

**STRONGER TOGETHER**

Charity No. 1147436



# PCAN ANNUAL REPORT 2018/2019

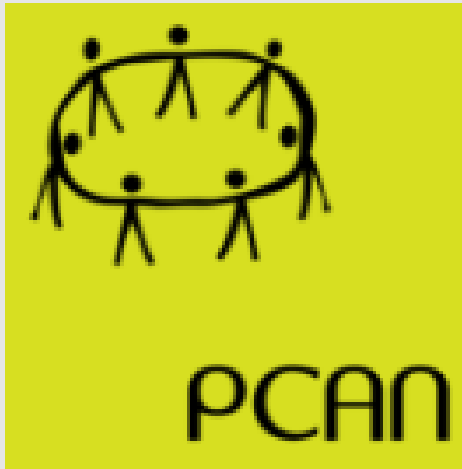
Compiled by the Trustees

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# PCAN Information



- PCAN is the independent, parent-led forum in Kirklees for all parents and carers of children and young people with additional needs aged from birth to 25 years. All Trustees are parents and carers themselves.
- PCAN provides good information, links to social media so parents can network with each other, and a range of social and other events to help us to develop a strong, collective voice so that we can work in partnership with service providers across Kirklees. Together we can improve services for our children and young people with additional needs!
- PCAN welcomes all parents or carers, whether you are just beginning to become aware that your child or young person may have additional needs, or if they have confirmed diagnosis or disability.
- Our work is divided into three strands:

**Good Information**

**Support and Friendship**

**Stronger Voice**

# Note from the Trustees



2018/2019 has been an eventful year. Our membership has continued to increase, we have run more parents' events than ever, supported more people with information and worked closely with colleagues from Kirklees Council and our local Clinical Commissioning Groups (CCGs).

Our team of Trustees mostly contribute their time and skills for free, and those who are self-employed and receive payment for their work also contribute at least as many hours a week on a voluntary basis. In planning PCAN's activities for the year, Trustees kept in mind the Charity Commission's guidance on public benefit.

Our Trustees for 2018-19 were:

Trace Smith-McQuillan

Carol Thomas

Anne Patterson-Brown

Johanna Hull

Anisa Kothia

Nicola Sykes

Suzanne Wright

Joanne Jackson

Rayne Sutcliffe

We would like to thank PCAN volunteers and members for giving up their valuable time to either help us with PCAN's work or come along to events, for filling in surveys and generally helping us to make a difference for everyone. We couldn't do this without you!

# Good Information



Parents and carers need good quality information to do the best job they can for their children and young people. Part of PCAN's work is about ensuring local parents and carers know about the activities, services, support and information that can make their life, and that of their family, better. Key activities for 2018/19 included:

- PCAN website and Facebook Group page regularly updated with relevant information. Information sent out and collected via Twitter. Our friendly and welcoming Facebook Group has over 700 members (as at 31.3.19, increase of over 200)
- Regular newsletters and e-bulletins to members (1145 members as at 31 March 2019 – increase of 220)
- Signposting in person at events or over the phone/email/post. Thanks to the supportive Facebook Group lots of parents are signposting each other to support.
- We held 33 regular parent events and visited SEND coffee events at 30 different schools.
- PCAN had a stand at the Autism Show and Local Offer Live events and shares information with local support groups such as Down's & Special Friends, Whole Autism Family, Huddersfield Support Group for Autism and with School Senco's and Family Support workers at the Kirklees Special Schools.

- We also hosted two Planning for Future Life events for parents of young people aged 16+ - very well received by those who attended. More events will be held in future to cover other areas identified by parents as important.

## Good Information – some feedback

The information is invaluable that PCAN offer, everyone is so kind and I don't feel so isolated now.

Thank you PCAN for telling me about DLA. I thought you needed a diagnosis to get it, no-one told me anything so I never bothered to get it.

# Support and Friendship

Helping parents to meet and support each other is a big part of what PCAN is about. We want parents and carers to feel less isolated and to be able to contact other parents who understand the challenges and the joys of having children and young people with additional needs.

## **What we did in 2018/19**

- Connected people via our closed Facebook group and social events
- Visits have been made by PCAN Trustees to school parents' groups and support group meetings which has helped parents to network and support each other.
- Over 500 parents attended social events and school SEN coffee mornings organised or supported by PCAN. These events are valued by parents and professionals, and have also been a source of information to contribute to PCAN's consultation and participation work with local service providers.
- A PCAN Trustee has been available to talk to parent carers who ring with concerns.
- We continued to supply Maxcards for families living in Kirklees.

