of this was PWSA UK providing us with the information required to facilitate my daughter receiving growth hormone treatment at a very young age.

Our family has continued its journey alongside PWSA UK. We have made lifelong friends and they have helped us all enormously in terms of knowledge and support. There is a real sense of family and community among us.

Today, the future of people with Prader-Willi is so much more positive, with real expectations of a better quality of life. We know more about the condition and with so much information, research and collaborative working within the community, the next generation has even more potential and will have positive outcomes.

The Association will need to continue to respond to the current challenges and changes. We will continue to work tirelessly to ensure that people with PWS are able to achieve their full potential in life.

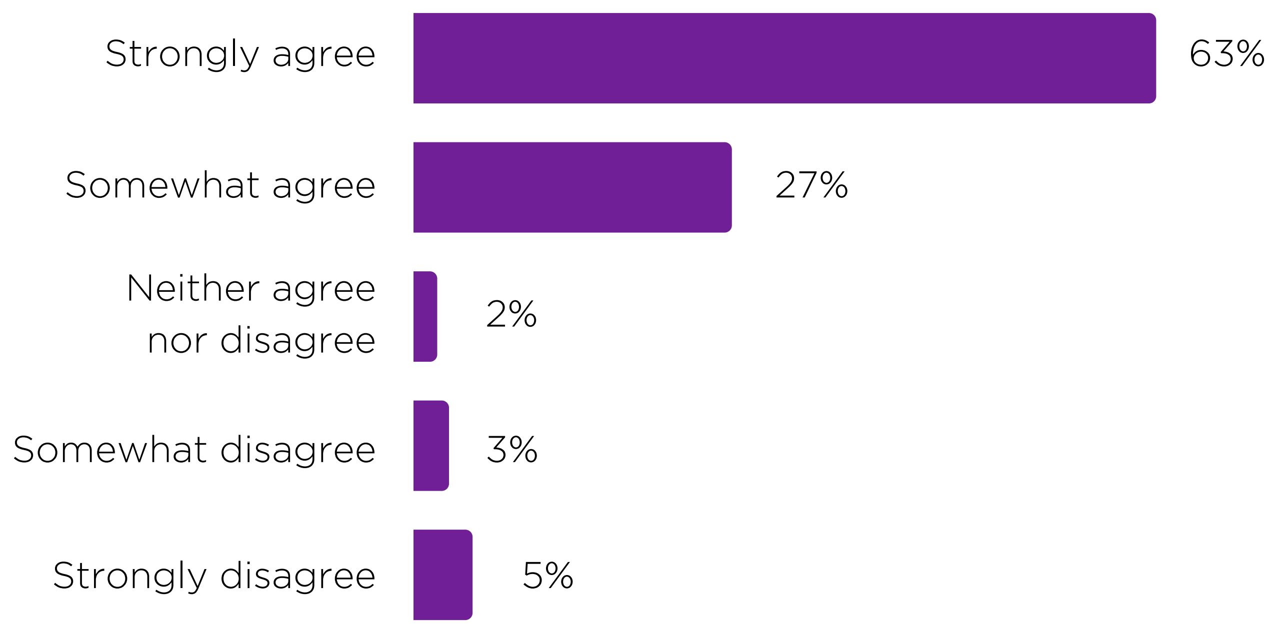
Ian Metcalf
Father of 23-year-old young person with PWS and PWSA UK Trustee

What the people we support say about us

Throughout our research for the evaluation, families and adults with PWS highlighted **what they most valued about our support**:

- **Comprehensive in-depth knowledge** about PWS, based on expert research and direct experience of the condition, that can be trusted and relied upon.
- ***“Lived experience”* of PWSA UK staff** members who have family members with PWS, which makes parents and carers feel truly understood.
- **Emotional support and reassurance**, whether that’s from the Association’s staff or from the peer support network, that makes a difference when families are in crisis.
- **Availability and promptness** – respondents noted we are ***“always there to talk when needed”*** and this helps ease some of the stress and anxiety of living with PWS.
- **Empowering and non-directive approach**, through outlining the options and encouraging people to make their own decisions.
- **Community building**, through our events and facilitated peer network, that enable people with PWS and their families to meet others with similar experiences, develop friendships, offer mutual support and experience joy together.

90% of parents/carers agree that PWSA UK is responsive to the needs of the PWS community



(86 survey respondents)

> ***For the Association to be able to cope with such a wide array of symptoms, the knowledge they have must be huge ... It's not just ‘one size fits all’, they've got to adjust to each individual case, which is obviously very good.***
>
> Parent/carer of child with PWS, interviewee

The difference we make

Our Theory of Change

Our Theory of Change below explains how our activities and services contribute to the positive changes (outcomes) we want to see in the people we support and our longer-term sustained impact goal.

The problem:

Prader-Willi syndrome (PWS) is a rare and complex genetic condition that causes excessive appetite and overeating. People with PWS often have learning disabilities and behavioural problems and it can be hard to manage life without the right support in place. Caring for a child or adult with the condition can have a devastating impact on the whole family, including their stress, mental health and finances. The education, welfare and health and social care system is hard to navigate, which means that families are often unaware of and able to access their rights and entitlements. It is difficult to find the right support, education and residential care setting (which is needed for most adults) that have appropriate behaviour and food management in place.

Who we support:

People with PWS (adults and children), their parents and carers, and the health, social care and education professionals who support them.

Activities

- Training, information & conferences
- Family events and peer support
- Advocacy, support and helpline
- Working with professionals
- Volunteer network and parent network
- Campaigning and influencing
- Supporting medical and social research
- Keeping abreast of relevant legislation and developments

Short Term Outcomes

People affected by PWS and professionals will be better informed about the condition

People with PWS and their parents/carers will feel less alone and be less isolated

Adults with PWS, parents & carers will have more knowledge of their rights and entitlements

Medium Term Outcomes

People with PWS will have increased mental wellbeing

People with PWS and parents/carers will have increased access to support they need

Sustained Impact Goal

People with PWS have a healthy and fulfilling life. Their families are able to access the support they so badly need, when they need it and how they need it, whether in crisis or not.

How we measured outcomes and evaluated our services

In 2022-23, we reformulated our monitoring and evaluation procedures.

We implemented two surveys, which informed our evaluation data for this report:

- One for adults with PWS,
- One for parents/carers of people with PWS.

We commissioned Insley Consulting to be our independent evaluators – they supported us in designing the survey, analysed the results and also conducted interviews and focus groups with people we have supported, including people with PWS, parents/carers and professionals in the health and social care sectors.

Going forward, we will continue to use the survey developed to evaluate our services and measure our outcomes.

120 people consulted and methods used

86

Parents/carer survey respondents

18

Adults with PWS survey respondents

13

focus group participants

11

interviews conducted

Improving understanding about PWS

Outcome 1:

People affected by PWS will be better informed about the condition

The rarity and complexity of Prader-Willi syndrome means it is not widely understood in society in general, and in particular within the health, education and social care sectors. This makes it **hard for people with PWS and their families to access the information, care and support they need** – sometimes even getting a diagnosis can be a challenge. This is why we provide information and advice through our resources, our helpline and our information events.

What people think of our advice and resources

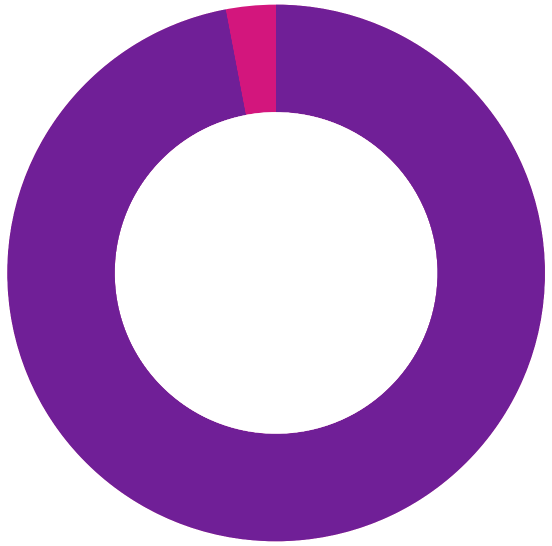
According to the evaluation data, parents and carers of people with PWS **find our resources *"helpful"*, *"valuable"* and user-friendly**, and many highlighted the usefulness of our information packs tailored to different age groups.

