

Round-up of complex needs meeting (May 2024)

We started by welcoming people to the meeting and then people introduced themselves in the chat. There was a brief summary of the previous meeting then we introduced today's session topic.

Topic: Personal Assistants

Have you used personal assistants?
How did you recruit them?
What is your experience?

Points from discussion

Parent One - A parent who had recently started using p.a.'s for her son gave a summary of how it had worked for them, summary of points below

Parents wrote a timetable outlining each day what the p.a. would support their son with

Social care assessment resulted in needs being identified and a personal budget to meet these

Negotiations with adult social care around hours and ended up having less respite and more p.a hours

Had the option for council to recruit someone and manage money or for parents to do themselves

Opted for a direct payment with parent managing a bank account in son's name

Only used external organisation for producing payslips

Agency recommendations didn't result in recruiting a pa

Wrote a job description for their son and asked local street whatsapp group if anyone was interested.

Currently have two p.a.'s on the books who support their son

Budget could not be used to pay mileage or expenses for p.a. and this needed to come out of sons money

Parent Two – A parent



Has had p.a.'s for a few years.

An independent organisation manages the budget and payroll.

Family chose the personal assistants, one a former teaching assistant in the son's school who had offered.

General discussion

One parent had not reached the point of thinking about support for her son and another was tentative about initiating a social care assessment although recognised that p.a.'s would be a good thing.

We mentioned how having some connection with children's social care services may make it easier to access adult social care.

One parent stated that she was happy to share her knowledge with others.

Useful Links and resources

[Social Care and Support Factsheet \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk)

[When Down's Syndrome and Autism Intersect: A Guide to DS-ASD for Parents and Professionals Second edition](#)
[Froehle & Sattel](#)

[Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges \(2nd Edition\) | Adult Down Syndrome Center \(advocatehealth.com\)](https://advocatehealth.com)

COMING SOON

Tuesday 9th July 10.30am - midday



Down's syndrome with complex needs
support for parent carers

To book any events please visit our Training Page - [Training - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk)

Complex Needs Webpage

<https://www.downs-syndrome.org.uk/about-downs-syndrome/life-journey/downs-syndrome-with-complex-needs/>

*******In person meetings*******



Down's syndrome with complex needs
Parent/Family carer
regional support meeting
South west London

Friday 14 June 2024 | 10am – 3pm | £10



Down's syndrome with complex needs
Parent/Family carer
regional support meeting
Central Manchester

Monday 23 September 2024 | 10am – 3pm | £10

Any questions, please email:

jane.mitchell@downs-syndrome.org.uk

or

stuart.mills@downs-syndrome.org.uk