# Support and Friendship

We teamed up with S2R in Kirklees so that parents could get a much needed break and meet each other in a relaxing setting to make beautiful things.

I feel myself again  
going to these events  
not just a mother or  
carer....I gave myself  
permission to look  
after myself.  
great course, thank u  
PCAN and S2R

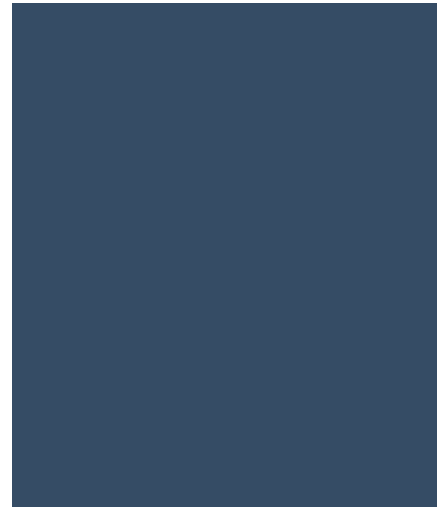


loved it  
..fantastic time  
out just for me



# Support and Friendship

We got a small Time for Me grant from Kirklees to run create events in the Crosland Moor area – parents had a lovely time, chatting, making things and chilling:

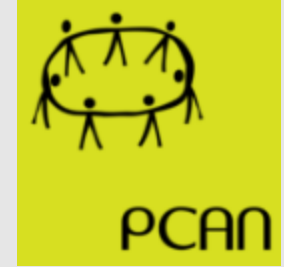


# Support and Friendship – what parents say

PCAN literally saved my life, I was so low and felt so isolated, I didn't know what to do and PCAN and the parents on Facebook have been a life saver.

The Facebook group helps me connect and meet new people, everyone is so generous with time and information and share their experiences with me...amazing support .

# Stronger Voice



PCAN works with local service providers to ensure that parents' voices are heard in the design and development of new and existing services (parent participation). It is a mandatory requirement for Local Authority and Health departments to gather the views of parent carers and this forms a large part of PCAN's work. Parent participation is all about making sure that parents of children/young people with additional needs can be involved alongside providers in service planning and decision making. The result is services that better meet families' needs and therefore are valued and have good levels of take up. PCAN receives specific funding from the Department of Education towards the cost of this really important work.

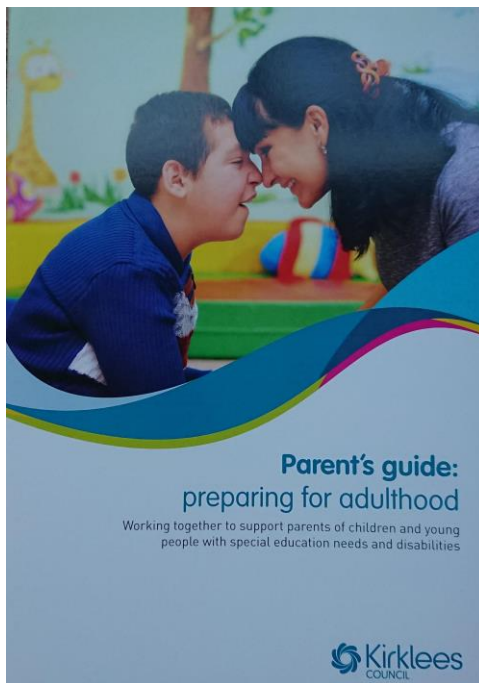
Parents voices were heard in health, education and social care during 2018/19. Achievements included:



# ACHIEVEMENTS

- Good progress on our Early Help project. Families have been telling us about the lack of appropriate early help for children with SEND in Kirklees. We attended the meetings on the new strategy and focus for children's services, met with Sal Tariq (then head of Children's Services) and others to ensure that Children with SEND were included in the overall strategy. This has informed our work with parents in the current financial year.
- We worked closely with Council colleagues on the revamped Additional Needs Register, commenting on the layout and testing it with parents – many thanks to those who took part. The Additional Needs Register provides vital data to assist with planning services for families in Kirklees. Data from it has reinforced feedback from PCAN members generally about how significant behaviour management is for our parents.
- PCAN sits on the KIAS Steering Group - 3 meetings a year. We help to oversee their work, understand their issues, share ours and support them eg when applying for additional grants (which they did for some post 16 work with young people).
- We sit on the parent monitoring group which meets 3/4 times a year to discuss SEN education related issues. Issues raised have been taken back as learning exercises and the department has been reshaped partly following input from parents (which includes PCAN members) over the last 2 years.