Parents and carers told us that **the Association is a consistent and reliable source of *"specialist expertise"*** about PWS and provides ways to deal with its challenges.

> ***The conferences and awareness courses are good. They always have help with the most obscure questions or situations.***

Parent/carer of adult with PWS, survey respondent

97% of parents/carers rate our information resources as good or excellent



(86 survey respondents)

Our online information pages were viewed

22,665 times

in 2022-23

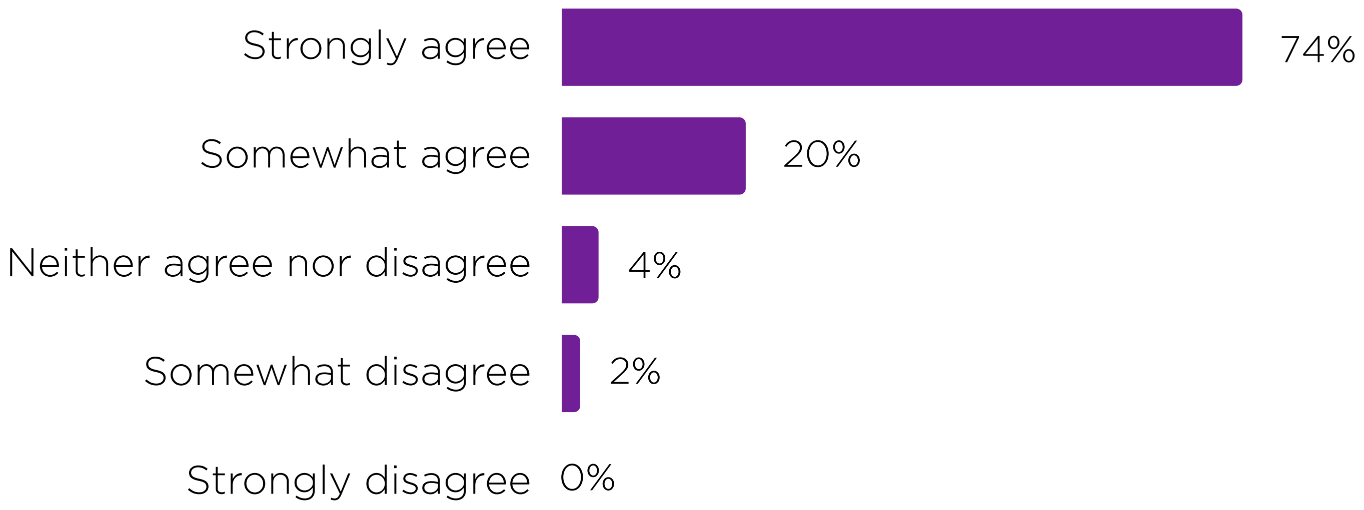
The difference that being informed makes to people with PWS and their families

According to our survey, **our support helped adults with PWS and their parents and carers improve their understanding of the condition**.

Several parents and carers pointed out that **PWSA UK was their only source of information about PWS**, and without us they would have been left to navigate this complex condition with fear and uncertainty.

> *“Without PWSA UK, no one else would help us – no one else knows anything about it. It’s not known, doctors don’t know about it; you have to explain it.”*
>
> Parent/carer of adult with PWS, interviewee

94% of parents/carers agree that they have a better understanding of PWS and the needs of their son/daughter as a result of support from PWSA



Number of survey respondents: 86 parent/carers

17 out of 18

adults with PWS think PWSA UK has helped them understand their condition better

The challenges of PWS are lifelong, and so is our support – most families get in touch with PWSA UK at the time of diagnosis and stay in touch. Many parents and carers told us we play a key role in **helping them stay *"up to date"* about the latest developments** and approaches.

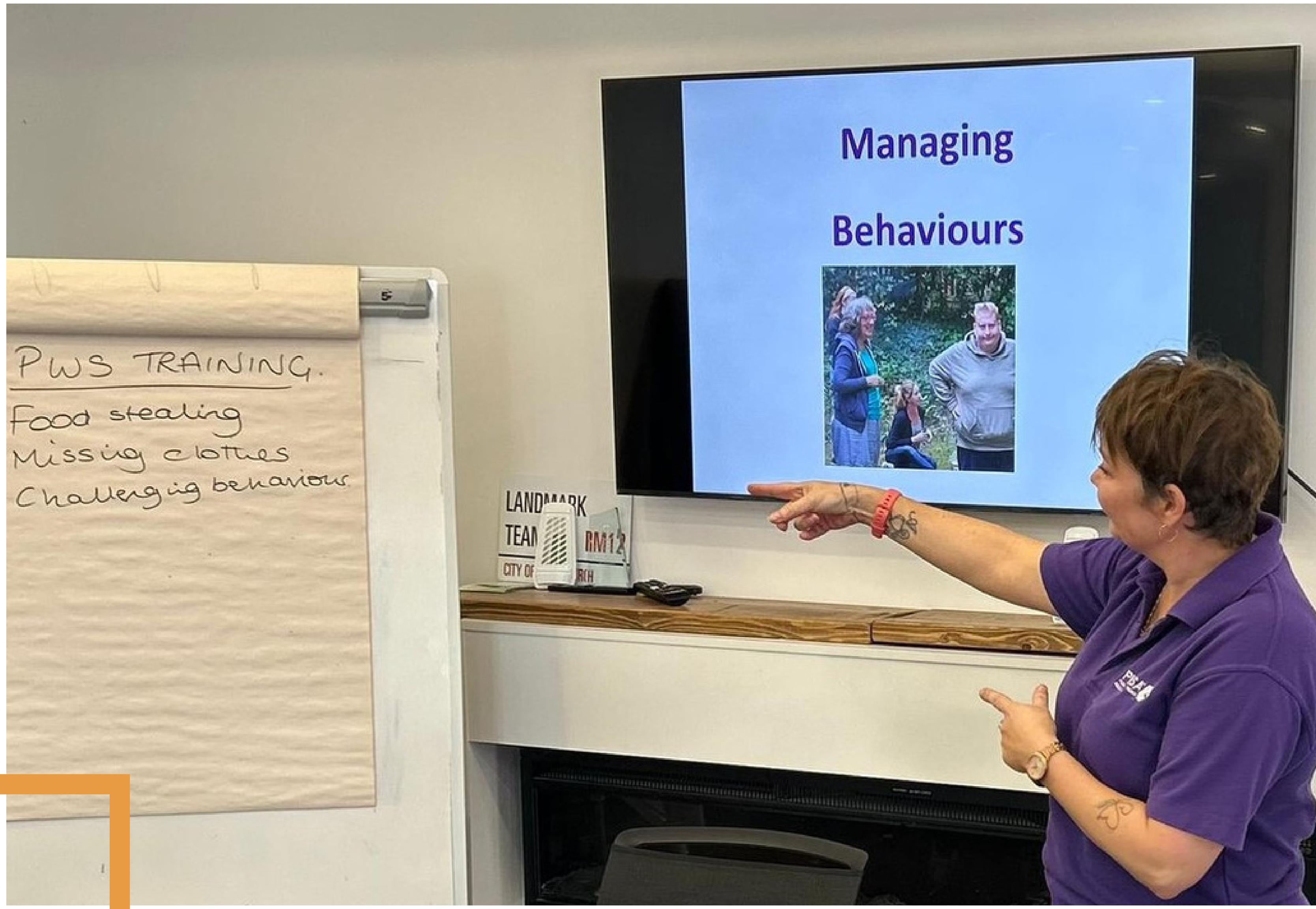
> ***The Association was a godsend when we first had our daughter … from the beginning when she was diagnosed at 3 months. We accessed lots of useful information about what to expect immediately, and also were given some more reassuring information about the future.***
>
> Parent/carer of young person with PWS, survey respondent

Being more knowledgeable about the condition leads to reduced anxiety, as both people with PWS and their family members feel more able to respond to the challenges the condition poses.

