Stresses and Coping Strategies of Parents of Adolescent and Adult Children with ASD’s

A Qualitative Study/Interpretative Phenomenological Analysis

Eight parents of adolescent/adult children aged 18 - 21 years

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Introduction

- Living with autism causes significant stressors in family life and ranks among the most stressful of childhood disabilities.
  - Lack of social skills
  - Problems with communication
  - Behavioural issues

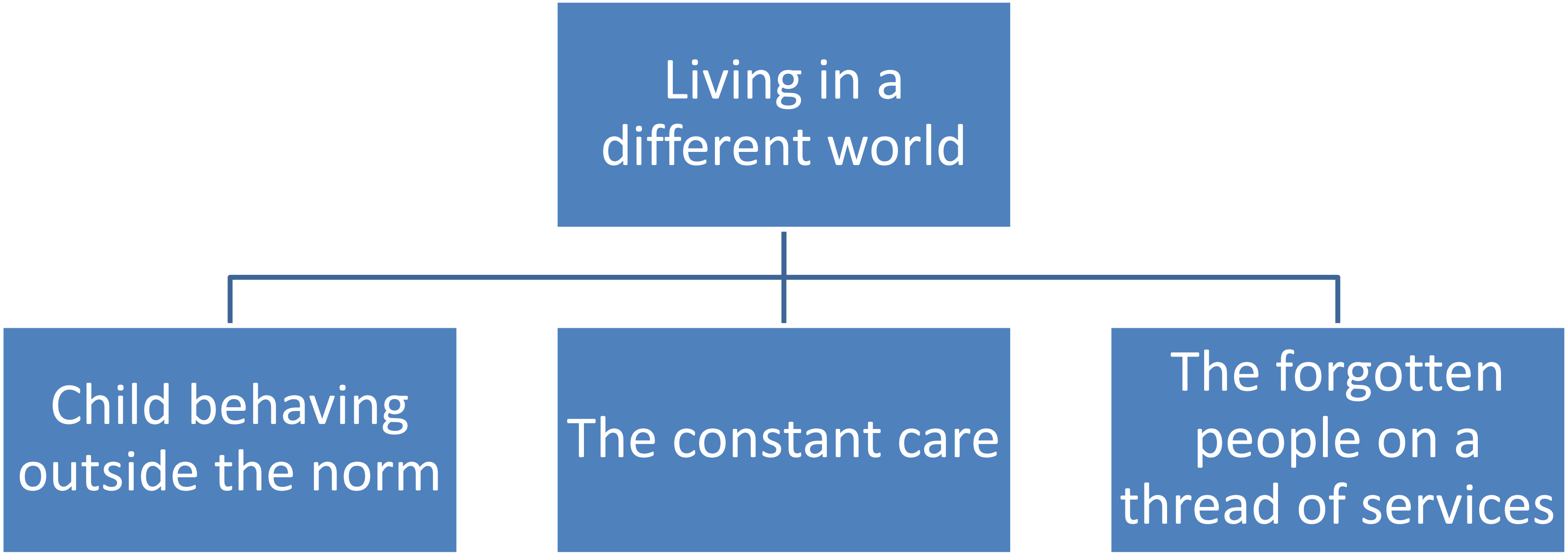
→ Stress on families

- Research has been largely limited to parents of younger children with autism but what about parents of ageing children?
  - Small body of emerging research shows:
    - No cut off point for parenting at usual adolescent and adulthood
    - Parental involvement and responsibility generally lasts to some degree for rest of parents life
  - Result - Parental stress …. Physically/Psychologically/Socially/Emotionally

- Need for understanding life trajectories of ageing children with autism and their families.

- Two overarching themes emerged in study. ‘Living in a different world’ described the stressors the parents considered they experienced and ‘making the best of autism over time’ described their ways of coping with autism.

