



# A manifesto for Flo

Born in Cumbria in July 2007, Baby Flo has given us the opportunity to dream. Her parents Anna and Ian have high hopes for their beautiful baby girl. Like all parents they want their baby to be happy. They want to do all the things other new parents and their babies do.

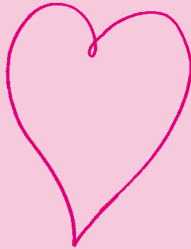
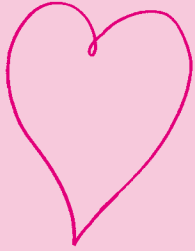
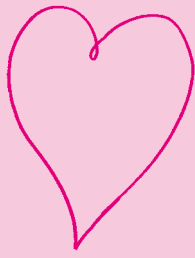
Anna and Ian dream of a world where Flo is valued exactly as she is. They know that their baby girl has the right to lead an ordinary life. They want her to have friends, go to playgroup, toddler group, nursery and school. They want Flo to belong in their community. They want to give her opportunities to do the things she enjoys and to feel the satisfaction of pushing herself to her limits.

Sadly, Anna and Ian can't take these very ordinary parental hopes for granted - because Baby Flo happens to have been born with Downs Syndrome. When they look around they see children with Down's Syndrome being excluded from local communities, being denied that all important sense of belonging. They know they will have to fight for some of the things other families so easily take for granted. They know that when one family member is excluded in this way, the whole family suffers.

We dream of a world where Flo and her parents do not have to fight, do not experience exclusion because their daughter happens to have an impairment. We dream of a world where Anna and Ian can expect Flo to go to their local community baby and toddler groups, nursery and school as a matter of course. No big deal! We dream of a time when Ian, Anna and Flo are given the support they need to live ordinary lives. And we want to do more than dream. We want to move from dream to reality in Flo's life time. We know we have the tried and tested tools, experience, knowledge, belief and commitment to help Flo and her family lead the lives they choose.

Putting our dream into action depends on the careful use of a range of person centred approaches, and a personal budget. We have a vision when all services adopt a person centred approach in all their work. We dream of that journey with Flo...

...as soon as she is born, we imagine Flo being celebrated by all those around her. No hushed tones, no whispered



voices behind closed doors. We know that a warm welcome by all professionals supporting her birth and those first days will give Flo and her family a sense of belonging, a sense of being perfect just as they are.

Within days of her birth, we envisage professionals working with Anna and Ian to ensure the support they receive is shaped by their wishes. We want them to have genuine choices now and in the years to come. For now we imagine that professionals in the local early years services, for example those working in the local children's centre, are trained and use person centred thinking tools and person centred planning with the family. We imagine a family person centred plan being drawn up with the Anna and Ian. This would describe what the family like about each other, what is important to each member of the family, and what support they need. And each professional they came into contact with would be able to provide information on how best to support the family, and this information would be added to the plan. Professionals would also help Anna and Ian think about how they could use their individual budget to buy support for Flo and her family.

In our ideal world, Anna and Ian would be supported and offered training, delivered by parents of disabled children, on what it means for families to live with impairment in a disabling world. They will learn about the history of disabled people, and how parents through the generations have fought for their beloved sons and daughters. Anna and Ian will be put in touch with other parents and offered parent mentors.

Meanwhile, within a few months of her birth, all the information gathered about both Flo's needs and the family's wishes has been collated so that Anna and Ian do not have to repeat their story to all the agencies they are working with. Armed with this knowledge, professionals will have worked alongside Ian and Anna to agree the support they will be provided with. This has already happened for Flo, and her one page profile, and how to support the family is attached to this paper.

So the early years will pass with Anna, Ian and Flo making new friends in their local community. In our brave new world we see Flo arriving at her local nursery without fuss or special negotiation. Here Flo and her parents will find skilled staff, trained in both person centred thinking and the reality of life in a disabling world, giving her maximum opportunities to engage in learning in ways that interest and motivate her. To do this, her learning will be based around what is important to her and she will be given the

appropriate support. Flo would go to the nursery with her one page profile, which gives the nursery the important information that they need about what people like about Flo, what matters to her, as well as the support that she needs.

This one page profile will be expanded as Flo prepares to move from Nursery to Infant School. Prior to starting visits to her school, Flo's class teacher will receive her one page profile so that when she meets her for the first time, the teacher will be able to talk about things that matter to her. As Flo grows this profile will expand to include support and communications sections as well as what people like and admire about her and what is important to her.

If Flo has a statement of special educational needs, all annual reviews will be person centred, and therefore run in a child and family friendly manner. Reviews will start with everyone present thinking about the things they like and admire about Flo – appreciating the unique gifts she brings to the world. The meeting will go on to consider what is working well and what is not working so well. Flo, Ian and Anna will be involved in setting educational targets. Each review will finish with drawing up a clear action plan. Anna and Ian will be expected to share responsibility for Flo's needs being met: person centred action plans set out the expectations and commitments of both school and parents.

Person centred approaches will run through Flo's school experience - parent evenings and reports will reflect this way of working. Teachers will personalise the curriculum so it reflects what is important to Flo as well as what she needs to learn. Flo will have a home/school agreement, based on a simple working/not working approach that is reviewed regularly. As Flo reaches adolescence, a person centred plan will be developed to prepare for Flo's transition to secondary school.

And as in her early education, professionals trained in person centred thinking will ensure the curriculum is personalized. The re-shaped curriculum will be crucial in informing later person centred plans and review preparation.