Several parents and carers also told us they **felt more able to support their family member with PWS at home and more confident in advocating for better care for them**. Our research shows that many family members of people with PWS feel like they have more knowledge about the condition than most health professionals they interacted with. In some cases, getting support from PWSA UK even helped getting an earlier diagnosis.

> ***When my son goes to hospital, I have a sheet that PWSA UK did … I can give that to a doctor … so they've got the main facts of Prader-Willi. It's given me skills to then help other people to support him.***
>
> Parent/carer of adult with PWS, interviewee

Understanding the condition better also **contributed to some parents feeling less alone and isolated.**



Training for professionals

We offer training to support professionals working in the health, education and social care sectors to understand Prader-Willi syndrome better – from teachers and social workers, to medical professionals and residential care providers.

20 **training sessions**

delivered to

239 **professionals**

in 2022-23

What professionals say

We also support professionals directly when they are working with someone with the condition. The two health and social care professionals interviewed by our independent evaluator **saw PWSA UK** ***"as the experts in PWS"*** **and felt their knowledge about the condition had increased through our support**, as it had enabled them to access information that was not available elsewhere.

They also thought that working with **the Association made their work more effective** by backing their decisions and making them feel supported.

> ***I have a lot of experience with people with PWS, but PWSA UK was always a very good reinforcer in the more difficult conversations, someone that 'has your back' … It was a real help. Sometimes, you can feel very alone working in learning disability.***

Health and social care professional, interviewee

Evaluator's conclusions

The evaluation makes a good case that support from PWSA UK makes a strong contribution to parents/carers and people with PWS feeling more informed about the condition and that this is a lasting change, as people remain consistently connected to the Association after their first contact. The evidence also points towards PWSA UK being the primary source of information about PWS for people with PWS and their families. We didn't conduct a survey with professionals, but there is emerging evidence that PWSA UK is a fundamental source of information and knowledge for them too.

The photograph used here is not the person featured in the case study.

> “I felt I was armed with information – things I could ask medical professionals about that I otherwise wouldn’t have known.”

CASE STUDY:
How PWSA UK supported me to get better medical care for my daughter

When Diane* was born and diagnosed, 24 years ago, the hospital gave me a one-page printout from the web. I got in touch with PWSA UK when she was a few months old – I rang them up and I remember feeling like I’d gone to the right place.

I found the conferences very good because they had workshops about particular issues that you might want to find out about.

Twenty years ago, when Diane was little, growth hormone wasn’t standard treatment for people with PWS, but I heard about it when I went to the conference. After that, I went to our consultant and asked him about it – he hadn’t heard about this treatment but said he would go away and research it. At our next appointment, he was able to discuss this with me and involved me in the decision to go ahead with it. The information I got from the conference empowered me to get treatment that helped my daughter.

I felt I was armed with information – things I could ask medical professionals about that I otherwise wouldn’t have known. It was very useful because, quite often with medical professionals, you know a bit more than they do.

I think having accurate information is really important. I have been provided with really useful information about the health implications of PWS, what to expect and perhaps what to look out for, as well as research – all things that you can speak to your consultant about.

PWSA UK is a great source of information and expertise about the condition. I’ve got lots of very useful advice over the years, both from staff members, volunteers and other parents. When problems arise in dealing with health, education and social care settings and provision, I don't panic because I always know I have the option of calling the Association.

*Name changed

Reducing loneliness and isolation

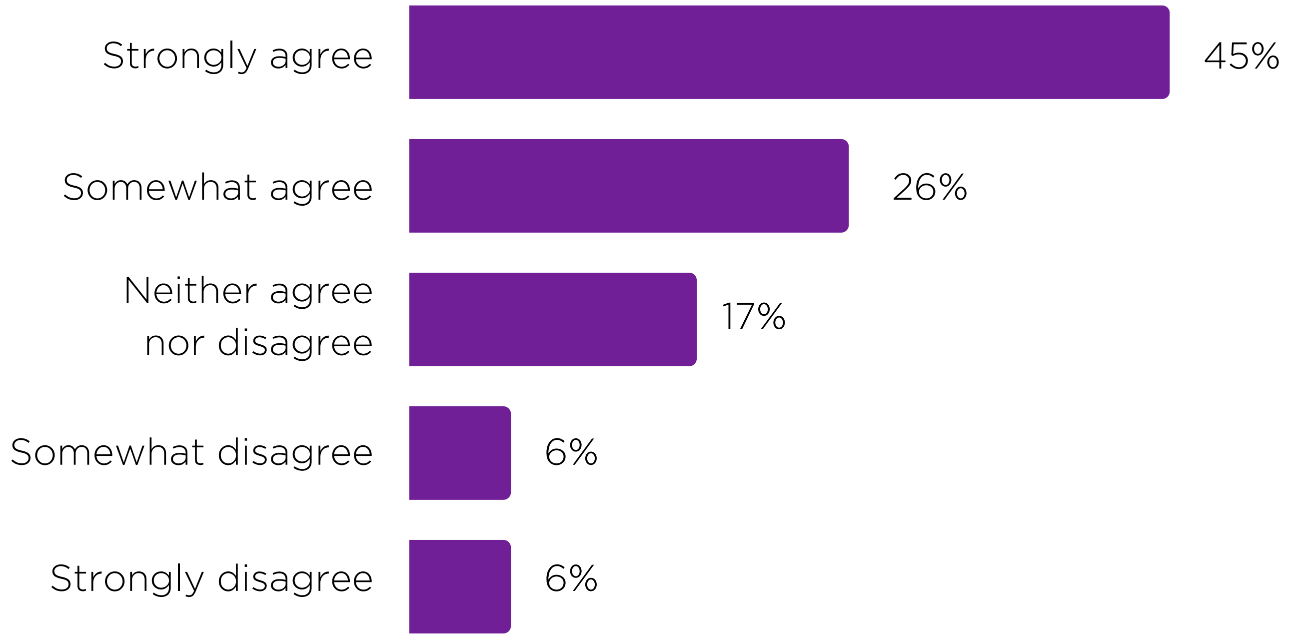
Outcome 2:

People affected by PWS and their parents/carers will feel less alone and be less isolated

People with PWS, their parents and carers tell us that **having this condition can be very isolating and lonely.** Friends, family members and even professionals often do not understand the complexities of the condition.

Loneliness and isolation of parents and carers

71% of parents/carers feel less alone since getting support from PWSA



(85 survey respondents)

More than two-thirds of parents/carers surveyed (71%) told us that **receiving support from PWSA UK has contributed to feeling less alone, leading to a reduction in their social isolation** (in 69% of parents/carers surveyed). They highlighted the importance of our work to **build a community** where they can meet other people who ***"feel the same"*** and ***"understand"*** them.

69%

of parents/carers feel less isolated since getting support from the Association

(80 survey respondents)

> ***The family days are just great … everyone understands about meltdowns, and you don't have to think about it … It's almost like you can relax because people will be watching out on your behalf and everyone's in the same boat. So it's a very good sort of sense of community.***
>
> Parent/carer of young person with PWS, interviewee

Family weekends and days out were described as providing a safe and supportive environment, where **friendships develop between peers – parents, adults and children with PWS alike.** Many continue outside of these events, through online or in-person contact.

91%

of parents/carers rate PWSA UK events as good or excellent

(67 survey respondents)

18 out of 18

adults with PWS surveyed think the Association's support and activities are good

1,099

adults and children with PWS and family member attended PWSA UK community and information events in 2022-23

Some parents mentioned that **events were an opportunity to interact with people with PWS of all ages** and get a sense of the ***"broad spectrum of PWS"***, as well as meet other families, which gives them the sense that they are not alone in their journey. Some parents interviewed expressed the view that attending events did not fit in with their family's PWS journey, but they benefitted from the PWS community in other ways – through the peer support Facebook group, for example.