Stressors



Living in a different world

Child behaving outside the norm

The constant care

The forgotten people on a thread of services

“living in a different world”

- Cut off from rest of society
- Daily difficulties due to autism
- Behaviours
- Extended care beyond the norm
- Battling for services/with service provisions
- Lack of constancy in lives/see saw patterns of ups and downs
- Differing stresses depending on where sons/daughters presented within ASD spectrum :
  - Lower autistic functioning: lack of respite/Constant care-giving
  - Higher autistic functioning: problems with integration/sexuality issues

Child behaving outside the norm

- Autistic behaviours of rigidity, repetition, routines = stresses of frustration, embarrassment, disablement of pursuing a normal life irrespective of where child's abilities lay within the spectrum.
- Inappropriate behaviours "outside the norm"

  "I'd let her sit there in McDonalds, but I couldn't interact with her, because if I interact with her even to give eye contact, she'd start obsessing, emmm mummy, emmmm, balloon, balloon, she's obsessed with helium balloons. Balloon, later, balloon later. Yes P we'll get the balloon later. Now a lot of the time, the shop may not open until after we've had lunch so I cannot explain that to her, well the shop isn't open till 2 and its now 1" Mother of 19 year old girl with severe/moderate autism.
- *Sexuality issues for four of the parents of higher functioning children*
  - *Difficulties in knowing how to deal with it*
  - *Isolation*

  "This is very personal now really, in so far as, you see we have to, I've explained to him that the whole hormonal thing and the whole sexuality thing is a perfectly normal so the only relationship he has is with me. So I respect that and I understand that and I will go along with it, and but I mean, L (sister) *has to lock her bedroom door, I have to lock my door because he's constantly in and out looking checking for stuff and he would take stuff and I understand where he's coming from, and I have to explains to him, R it's perfectly normal, don't let it be something that you need to be secret but you need to do it in your room whereas he may not and that, this is a whole, and this is very hurtful for me"* Mother of 19 year old son with high functioning autism.

The constant care

- Never ending parenting: physically/emotionally = living in a different world to parents of atypical older children.
- Physically harder due to ageing process

  "The extra care, yeah, when she's younger, you're younger as well like, when you go back 15 years or so when she was 3, I was 15 years younger, you were in the caring mode as well, everyone else was caring, everyone else was caring, maybe not as much as you but they were caring for their children, they were bringing their children to school and that kind of thing but them, they move on and you are still left in the caring mode" Mother of daughter aged 18
- *Emotionally draining – chronic worry due to long term care into the future*

  "Of course the other stressor is the worry of what will become of the girls when they finish, and where will they end up? Who will look after them? Will they be able to manage things on their own? That's why I want them to become independent as much as possible" Mother of twin girls (22)
- Gender equality in worrying about long term care of sons/daughters

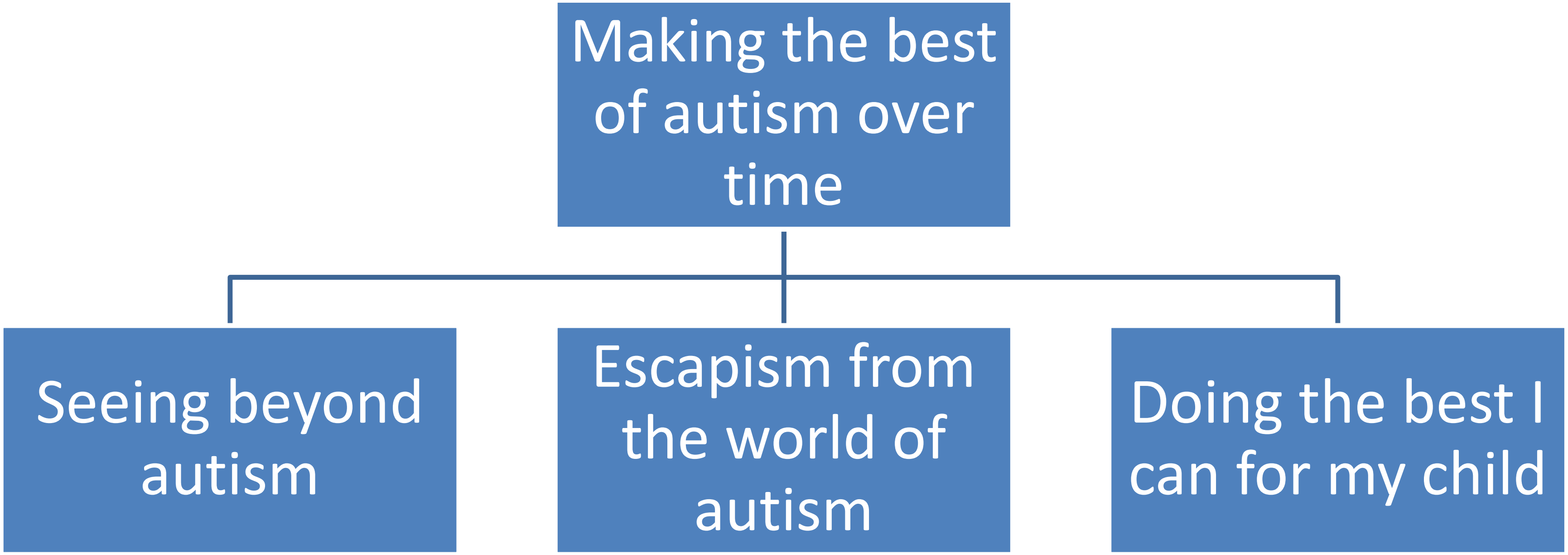
  "I can try and project it further down the road, well if I was really to be honest with you, what's going to happen when Mammy and Daddy aren't here? That's really what bothers me. Amm thankfully I'm still young enough, I'm hoping there's another 20 years in me. A semi-independent setting… that would be ideal. That would be our dreams come true" Father of 18 year old son

