

Making The Future Together



in Control



Lynne and Nicola

Two Mothers both changed by a child

1972 - 2012



Nicola



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- Nicola was perfectly eligible to live in an institution. she never had full use of her body in 32 years, but for all of those years we were encouraged to ‘put her away’ into ‘special care’ were they would pay £60.000 - £100.000 How ever much it took to work on her becoming a person who walks, talks and moved her arms.
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As her parents

We were driven by emotion - anger, frustration,
We had no plan or knowledge to support our child
who had different support needs
no guide book, no strategies.

Nicola's life consisted of her trying
to prove she was good enough,
and failing.

We learned by making mistakes,
but we learned.

We learned to be drawn by hope not driven by anger and frustration

We learned to continue to dream for Nicola as we did for our other children.

People don't stop dreaming because their child is disabled, they stop when services systems make it so hard.

by bringing Family leadership courses to the UK in 1996
We have created a network of over 2.000 informed people who share
creative ideas and help each other.



We need to train Families alongside the people who support them
they are there for the long haul
We need to trust and believe them to know the best for the person they love.

We are all colleagues together in a very important mission.

Ultimately our goal can be nothing less than total transformation of our culture.

Only when the most vulnerable of us is valued and appreciated for his or her gifts

will everyone be safe and supported to be a fulfilled person.

Inclusion is in the journey, not in the goal.

Each step of the journey is as important as the ultimate destination.

Judith Snow



Ethan Dalgarno

Exactly The Person He Is Meant To Be

"Motherhood is about raising and celebrating the child you have, not the child you thought you'd have. It's about understanding he is exactly the person he's supposed to be. And, if you're lucky, he might be the teacher who turns you into the person you're supposed to be."

The Water Giver

My Child has a disability, not a disease.

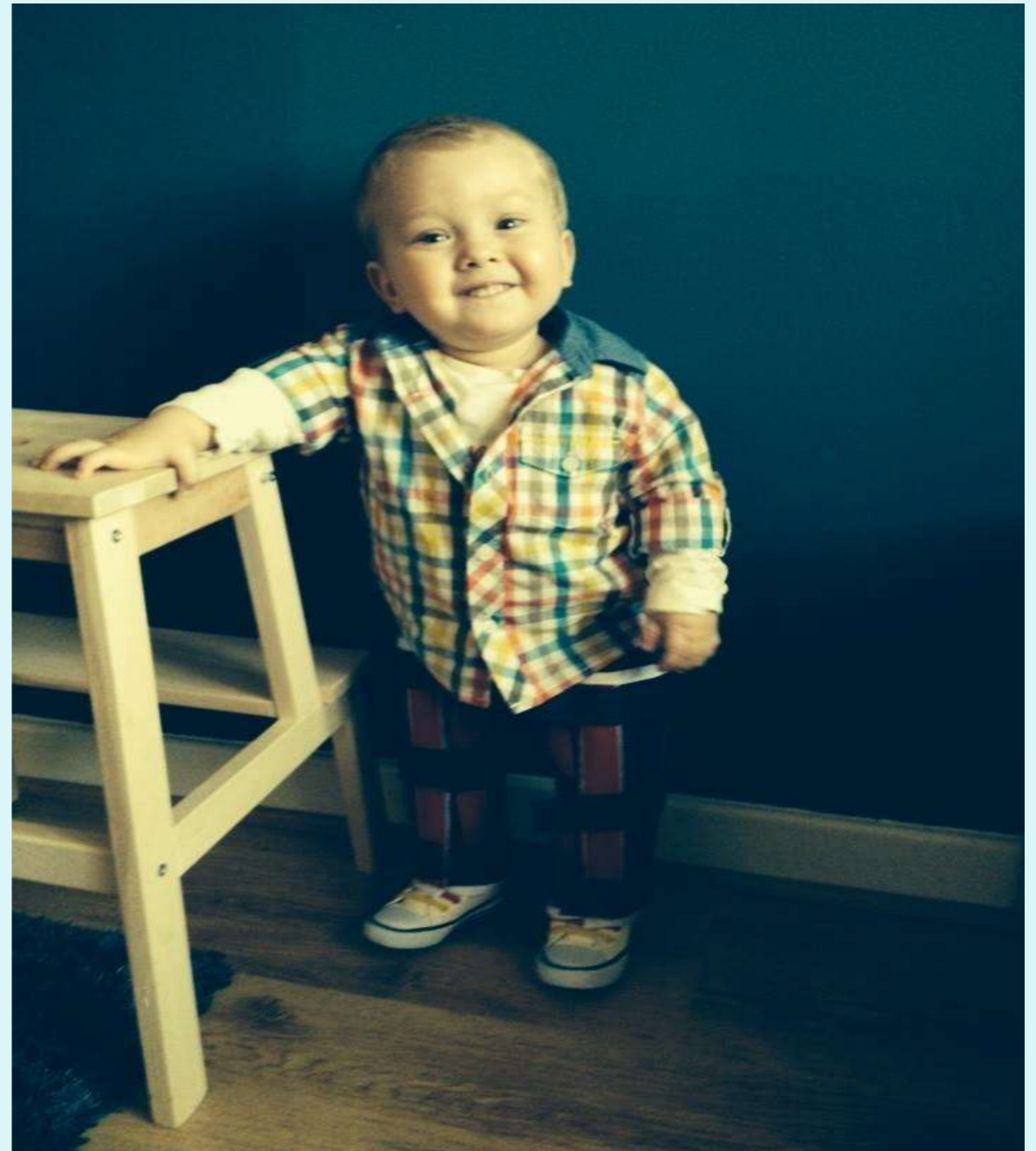
“Suffers from Spina Bifida”

“wheelchair bound”

“what’s wrong with him?”

“his crippling condition”

These are all phrases we have heard countless times.



Termination and Discrimination



To walk or not to walk....



There is a lot of emphasis on helping Ethan to stand or walk.

Yes of course we would love to see him stand or maybe take a few steps one day, but we don't ever want him to feel he has "failed" if he doesn't.

If he does stand or walk has he "overcome" his disability?

We don't want Spina Bifida to be his sole identity.

I don't want Ethan to grow up in a world that pities him.

I want people to see him for the funny, cheeky and playful little boy he is, and not "despite"

having spina bifida, but just because that's who he is.

Little ways we try to help...

- × We volunteer ourselves as a contact family for newly diagnosed parents.
- × we offer support and a “real life” perspective.
- × Completely pro choice.
- × From the handful of families which have chosen to meet us they have all continued with their pregnancy.
- × we run a support group for children under 5 with spina bifida and/or hydrocephalus.

**Ethan on the
move!**



Where Would We Like To See Things Go From Here And How?

- × OT waiting lists cut and children assessed on a need basis. Extensive waiting list for assessment 3-5 years.
- × Parents attending not only Early Years Forum Meetings but any meeting regarding their child's future.
- × Choice of which services we use.
- × Establish a parent support network at maternity hospitals and nicu for newly diagnosed families.
- × links with specialist hospitals during pregnancy for support and a chance to see where baby will be cared for after birth. For example, visiting nicu, meeting staff etc.

**If you want to walk
fast, walk alone.**

**If you want to walk
far, walk together.**

– African Proverb