> ***When you meet up and see that other families with children with PWS are like normal families, it's nice.***
>
> Parent/carer of child with PWS, interviewee

Many parents/carers said that interacting with other PWSA UK services (e.g. the helpline) also provided them with ***"invaluable"*** **emotional support** in moments when they felt ***"lost and isolated"***.

45

parents, carers and family members of people with PWS attended peer support group sessions in 2022-23

673

people are part of our "Empowering Life with PWS" Facebook group

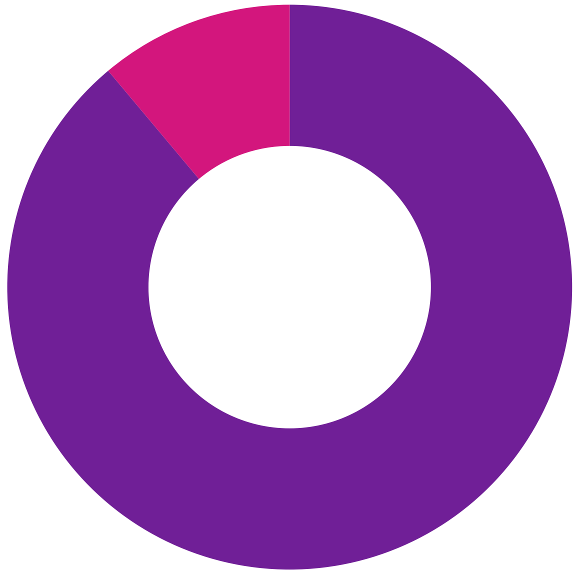
Our research showed us that **parents also value the peer support that we facilitate**, through the "Empowering Life with PWS" Facebook group and volunteer-run support sessions. In these spaces, parents can support each other (sometimes ***"in the middle of the night"***) by sharing experiences, offering advice, and providing emotional support.

> ***It's actually the peer support from other parents that is priceless ... I cannot imagine the isolation I would feel if I didn't have that, because you really doubt yourself.***
>
> Parent/carer of child with PWS, interviewee

Reduced loneliness and isolation of people with PWS

Adults with PWS surveyed felt able to meet new people, experienced happiness and got a sense of belonging from taking part in PWSA UK events, where we create an environment where they can have fun and express themselves without facing judgement.

16 out of 18 adults with PWS responding to our survey have made new friends thanks to PWSA's events and activities



> *At the PWSA UK weekend event it felt like being accepted. They accepted me for who I am. It's helpful when you feel accepted.*
>
> Adult with PWS, focus group participant

16 out of 18

adults with PWS think PWSA UK has helped them feel part of the PWS community / connected to other people with PWS

9 out of 18

adults with PWS think PWSA UK has helped them feel part of their local community

48%

parents/carers think their son/daughter with PWS feels less isolated as a result of the Association's services
(81 survey respondents)

We see similar changes in children and young people, with some parents/carers mentioning that **events also helped their children feel part of a community and create close friendships**, which hadn't previously happened in other environments like school.

> *I went to the PWSA UK conference a few years ago. It was nice to stay away and meet new friends and socialise. Seeing people was the best bit. It made me feel happy.*
>
> Adult with PWS, focus group participant

Evaluator's conclusions

There is strong evidence that PWSA UK's work contributes to reducing loneliness and isolation in parents and carers of people with PWS. There is less of a case with loneliness and isolation in adults and children with PWS, especially when it comes to supporting them to feel integrated in their local community, with some focus group members expressing a desire for more opportunities to socialise – this can point to PWSA UK investing in working with parents/carers and people with PWS to signpost to local services.


The photograph used here is not the person featured in the case study.

> “Being able to make friends with other children with PWS and meet up with them at family events is so important to our daughter. Without the Association we would really struggle to make those connections.”

CASE STUDY:
PWSA UK's events give our child a sense of belonging

Heather* is nine and she was just under a year old when we contacted PWSA UK for the first time, about going to an event. It was a daunting prospect – we didn't know what to expect, we'd never met anyone else with PWS. It was nice to go to this event and meet other families.

Heather is aware she is different. She is in mainstream school, where there are some children with support, but they are scattered around. We're joining a local playgroup soon and she asked if there will be someone with PWS there – she's always looking for other people with PWS, but I doubt there will be someone else.

So it's important for her to go to the Association's events and meet people like her. At an event, she'll meet another girl, they'll hug and be best friends. Knowing there are other people that are just like her, and being able to meet them, is such a reassurance for her. For example, she understands she needs a healthy diet 'just like her PWS friends' and it helps make that more manageable.

If PWSA UK closed tomorrow, Heather would be devastated. I think she would wonder: “How do I meet other people like me?” She would feel more isolated and different. Being able to make friends with other children with PWS and meet up with them at family events is so important to our daughter. Without the Association, we would really struggle to make those connections - the service is brilliant and vital.

We would also find it difficult to meet people that have the same experience – and we'd probably always be wondering if we were doing things right, if other families are like us. When you meet up and see they're normal families, it's nice. We really appreciate everything the Association do and feel so lucky to have their support.

*Name changed

Knowledge of rights and entitlements to financial support

Outcome 3:

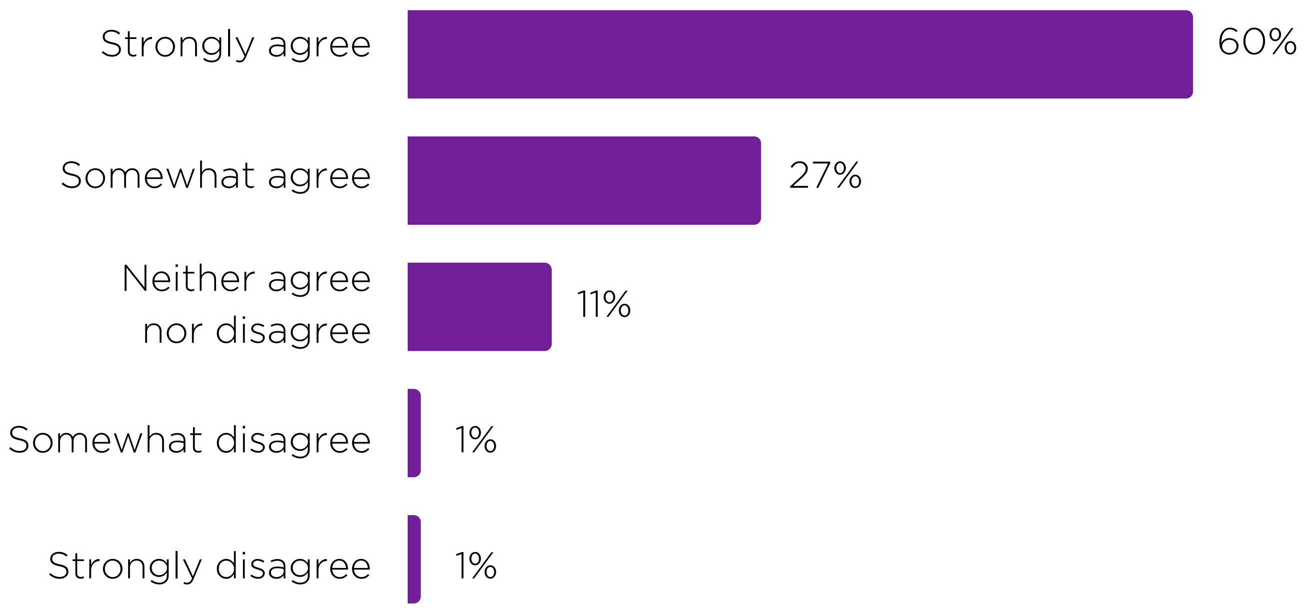
Adults with PWS, parents & carers will have more knowledge of their rights and entitlements

People with PWS and their families **aren't always aware of the much-needed financial support they are entitled to** due to their condition.