The forgotten people on a ‘thread of services’

- Struggles with transitions from child to adult services ‘like falling off a cliff’.
- No choice re services
- Concerns re services and need for media interventions at times.
- Getting ‘on a thread’ re respite services
- Stretched by a thread re other family members with separate demands e.g. older parents, other siblings.
- Felt forgotten by other members of extended family > isolation and loneliness.

  “It’s always a battle, you are always looking, for instance your adult children usually do their leaving cert, then hopefully go to college, travel or get a job or do something in the meantime. I mean everything really to do with autism, you’ve got to nearly invent. You nearly have to invent a school, then you get the school and you breathe a sigh of relief and he’s there until he’s 18 and then you are told, day centre is next. But there is none. So you nearly have to invent everything, you have to go to whoever is in power at the time and beg and you think that, you were asking for, I don’t know, what? It’s like ammm you know, services are for everyone, prisoners have services, you know? They do, like, because they have to. But we are the forgotten people really. And not only the people with autism are the forgotten people, the parents and families are as well. We’re left with the fallout” Mother of son (20)
- constant fluidity of stressors over sons/daughters lifetimes indicating the need for strong coping strategies to be put in place for parents well-being.

Coping Strategies



Making the best of autism over time

Seeing beyond autism

Escapism from the world of autism

Doing the best I can for my child

Seeing beyond autism

- Recognising the real person in their child/what they believed true nature of their child to be
  - Special qualities in child
  - Humour in autism
  - Helped make sense of the situation over time

“Yeah, I can see that character in him, you know, he’s a bit of an old rogue and he’s an old slob, just a typical boy. I try not to think about that anymore. Maybe I would have done that some years ago but now that I’ve come to accept it and that took a long time, you know I love him for who he is, the person that he is and I’m glad I can say that now without, yeah, without crying, you know” Father of son (18)

Seeing beyond autism

- Being normal ‘as near as possible’
  - achieving normal family lives as much as they could
  - Getting on with the simple things in life eg holidays, breaks, Sunday activities.
  - Getting up and on with things
  - Trying to find enjoyment and good times.

“What helps me is thinking or trying to achieve my life in as normal as possible, to function as normal as possible, family life. So if we can just do the simple things. That’s all. That actually is my aim. That we can do most things, that we can get a holiday and we do. So to get away, a few breaks, to make family life function as much as possible…I mean I don’t think you’ll ever achieve it in comparison to normal families but just to get it as near as possible will do” Mother of son (20)

Seeing beyond autism

- Setting goals in life for ourselves and our family
  - Thinking ahead for the long term for themselves eg bucket lists, both for themselves and other atypical family members

"You have to have goals and things you want to do, I want to do something in life. My wife had certain things that she wanted to do, she wanted to go to New York so I said fine, let's do it. And funny you mentioned 40 because when we turned 40 my wife and I, we said, do you know what, we're 40, God almighty, we're 40 and we started saying, but god we weren't that old, 'bucket list', the things you want to do in life. So we started scratching away, and it was a good relief from whatever we were stressing about at the time, it's like planning a holiday, it's great fun, it takes the worries away from the misery of winter" Father of son (18)

  - Wellbeing and personal lives of other siblings important – parents wished siblings to have their own lives without being adversely affected by autism

"L is a very good girl; you know it's such a pleasure talking to her, because you can't have a conversation with Rob. But she's a great girl, I need her to…. And she's doing it; I want her to have her own life" Mother of son (18)

Escapism from the world of autism

- Seeking distractions
  - Mothers used pleasurable activities such as shopping, fashion, reading, walking, coffee with friends, exercise
  - One father used work as distraction but also sport, exercise and other enjoyable activities.