You will find a series of guides covering key areas of information to help and support you guide your son/daughter to prepare for adulthood.

1. Introduction
2. Benefits of preparing for adulthood and transition
3. Preparing for adulthood – what to think about
4. What is person centred/family centred planning?
5. What happens at year 9 onwards (age 14-16)?
6. What happens at year 11 onwards (age 16-18)?
7. What happens at age 18 up to 25?
8. Finance and benefits
9. Personal budgets
10. Mental health and being healthy
11. Mental capacity
12. Being independent and part of society
13. Support for carers
14. Useful websites and contacts

The fact sheets provide you with basic information that enables you to find out more specific information about the areas that are important to you.

◦ The Parents' Guide to Preparing for Adulthood was finally published!

◦ You can find it here:

<https://www.kirklees.gov.uk/beta/preparing-for-adulthood/pdf/parents-guide-inserts-to-preparing-for-adulthood.pdf>





## ACHIEVEMENTS

- We developed a survey to evaluate the first phase of the new CAMHS Thriving Kirklees service in a very short space of time - thanks to all those who completed it. A full report following this was sent to the commissioning officer to inform the ongoing progress of the Thriving Kirklees contract. We also met with external consultants who were commissioned by the Council for a review of CAMHS who listened to our (parents') perspective as part of their review.
- We continued to be involved and to evaluate the CAHMS service by inviting the commissioners and CAMHS staff to present to parents about how things had changed since the last parent meetings and listen to their feedback - March 2019.
- Work following the High Needs Review continued with a special focus on transitions - thanks to all those who completed the transitions questionnaire. A report was compiled following this and Education are working on a "Best Practice" guidance for schools using the information supplied by ourselves and schools. We hope this will aid the transition process.
- We continued to sit on the Preparing for Adulthood task group and supported the development of checklists for schools for pupils with EHCPs or My Support Plans to support their transition to adulthood.
- 5 of our Trustees are trained "Community Voices" - individuals working in the Voluntary, Community and Social Enterprise sector who are trained to engage with the local population on Greater Huddersfield CCG's behalf and talk to them about changes and developments in health services. Thanks to our previous work on wheelchairs, and our good links with the CCG we co-produced the engagement around the new postural and mobility service.

# ACHIEVEMENTS



## Wheelchair Services Project

PCAN were commissioned by Greater Huddersfield CCG to carry out research with users of wheelchairs and postural equipment and their carers about how the new service should look. This involved co-producing events with the CCGs, carrying out a survey across Calderdale and Kirklees and producing a report which informed the service specification for the new service. PCAN Trustees and wheelchair users and carers were part of steering group to feed into the new service specification, and met organisations who were tendering for the contract. As a result of this work, wheelchair users were part of the selection committee for the successful provider for the first time.

The survey had 465 qualitative responses and our report can be found here:

<https://www.greaterhuddersfieldccg.nhs.uk/wp-content/uploads/2018/11/Wheelchair-Services-Report-on-pre-consultation-engagement-work-Final-14.8.18.pdf>





# ACHIEVEMENTS

- We held several discussions this year at our social groups with representatives from school transport who were looking at more innovative and flexible ways to deliver this for school age children up to 16. This work is ongoing.
- We also sent in a PCAN response to the call for evidence for the Education Select committee - their report was published only last month. Our evidence is in the appendices. You can find their report here: <https://publications.parliament.uk/pa/cm201920/cmselect/cmeduc/20/20.pdf>
- We were invited to take part in the discussions about Project Search (the supported internship project). A PCAN representative was involved in the initial discussions about how this could look within Kirklees as part of an overall committee.
- We presented to a room full of people from Kirklees Children's Services in both Huddersfield and Dewsbury as part of the event to introduce Mel Meggs, the new Director for Children's Services.
- We were invited to take part in a local offer peer review in February which gave an impetus to further work within the council to improve this - ongoing.