Both adults with PWS and parents and carers told us that **PWSA UK is a valuable resource to them by providing information on what their rights and entitlements are** and how to access them. We tailor this support to each person with PWS and their family, according to their age, and supported many people to discover benefits they didn't know existed or that they weren't aware that they were eligible for.

> ***"If it wasn't for the PWSA UK staff members, I wouldn't have got any help. It's made a difference to me. I don't have to worry so much – I've got money to spare … I could struggle with money before, had to borrow from friends and pay it back. PWSA UK staff said I was entitled to this money 30-odd years ago, but I didn't know, and I didn't get any help then."***
>
> Adult with PWS, interviewee

87% of parents/carers agree that PWSA helped them to have a better understanding of their rights and entitlements and those of their son/daughter with PWS



(82 survey respondents)

90%

of parents and carers know how to access their rights and entitlements at least partly as a result of PWSA UK's services

(79 survey respondents)

12 out of 18

adults with PWS feel that PWSA UK has helped them to understand their rights and how to access them

> ***When we had trouble with his benefits, which were stopped, one of the ladies from PWSA UK came and helped out.***
>
> Parent/carer of adult with PWS, interviewee

We also **provide practical assistance in applying for these benefits** – with form filling, collecting supporting evidence and supporting families through the appeal process, if needed. Several decisions to not award benefits to a person with PWS have been overturned on appeal with our support.

Our research shows that some **parents and carers also access information about benefits and how to navigate the system by contacting other families** through the peer support network we facilitate.

Evaluator's conclusions

There is compelling evidence that PWSA UK contributes significantly to parents/carers' knowledge of rights and entitlements, and ability to access those that they are entitled to under the UN Convention on the Rights of Persons with Disabilities. We did not explore in detail if adults feel supported to access their rights and entitlements, but there is some evidence of this happening.

People with PWS will have increased mental wellbeing

Outcome 4:

People affected by PWS will have increased mental wellbeing

We know that people with Prader-Willi syndrome experience low mental wellbeing because it is a **lifelong condition that poses many challenges and affects their quality of life**.

42%

of parents/carers agree that PWSA UK helped their son/daughter feel less anxious

(79 survey respondents)

51%

of parents/carers agree that their son/daughter feel happier as a result of support from PWSA UK

(81 survey respondents)

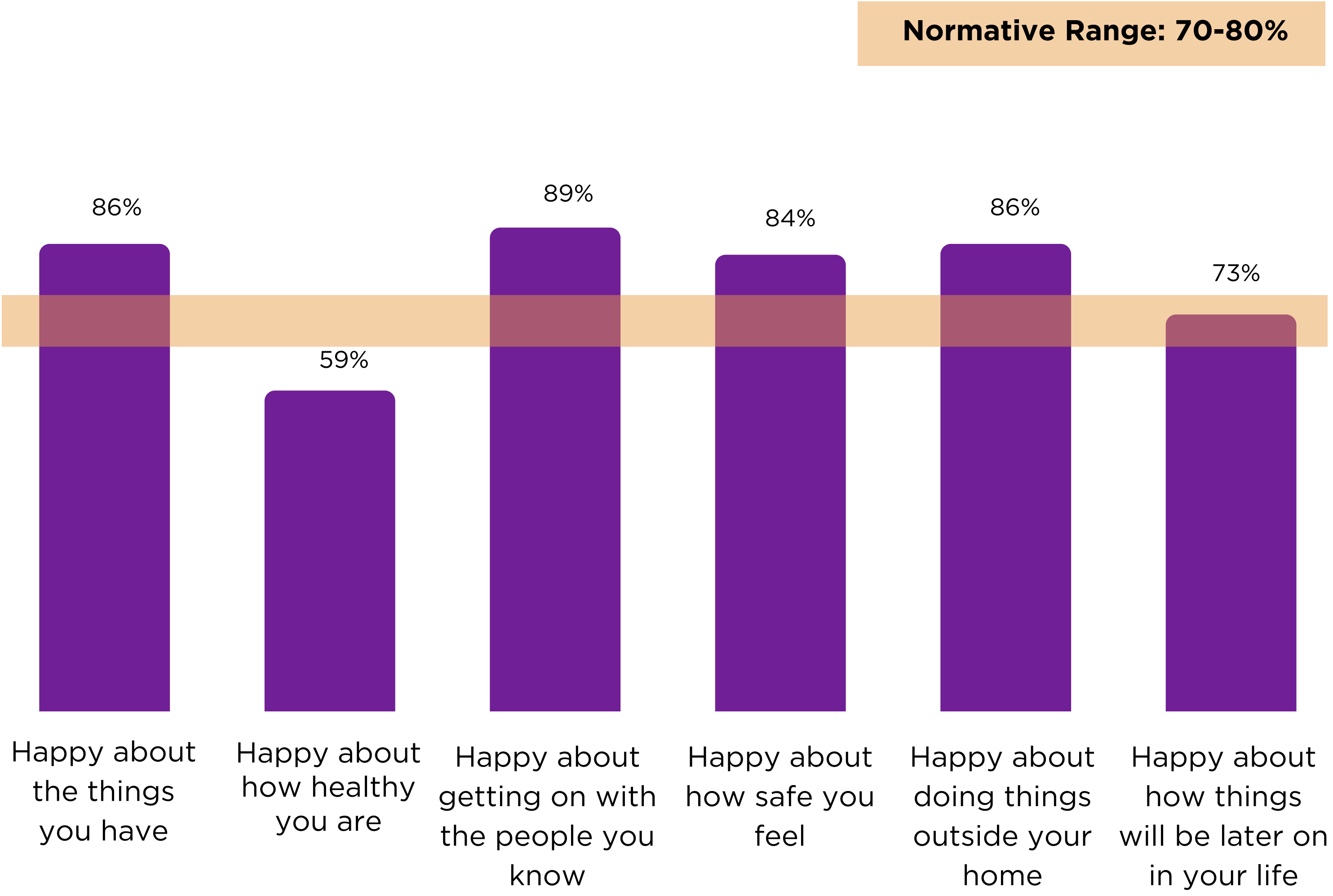
13 out of 14

people with PWS rated themselves as ‘happy’ with their life as a whole

Mental wellbeing of people with PWS

As part of this research, we surveyed 14 adults with PWS using the Personal Wellbeing Index for people with learning disabilities (International Wellbeing Group, 2013). When compared to people with learning disabilities in general, **adults with PWS who responded to our survey who have received support from PWSA UK demonstrate better wellbeing in most domains** (standard of living, personal relationships, personal safety, connecting with their local community) than people with learning disabilities in general.

Personal Wellbeing Index of Adults with PWS Surveyed



(14 survey respondents)

When compared to other people with learning disabilities,

14 adults with PWS surveyed demonstrate higher personal wellbeing

in 4 out of 6 domains

The exceptions are future security, where respondents scored within the normative range, and personal health, where their wellbeing is below the normative range. This is to be expected when we consider that PWS is a lifelong condition that can have a serious impact on physical and mental health.

Engaging with the PWS community through online and in-person events, as well as the quarterly magazine and newsletters (which include content produced by people with PWS), has **led some adults with PWS to feel happier and less anxious**.

Adults with PWS told us the community weekends and walks organised by PWSA UK contribute to their happiness and some mentioned the physical activities they took part in had a positive impact on their physical health. There is strong evidence that staying active and being in contact with nature improves mental wellbeing (“Five Ways to Wellbeing”, New Economics Foundation, 2008).

> ***“I like to go on the PWSA UK walks to get the weight off …The walk is tiring but good. It feels like achieving something when I’ve done it.”***
>
> Adult with PWS, focus group participant

Being part of the PWS community, which we aim to make a safe space that is free of judgement, can also **boost the confidence of people with the condition and support them to try things they didn’t feel able to do before** – from singing and dancing in front of other people, to writing articles for the PWSA UK magazine about their experiences.

