

Record

149

File Number

10121

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Title: Having a baby

Original source: On the Level

Resource type: Written

Publication Date: 01/01/91

Publisher Info: FPA

Abstract

This article is the result of two interviews given by Robert and Julie Strike, 6 months before the birth of their daughter and then 2 months after. The Strikes discuss their intellectual disabilities, their decision to have their baby and the disheartening attitudes of people other than family and close friends. They describe the birth experience, the difficulties they faced physically and emotionally, and the pride they have in themselves and their baby. **Keyword: Attitudes**

HAVING A BABY

On the 12th June, 1991, Amanda-Lee, a healthy, if tiny, baby was born to Robert and Julie Strike, two parents with an intellectual disability. Six months before the birth and again two months after the birth Judy Searle interviewed them about their experience of having a baby.

Judy: Where did you two first meet?

Julie: We first met in 1986 at a Self Advocacy Conference at Nambucca Heads. Robert was the organiser of the conference and I was a very shy nineteen year old working at a Challenge Adult Training Centre. I had never heard of Self Advocacy before and was very impressed with Robert and the things he had to say about the rights of people with a disability. A year later Robert came to Lismore to help set up the Lismore self advocacy group, Ability Incorporated, and we became friends.

Judy: How did you get together with Robert living in Sydney and you living in Bowraville?

Julie: We became friends, but in 1989 I realised I really had a crush on Robert. I waited to be sure for a few months and when it was clear that Robert wouldn't ever make the first move I did. Being part of Self Advocacy had made me a lot more assertive but I was still really scared. In August of 1990 we made a long term commitment to each other with plans to get married in 1992. All that changed of course when I found out I was pregnant.

Judy: Did you plan the pregnancy?

Robert: No. Like many peoples' pregnancy it came as a surprise. When we first suspected Julie was pregnant we sat down, just the two of us, and discussed what we would do if she was. We knew there would probably be a lot of pressure on us to give up the baby and that we should make a decision before everybody else started to add their expert advice. We realised we were quite excited at the idea of having a baby and decided before we got the test results from Family Planning that we would keep it and bring the date of the wedding forward.

Judy: When you were younger did you ever think you would find yourself having to make this decision?

Robert: No. I spent many years of my life in a large residential institution where I learnt that people like me had no right to have children. If I hadn't got out of there I wouldn't have had this opportunity. When I did get out in 1975 my life changed drastically and so did I. Several years ago, before I met Julie, I went for genetic counselling and got an all clear. I needed to know for myself that I was okay.

Judy: What about you Julie?

Julie: I lived with my parents all my life in a small community where everybody was supportive and friendly so Robert and I had very different life experiences. I never considered that I would have children. This was not because I have an intellectual disability but because I've always considered myself a career oriented person.

Judy: What were the main concerns when you found out you were pregnant?

Julie: Our main concern was how we were going to cope with other peoples' reactions. It didn't concern me how I was going to cope with being a mother, in fact I didn't even think about that until I was in hospital.

Judy: How were other peoples' reactions?

Robert: Pretty much as we expected so we were very glad we had already made our decision. Even our main support people tried to talk us into an abortion which was very disheartening. Many people didn't say to our faces that they thought we wouldn't cope but you could tell what they were thinking. You develop a sixth sense when you live in an institution. What was most important to us was the support we got from my family who are busy making up for the lost years. Julie's family were also supportive and our close friends were all for it.

Judy: How did you prepare for the baby?

Robert: One of the things we decided to do was to find out the sex so we knew what we needed to buy. Unfortunately the baby was in a position that we couldn't tell the sex. We also applied for a two bedroom Housing Department flat instead of the one bedroom we were in. They wouldn't give it to us until after the baby was born so this caused us anxiety and made us feel not at all prepared. We both attended the prenatal classes at Westmead hospital. These were classes for all people going to be parents and not just people with a disability which we were pleased about. We had a support person to help us to do the things we needed to do. Julie kept working right up until the birth and was very calm about it all until she went into labour.

Judy: How was the birth?

Julie: I was in hospital a month before I was due as the baby was very small and I was feeling less than 5 movements a day and I had been told I should feel ten movements a day. It was a real shock to me when they came and asked me if I would like to give birth the next day. They induced me a month early as the baby had foetal growth problems. I don't think I coped with being in labour very well and was happy to have a caesarean when they offered me one after 5 hours. Robert had hoped to be at the birth because he is a strong advocate of fathers being involved all the way. He was the first to get to hold Amanda-Lee. I didn't get to hold her for two days as I was still very weak and groggy. Amanda-Lee was in the humidity crib as she weighed only three lbs and three ounces. I would go and look at her but I didn't want to pick her up until I felt stronger.