Meanwhile, Flo's parents will be supported as they use individual budgets to secure support for her both in and out of school.

As she approaches the end of her school career, Flo will be helped to assume an independent role in planning and purchasing her own support. With the Year 10 Review pivotal, Flo and her parents will know what the indicative

individual budget is for purchasing support into adulthood before it takes place. And after happily spending more than a decade in school, Flo, her family, friends and the professionals working with her will conduct the Citizenship Review at Year 10. Flo and those closest to her, supported by the professionals, will consider how she would like to live her life - including whether she will work and where she will live. They will know roughly how much money they have to buy the support she needs. Soon after the review, care managers will sign off her support plan and Flo will take the first steps in the exciting world of adulthood.

Schools, health and social care agencies will not be on their own in taking a person centred approach, but will be supported by local and regional multi-agency protocols. And Flo's experience, along with others requiring additional support will be used to influence the development and commissioning of local services.

We know all this is possible. We know that Flo, Ian and Anna will have an easier and happier life if it were in place. We dream for Flo, Ian and Anna. We dream for all vulnerable children and their families.

**Pippa Murray**

**Helen Sanderson**

**Lori Erwin**

**Anna and Ian Waugh**



# What we love about Flo

- She is beautiful - she has beautiful hair, eyes and smile.
- She has a gorgeous giggle.
- She is content and patient - she rarely gets upset and when she does you know there is something missing!
- She is cuddly - she grips like a koala bear!
- She is observant and alert.
- She is a chatterbox, is always making noises and responds to people she knows making lots of different sounds.
- She sleeps through the night!
- She has a great sense of humour - she loves being tickled and bounced on Mummy's and Daddy's bed.
- She's tough! She takes her brother Thomas' 'rough and tumble' all in her stride!



# How to look after Flo

Flo has low muscle tone and we do exercises with her legs and arms every day (moving them for her). She is also put on her tummy everyday (sometimes with a rolled up muslin square underneath her) and we encourage her to lift her head up.

She rarely cries, and if she does, it usually means that she is tired and needs to be put down in her cot and left, gets bored, has a dirty nappy or if she wants a bottle earlier than usual.

To have a bottle ever 3 hours - she drinks between 5 and 7 ounces.

She sometimes has reflux problems and needs to be handled gently after a feed and properly winded (kept upright). She sometimes becomes constipated, and may need very diluted orange juice.

To have her nappy changed before every feed (unless it is obvious that she needs a change before this!). She gets upset if she has a dirty nappy.

Her right eye gets sticky and must be cleaned with cooled boiled water as and when needed. Sometimes it helps to gently massage Flo underneath her eye with circular movements to help unblock the tear duct.

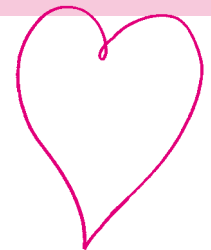
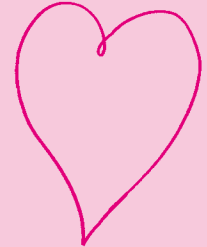
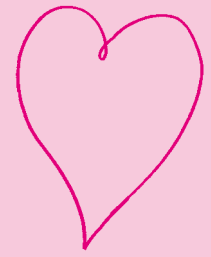
Flo has her last feed between 8 and 9pm, and this is a great time for her parents to have individual time with her.

Flo needs to be kept stimulated as she can get bored quickly. She needs to have a change of scenery and/or toys. This can vary but she tends to enjoy things for up to half an hour and unless she is happy, we would move on to something new, such as a different play gym or we would go for a walk.

# What is important to Flo?



- Being massaged and stroked on her face - particularly her nose and cheeks.
- Being cuddled by people she knows, including being cuddled and kissed by Thomas!
- Playing under her baby gym every day, particularly playing with the colourful rattle with beads on it. Flo also loves to grab hold of and shake the soft toys that dangle down from the gym.
- Being sung to. She likes most songs but her favourites are 'Twinkle twinkle little star' and 'We went to the Animal Fair'. Flo has also started to do some of the Twinkle Twinkle actions and Thomas enjoys joining in.
- Blowing raspberries and having them blown back to her.
- Having raspberries blown on her tummy.
- Being bounced on her parents and grandparents knees.
- Sparkly things - like the butterflies above her changing station.
- Contrast in colours - for example Grandma's and Granddad's beams in their house!
- Following people as they move around.
- Being talked to.
- Watching and listening to her brother Thomas' noisy play.
- Watching other children play including Flo's and Tom's cousins Lucy and Charlie and Thomas and his friends.
- Watching and listening to Thomas' noisy 'rocket balloons'.
- Being out and about, particularly busy places like the café in Marks and Spencer!
- Splashing and relaxing in the bath.
- Going to 'Rhythm Time' with Thomas and his friends on a Tuesday afternoon. Flo listens to the songs and shakes rattles!
- Looking at colourful books.



## When you are with us please...

Let's keep focused on Flo and what will help her and us.

Know that we want Flo to do what she wants in life and to be given every opportunity to achieve her full potential – starting now!

Be specific about what support you can offer and how we will know if this has been successful.

Help us with information that we can put in this plan.

Share what we are all doing so that we can work seamlessly towards our goals with Flo.

Give us a copy of any paperwork as we may find it difficult to remember all the information we are given.

Give us time to think during meetings, so that we are able to make decisions well.

## When you are with us please do not...

Refer to Flo or other children as 'downs'.

Use jargon.

Make assumptions that information you have about us has been shared with us.