Some adults with PWS also told us that having the opportunity to be heard and to support other people with PWS – for example by taking part in PWSA UK’s “Our Way of Life” group for adults or writing for our magazine – was important to them and gave them a sense of belonging.

> ***“I don’t usually do things in front of people without getting embarrassed. But when I went to the conference in Skegness, I sung with the PWSA UK staff member. I felt confident. I just felt comfortable in that environment. I always wanted to do it because they do karaoke all the time, I’ve always wanted to join them and now I have.”***
>
> Adult with PWS, focus group participant (paraphrased for clarity)

People with PWS, regardless of age, can have behavioural issues – these can be an indicator of high anxiety. Managing the behaviour of their son/daughter was the most frequent issue that led to parents/carers reaching out for our support in 2022-23, with 181 occurrences.

12

adults with PWS are members of PWSA UK's "Our Way of Life" focus group

The group took part in

4

meetings and

1

mini online conference in 2022-23

60%

of parents/carers agree that PWSA UK has helped them to manage their son/daughter's behaviour

(Number of survey respondents: 45 parent/carers)

42%

of parents/carers agree their son/daughter is able to regulate their emotions better as a result of the Association's support

(Number of survey respondents: 45 parent/carers)

Parents and carers told evaluators that PWSA UK **supported them to better manage their son/daughter's behaviour inside and outside of the home** – for example, by providing guidance on discussing the situation with the child's school or assessing if their current school can meet their needs.

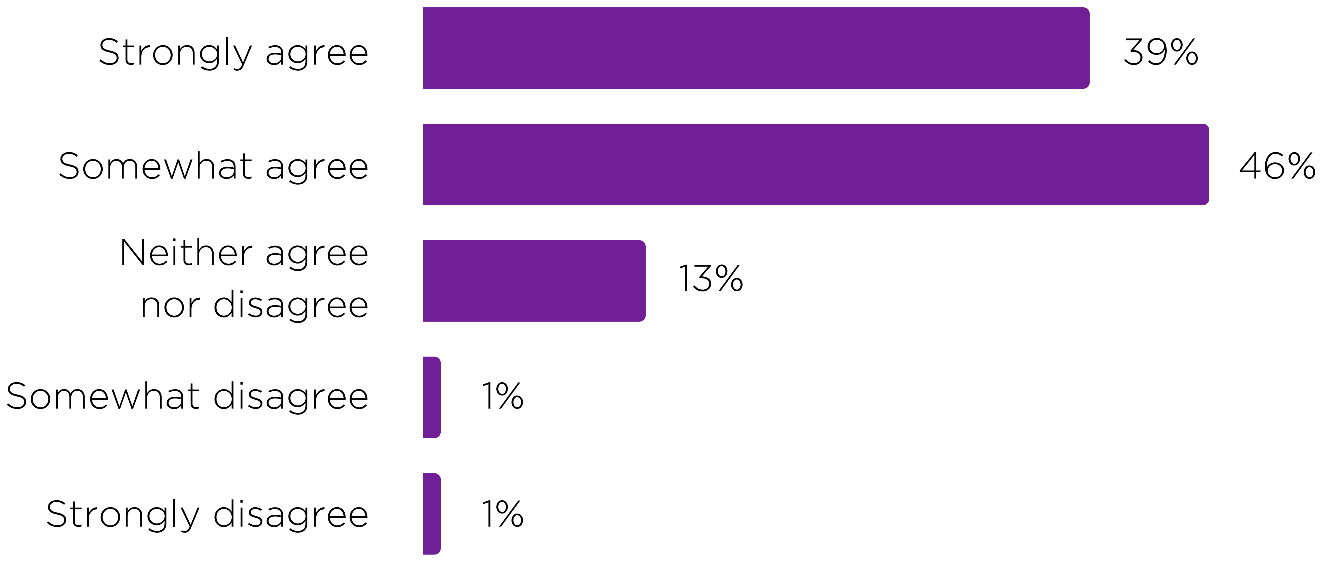
However, there are limitations in the changes we can bring about given the cognitive effects of the condition, as less than half of parents/carers feel that their son or daughter is better able to regulate their emotions as a result of our support.

Mental wellbeing of parents and carers

Many families of people with PWS tell us the stress of coping with the challenges of PWS and the strain this puts on relationships and finances can take their toll on their wellbeing. As already mentioned above, support from the Association can help improve behaviour and, therefore, have a positive impact on families' wellbeing.

Parents and carers told us the support they got through guidance from PWSA UK staff and connecting with other parents through our peer network helped them **feel more confident in facing everyday challenges.**

85% of parents/carers agree that they are able to manage worries about their son/daughter with PWS as a result of support from PWSA UK



(84 survey respondents)

Some parents mentioned **how important getting positive reinforcement and encouragement from PWSA UK staff and other families was for them** – as day-to-day difficulties made them ***“doubt”*** themselves and feel like they are ***“failing as parents”***.

> “*It’s kept me as a single parent afloat. It’s sustained my mental health thus enabling me to provide better quality parenting.*”
>
> Parent/carer of adult with PWS, survey respondent

Knowing that PWSA UK is there to support them, for some families, helps to reduce their fears about the future – namely about how the person with PWS will cope without family support or if they will be able to live independently.

> “*Thinking about the future and how things will go - without PWSA UK - you would still be kind of worrying about that and wondering what we are going to do and what help is out there.*”
>
> Parent/carer of young person with PWS, survey respondent

Evaluator’s conclusions

There is good evidence that PWSA UK’s support contributes to an improvement in the mental wellbeing of parents, by helping them manage their worries and feelings of anxiety around their son/daughter’s condition, as well as reducing family stress due to better behaviour management.

The Association’s impact on the mental wellbeing of adults with PWS is less clear due to limited survey responses. Still, there is emerging evidence of adults supported by PWSA UK having better wellbeing than the general population of people with learning disabilities. More opportunities to socialise and integrate with the community, as well as more events and activities focused on adults with PWS should contribute to improvements in the wellbeing of adults with PWS.

Evaluators did not assess the wellbeing of children with PWS, which could be a focus of future research, although it would be hard to assess for children with a learning disability.

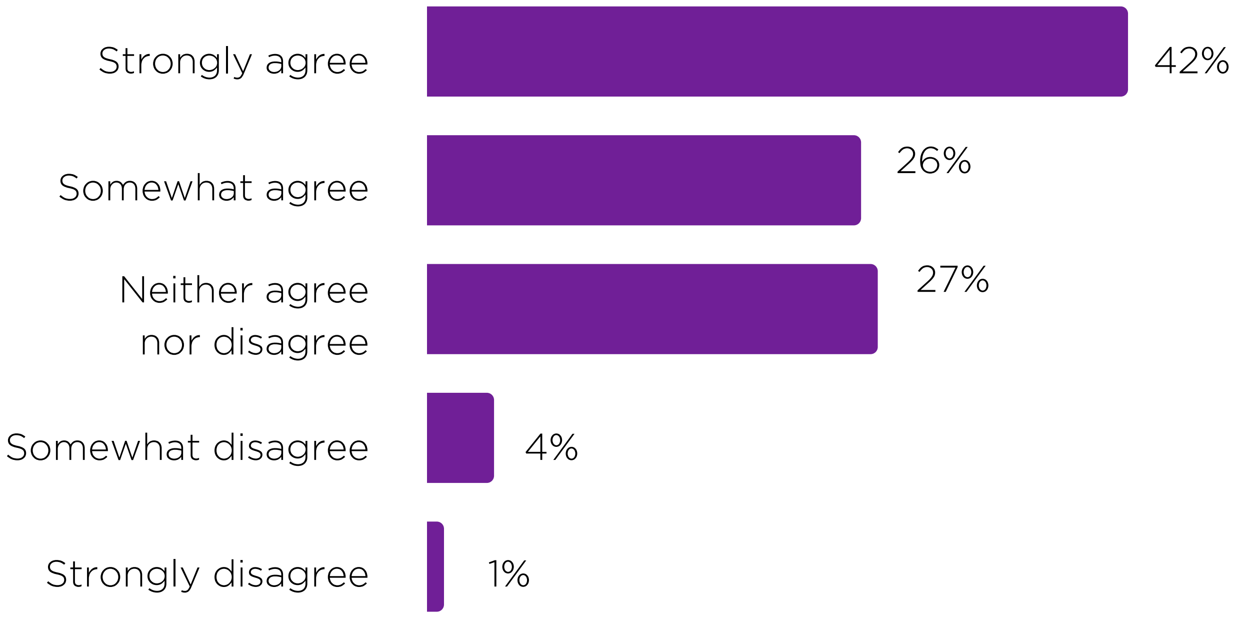
Supporting access to other services

Outcome 5:

People with PWS and parents/carers will have increased access to the support they need

Children and adults with PWS face challenges that frequently require extra support from professionals in the education, health and social care sectors. The rarity and complexity of Prader-Willi syndrome mean **people with PWS and their families don't always know what services can help**, and also that **professionals don't always have the necessary understanding to meet the specific needs of people with the condition**. Having access to the right support can help families of children with special healthcare needs, such as PWS, experience fewer financial and employment problems (Looman et al. 2008).

