

The Rules

<p>RULE 1 Stay in control, trust your guts and surround yourself with people who will help you see that you are losing control and the system is taking over your life. Keep the balance right and services know when to let go you nurture the very dependency you then criticise people for later in life</p>	<p>RULE 2 Stick to your guns. This is not a social experiment this is about your Childs life including their adult life. It is not about what is easiest for the system/ teachers. You know your child believe yourself.</p>	<p>RULE 3 Be a Meerkat, there are rarely 'innocent conversations' with services/ teachers, be careful you don't inadvertently agree to something in a corridor - it will come back at you in a meeting. If they get you on the phone always follow up with a 'to confirm what we discussed' email.</p>
<p>RULE 4 Blag, if you want time to check use phrases like - let me check the SEND guidance I am sure I read something that might help us get the best outcome for NAME.</p>	<p>RULE 5 Have a long memory for important things (not things like times and birth weights obviously lo) but the joy it brings you to quietly stick 2 fingers up is simply blissful.</p> <div style="text-align: center;">  <p>BRINGING US TOGETHER</p> </div>	<p>RULE 6 Don't 'settle' - My Gran always said have no regrets. If you have done something wrong apologise and move on but really don't have regrets for things you wish you had done, have a go even if its wrong and goes on your 'never, ever again list' or you have to rethink it its far better than getting to my age wondering what would of happened.</p>
<p>RULE 7 Keep your cards close to your chest and don't 'show your hand too soon. Bide your time. Don't let on you might know the Law (or refer back to RULE 4 BLAG) if they know too soon they will have legal services and tem managers checking emails before they are sent - Refer back to RULE 5 confirm things in an email.</p>	<p>RULE 8 Get independent advocacy support for your young person so you can be confident that it is there voice that is leading planning not you. You can start to believe that this just might be your unrealistic expectations and what YOU want. RULE x and Y will help you stay confident about whose life it is your are doing battle for.</p>	<p>RULE 9 Keep people who live in the real world around you. It is so easy to get sucked into believing what you are told- people in the real world will say "that's stupid why"</p>

The Lessons

LESSON 1

Remember the privilege of being invited into someone's life. No one wakes up wanting a nurse or social worker - trust me if you are there you are probably the last hope they have of support. Think about how hard it is to pick the phone up and ask for help.

LESSON 2

I don't want to be her only friend or her my only friend - the right order of things is that parents die first, if you think that mums and dads don't think about it before they close their eyes each night or as soon as they wake up your are deluded. To build and maintain friendships with your child takes energy, creativity and commitment.



LESSON 3

Have a read of the poem 'Welcome to Holland' by Emily Perl Kingsley, for me that perfectly expressed how I felt. I don't normally do vomit inducing poems/ words of wisdom but this did help me find some words to express that I had no 'adversity' to overcome. Emma is no more, or less, special than her brothers and sisters.

They all have needs that are 'special' to them. The exhausting thing about being Emma's mum are the folk who feel they have a right to an opinion or feel it's their role to make accessing support as bloody hard as it could possibly be.

LESSON 4

Do not let our young people 'settle' at 16 because that is easiest. If the extent of our ambition and expectation is Life Skills and maybe an Internship and staying in FE until they are 25 because they can with a funded EHCP then do not be surprised or complain at the dependency you create.