# ACHIEVEMENTS

- We continued to sit on SEND Strategy, Integrated Commissioning Group (ICG), Carers Strategy and PCA (Person-Centred Approaches) Champions groups. As part of ICG we gathered information from parents about therapy services (thank you to those parents who commented) and commented on the first phase of the contract review. This work is ongoing.
- We continued to deliver “Day in the Life” training to SENCos as part of their learning and development.
- We contributed to the SEND Peer Review within Kirklees and received a very gratifying positive comment from the inspectors about our role and how we work.
- We were part of the interview team for senior and junior staff for the SENDACT review in August and September 2018 with a focus on person-centred thinking in our part of the interview process. We have been involved on an ongoing basis since.
- We worked with Kirklees Adult Services on the development of a new policy for Direct Payments.



# ACHIEVEMENTS

- We started to work with Kirklees Children with a Disability Team to develop a new “Help for Families” project.
- PCAN Trustees and volunteers attended over 110 meetings over the 12 month period.

Feedback from Tom Brailsford , Service Director Resources, Improvement and Partnerships

“ Kirklees Council and Kirklees CCG’s continue to value PCAN as a key strategic partner and continue to co-produce services and local strategy together in partnership with our local children, families and carers.”

	Total	Unrestricted	DFE	Kirklees 1	Kirklees 2	CCG	Time for Me
Receipts							
Grants	40,150.00	0.00	15,000.00	20,000.00	0.00	4,650.00	500.00
Training income	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Consultation income	0.00	0.00	0.00	0.00	0.00	0.00	0.00
MAX card income	711.50	711.50	0.00	0.00	0.00	0.00	0.00
Donations	110.00	110.00	0.00	0.00	0.00	0.00	0.00
Christmas party	458.00	458.00	0.00	0.00	0.00	0.00	0.00
	41,429.50	1,279.50	15,000.00	20,000.00	0.00	4,650.00	500.00
Payments							
Co-ordination services	14,007.10	0.00	0.00	9,918.75	0.00	4,088.35	0.00
Event costs	4,056.76	0.00	3,538.00	59.70	0.00	213.80	245.26
Travel expenses	2,870.95	0.00	2,103.30	0.00	419.80	347.85	0.00
Volunteer expenses	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Postage, stationery & consumables	510.67	0.00	510.67	0.00	0.00	0.00	0.00
Phone	400.24	0.00	400.24	0.00	0.00	0.00	0.00
Parent remuneration	458.40	0.00	458.40	0.00	0.00	0.00	0.00
Promotional material & publicity	90.00	0.00	90.00	0.00	0.00	0.00	0.00
Training	352.80	0.00	352.80	0.00	0.00	0.00	0.00
Outreach	0.00	0.00	0.00	0.00	0.00	0.00	0.00
Website	149.87	0.00	149.87	0.00	0.00	0.00	0.00
Insurance and indemnities	784.77	0.00	390.00	394.77	0.00	0.00	0.00
MAX card expense	510.82	510.82	0.00	0.00	0.00	0.00	0.00
Equipment	719.82	0.00	719.82	0.00	0.00	0.00	0.00
Liaison Services	9,392.50	0.00	6,286.90	3,105.60	0.00	0.00	0.00
Education Role	4,328.25	0.00	0.00	0.00	4,328.25	0.00	0.00
Christmas party cost	419.00	419.00	0.00	0.00	0.00	0.00	0.00
	39,051.95	929.82	15,000.00	13,478.82	4,748.05	4,650.00	245.26
Net receipts / (payments)	2,377.55	349.68	0.00	6,521.18	-4,748.05	0.00	254.74

# PCAN FINANCE REPORT 2018/19



# Funders and Supporters

- Many thanks to Kirklees Council for providing us with a grant of £13500 for 2018/19 to support PCAN's work
- Many thanks for the Department for Education for their continuing grant of £15,000 (specifically aimed at engagement and co-production).
- Thanks to the Greater Huddersfield CCG for the funding that enabled PCAN to gather the views of 465 wheelchair users and their carers across Calderdale and Kirklees.
- Thanks to Kirklees Council for their Time for Me grant funding which has supported families in Crosland Moor to have a bit of time out for themselves.
- Thanks to S2R for supporting parents and carers of children with additional needs to get some much needed time out.
- Huge thanks for all the PCAN Trustees, volunteers and supporters who give up their time for the benefit of others. We couldn't do any of this without you.