68% of parents/carers agree that PWSA has helped them to access better support from external organisations



(84 survey respondents)

Parents and carers learn about the different services they might need to access through our online information hub, helpline, and peer support network, where they can access support and information about navigating the complex education, health and social care systems.

Through our tailored support, families described how we helped them to identify services that meet their needs. Some parents highlighted how **we lend weight to their concerns, which were not being heard by their local services** – for example, when discussing with their local authority the need for specialist educational provision for their child.

> *PWSA UK has been there from day one of my son's diagnosis. They've helped me come to terms with his diagnosis and helped me support him and his needs in the best way possible. They helped me get an EHCP and find a more suitable school, including helping his transition go smoothly.*

Parent/carer of child with PWS, survey respondent

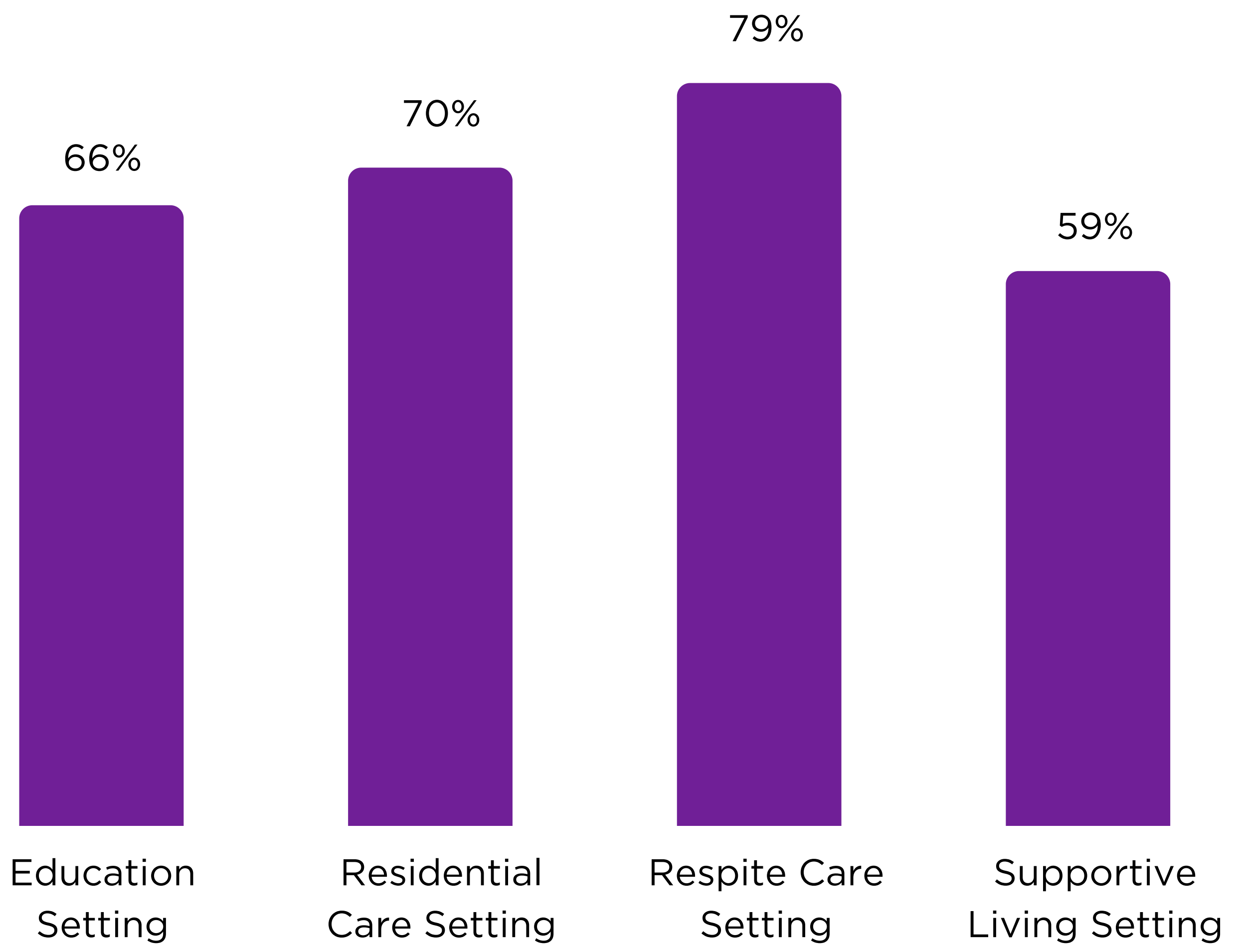
In healthcare, **PWSA UK's signposting to specific medical professionals helped families that did not otherwise know where to go** or what specialist care their son/daughter needed.

> *Without the Association, we wouldn't have known who to go see, what therapist we needed and what doctors we needed.*

Parent/carer of child with PWS, interviewee

The Association has advocated for better care for people with PWS, for example when they are in hospital. One of the professionals interviewed by our evaluator described how a PWSA UK staff member had advocated to keep a person with PWS in hospital when clinicians had intended to discharge them, as they had overlooked that she was not eating. The PWSA UK staff member knew this was unusual in someone with PWS and therefore was a sign that something was very wrong.

Around two-thirds of parents/carers agree that their son/daughter with PWS is in an education or residential setting that meets their needs



Number of survey respondents: 50 for education setting, 27 for residential care setting, 14 for respite care setting, 17 for supported living setting (respondents could answer for each setting or indicate that it doesn't apply to them).

Several parents highlighted how PWSA UK had **supported them in finding adequate schools or residential placements for their son/daughter with PWS and helped them with the transition**. Without this support, families felt they would not have been able to ensure their child received care tailored to their needs. However, as indicated in the chart above, there is still some way to go to ensure that all people with PWS are in a setting that meets their needs, particularly within supported living and education.

What professionals say

The professionals that evaluators interviewed as part of this research reported that **we bring *"valuable"* expertise** and our understanding of the needs of people with PWS helps them in their work.

> ***Having that experience and the knowledge, having the support of a PWSA UK staff member at those meetings to advocate for this person with PWS was so valuable.***
>
> Health and social care professional, interviewee

Evaluator's conclusions

There is good evidence that PWSA UK contributes positively to helping people with PWS and their families access better support from external services. The data collected also points to PWSA UK doing well in supporting people with PWS to have their needs met in respite and residential care settings, but there is still room for improvement in education and supported living settings. However, it is recognised that there will continue to be challenges outside the Association's control when supporting families to access appropriate external services, as they are operating within a resource-constrained system.

The photograph used here is not the person featured in the case study.

> “The PWSA UK staff member who supported us shared a list of places that were PWS-specific and worked with our daughter one-to-one, offering reassurance that came from someone who understood her.”