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Judy: How were the first few weeks?

Julie: I started breast feeding a week after she was born and I tried it for two weeks but it wasn't for me. I'm too active and I didn't like having to drink the three jugs of water I had to drink a day to produce the milk. I wanted to try it, but I'm happy with the decision I made as now we can both feed her. Amanda-Lee had to stay in hospital until she weighed five pounds, so I came out before her so we could move house and prepare her room. I was pretty depressed in the first three weeks, but that is quite normal.

Judy: Did the initial separation from Amanda-Lee make it harder for your to bond?

Julie: Robert bonded straight away and I am bonded now. I was happy with the way they treated us at Westmead and everything about the birth. The only bad experience I had was when I was very tired one night and I didn't want to get up to go and see her in the nursery and the nurse told me off for ignoring my baby. I felt she was telling me I couldn't be a good mother and I was very hurt and still crying when Robert came in the next day. I should have said something to her but I couldn't. I think people do have certain expectations about you when you have a disability, whether they mean to or not.

Judy: What did you do when Amanda-Lee first came out of hospital?

Robert: We were advised to go to Tresillian for the first week. We both went and lived in and they taught us about all the things we needed to know such as getting into feeding routines and what to do when she cried and how to bath her and change nappies. They taught us to wait three minutes before giving her dummy and another three minutes before picking her up to feed her every four hours.

Judy: Do you still do everything you learned at Tresillian?

Julie: At first we thought we would try some other ways like demand feeding, but now we have gone back to all the routines they taught us and it is much easier. When you do have difficulty learning things it is very useful to have the consistency of the same routines. We like to try things out for ourselves and come to our own decisions and not just do them because we are told.

Judy: Did you get any extra support because you had a disability?

Julie: We had a community nurse come to visit us once a week at our home for eight weeks. We could ask her any questions and she weighed the baby and checked her feeds. Now we go to the regular Community Health Centre. We also attended parenting classes at Family Planning. They were very good classes and we wish we had kept them up longer.

Judy: Where does your support come from now?

Robert: Our Auntie is very supportive and does a lot of baby sitting of Amanda-Lee. We also have a friend who has a two year old who gives us tips. Our support is mostly from our family and friends which we are very lucky to have.

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There would still be support for us if we didn't have our own networks but I think it would be very difficult.

Judy: How do you share the work load between you?

Robert: We very much share everything. I believe men should pull their wight and change nappies. I enjoy doing these things. It annoys me when men think it is women's work. I am happy for Julie to go back to work when she wants to as I am a firm believer in the rights of each individual to do what they want. Growing up in an institution with few rights makes you that way.

Judy: How do you see the future?

Julie: Robert is now back at work for NSW Self Advocacy. I am president of Self Advocacy so I am also in there most days doing voluntary work. I am not really one to sit at home with a baby all day so we are lucky we have jobs where we can bring Amanda-Lee. I hope to go back to full time work when she is about three years old. Having a baby certainly changes your life more than we ever imagined. We both really enjoy parenthood despite it being very hard sometimes.

Judy: Do you have any advice for other people with an intellectual disability wanting to have a baby?

Julie: The main advice we have is don't be afraid to ask questions no matter what they are. We were afraid at first that others would think we weren't coping if we asked too many questions. Many things are so simple to fix once you ask. For instance, we were having so much trouble with bottle feeding until we found we had the teat on the wrong way. The communication you have with each other is also very important. You need to have patience not only with your baby but with each other and spend a lot of time talking and solving any problems. We would also recommend people to go to the Family Planning classes before birth and to keep them up after the birth. We only did one after and we should have done more. Once you find out you are pregnant you should concentrate on your baby because there is so much to do and to learn.

Judy: How do you find people's attitudes now?

Robert: People's attitudes have really changed now they see how well we are coping. You just have to show people that you can do it. We are both proud of ourselves and of our baby. There are still some ignorant people around that you can't get away from. Just the other day we were shopping and a stranger said to Julie "Why would you want to be married to someone like that?" I look like I may have a disability and Julie doesn't. Comments like that still hurt but I guess they will always be there until the community at large learns about intellectual disability. You just have to feel sorry for them.

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