CASE STUDY:
PWSA UK's support was crucial in helping us find a better residential place for our daughter

Simone* is eighteen and was diagnosed with PWS when she was five weeks old. We got involved with PWSA UK when she was four or five – we looked at their website and the age-appropriate handouts, and also used the helpline to help with her behaviour.

As she progressed into adulthood, Simone wanted to become more independent and so we got her a place at a supported living unit near us, to ensure we could visit her three times a week, but they ended up being very poor at meeting her needs. They initially didn't have any training and then got some training about PWS, not from PWSA UK, which was very inadequate. Simone must have felt so isolated there.

We got in touch with the Association and, at first, they offered to train the staff where Simone was living, but the staff weren't interested. So, with the Association's help, we found a new residential place for her that is PWS-specific and could meet her needs.

The staff member who worked with us shared a list of places that were PWS-specific and worked with Simone one-to-one, offering reassurance that came from someone who understood her. This new residential place was very proactive and showed interest in a way that none of the other homes that we contacted did.

Simone has been there for two and a half weeks, and she's done more activities there than in the previous seven months, where she was living previously. We are hoping that being in a place with greater understanding will improve her quality of life and happiness.

It is helpful knowing PWSA UK are there when needed, they explain things to others much better than I can. We don't feel so alone, we are not struggling – we are so grateful to PWSA UK.

*Name changed

We haven’t got it all right

This research has highlighted where we are doing well and brought into focus things that the PWS community would like us to improve on or develop, including:

- More age-appropriate support and social activities for adults with PWS, including people over 40, and their families.
- Expanding our information hub, showcasing success stories in the community and increasing communication about research that is in progress.
- Ensuring that events reflect our community and their changing needs.
- Providing financial support so that cost is not a barrier to attending our events.
- Increasing our geographical reach.
- Training more professionals and partnering strategically with external services.

We thank everyone for their feedback and will consider these points in our planning for the future – so that we can continue to respond to the PWS community.

Our plans for the future

At PWSA UK, we are committed to responding to the needs of the PWS community and listening to what they tell us.

Our plans for the future include:

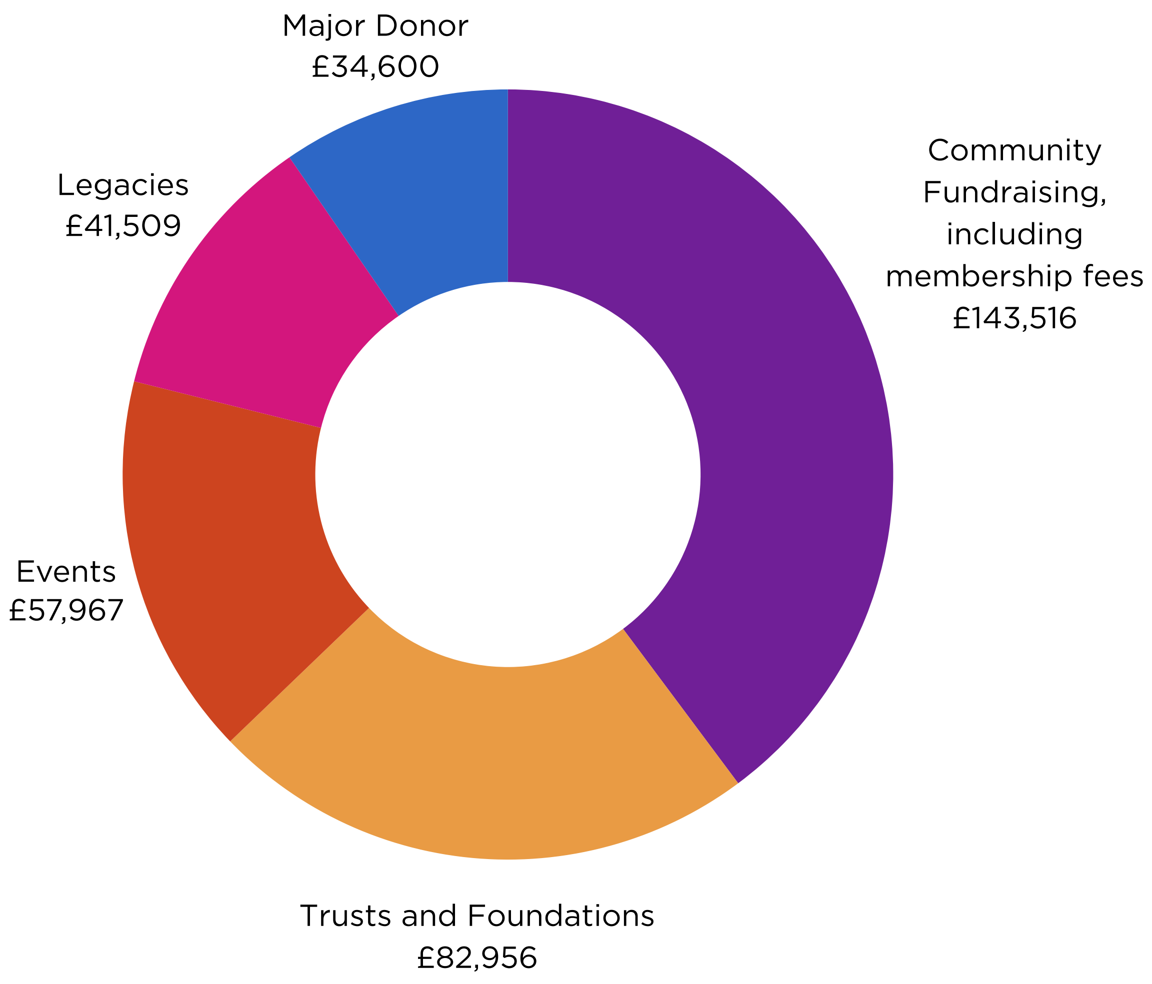
- Continuing to develop the services and support we provide for adults with PWS – including by increasing engagement with them through the "Our Way of Life" group.
- Growing our presence to reach all areas of the UK and diverse communities – through running more events locally and partnering with PWS specialist clinics.
- Improving our support to families through key transition stages in the life of their family member with PWS.
- Continuing to provide accurate and useful information – by reviewing our resources and launching new materials.
- Developing our support and advocacy services further.
- Increasing our support to people with PWS living in residential settings and working with service providers to raise standards in these homes.
- Strengthening our partnership with the Foundation for Prader-Willi Research UK (FPWR UK) to continue to support research into PWS and its impacts.

How we are funded

Our work is funded mainly thanks to the fundraising efforts of our members, with further financial support coming from a diverse pool of donors.

We are grateful to all of them for supporting our work and ensuring we can continue to provide vital services to the PWS community.

Where our income comes from



Total income in 2022-23
£362,400

We want to thank you

We could not do our work without:

- The trust placed in us by all **the children, young people and adults with PWS we work with, as well as their families** – we are privileged to be a part of their lives.
- The generous participation of **all the people who completed the surveys, took part in the focus groups and were interviewed for this research** – a special and heartfelt thank you for your time and contribution to demonstrating the impact of PWSA UK's work and helping us understand how we can improve.
- The vision and determination of **the founders of the Association** – you inspire our work every day.
- The support and funding from a**ll of the people who have backed PWSA UK's work** over the years.
- The unwavering work of **PWSA UK's amazing staff team**, in supporting the PWS community.
- The commitment of our **Board of Trustees and our volunteers**.
- The collaboration of **all the health, social care and education professionals** that we have trained and supported throughout the years.
- The funding for this impact and evaluation project, from **Charities Aid Foundation**.
- The work of **our evaluators, Insley Consulting - Emma Insley and Joana Martinho**.

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> ❝ *It's made such a difference in the fact that we don't feel alone. We're not struggling to cope on our own … The support and the hand-holding has been really important to us.* ❞

PWSA UK
PRADER-WILLI SYNDROME ASSOCIATION UK

3 Deer Park Road
Moulton Park
Northampton
NN3 6RX

Registered charity no. 1155846

Evaluation by:

INSLEY CONSULTING