"Ammm, just escapism really, a book, clothes, fashion, you know, all those small little things, a chat, get away, have coffee, somewhere just on your own. Just time out really. They're my main things. Sleep…(laughs)" Mother of son (20)

Escapism from the world of autism

- A little bit of respite
  - More mothers than fathers used work as respite/may have been a more important coping strategy for the mothers in the study as these mothers tended to be the main care givers of their adolescent and adult children with autism.

"But when I get to work, like no matter how stressful the week has been….I go to work on a Thursday and I just leave it there like, you know I can't… it can't be on my mind there so I just switch off"
Mother of daughter (18)

  - Formal respite/breaks
  - Considered formal respite important to recharge the batteries and have a well-deserved break from caring
  - Not enough provided!!

Escapism from the world of autism

- Taking the edge off with medication
  - Three parents (Two mothers/One father) and one spouse reported usage of anti-depressant medication
  - Care-giving strains associated with providing care for grown up children with ASD’s may offset improvements with age in emotional well being for midlife and ageing mothers/changes in child residential status not associated with depressive symptoms.
  - Long lasting effect of parenting stress remained with mothers and maternal depressive symptoms increased over time (Barker et al, 2010)
  - Menopause?
  - Parental lives are linked to and travel together with lives of grown children in midlife and old age (Barker et al, 2010) = important implications for health professionals understandings of such parents vulnerabilities.

Doing the best I can for my child

- Easing my child
  - Fundamental respect of intricacies of autism as part of the individuals make up
  - Innate understanding of child’s needs
  - Going with them and gleaning pleasure from observing child’s satisfaction

“David loves having showers, and he has 3 a day, you know if he wants a shower, he has a shower. Then he does this thing, he gets into the car, he wants a spin. I often bring him around the block just to give him a spin, so I do do things just to keep him happy. Ummm, quite a bit. More than I would probably have thought. You want them to have the same as everyone else and I just think that David has not a lot in his life. And maybe, he’s been in the house for quite a long day and sometimes I just say, oh come on, we’ll go for a spin. It’s no load. So I don’t think about it too much, I just think it's a little spin for him. And if he wants another shower, well, he feels good. You see, I’m not sure really where the line is drawn. I mean, does it help me cope? Probably. Do I really want to do it? Probably not but he’s happy, I’m happy. Relatively...” Mother of son (20)

“God, well, I suppose just try and listen to him. I guess, try and understand him, I suppose, it depends on the situation, but if you are able to, if you are in that space where you are able to switch off and say I need to just stop what I’m doing now and just listen to R, whatever is stressing him” Mother of son (18)

Doing the best I can for my child

- Pulling and sticking together
        - Decline in family relationships as child becomes older
        - Less recognition for an adult child
        - Decline in other relationships
    - Informal support from spouses/other siblings/significant others
    - Invaluable bonds help cope over child’s lifetime
    - Success in finding people who accepted adult child’s disability

“I do have plenty of friends that have children that have special needs who are adults now at this stage like myself at different levels and you nearly feel like you have grown and your families have grown with them so you experience the same things, so emotionally I think I couldn’t have done it without them. There is a huge difference in the friends that would have children with disabilities versus the ones without and they would both be a great help but there would be no real comparison between those with and those without because those with ammm, just have walked in my shoes.”
Mother of son (20*)*

Doing the best I can for my child

- Planning ahead for now and the future
  - Strategies to help get through day to day basis
  - One step ahead in daily routine
  - Also thinking and planning ahead for the long term

"Well, if you realise you are gonna have bad days, but there's also good days, that's one thing. You need to kind of say whatever situation you are in and you'll have different, look life with an autistic child, it's like running a steeplechase right, you get over one barrier and guess what, you're galloping to the next barrier, but there are times, flat times, plateau times when there aren't all stresses. But you need to understand, if there is a barrier there, you come to this God damn Beechers brook, right, there are ways around it right. Amm and its, you will get over it one way or the other, in most cases you will get over that obstacle and you'll move on" Father of son (18)

Recommendations for education and practice

- Sexuality issues
  - Major concern for parents (DeMyer, 1979)
  - Persons with ASD display sexual interest and wide range of sexual behaviours but may naively engage in inappropriate or intrusive courtship behaviours due to their social ineptness (Stokes, Newton and Kaur, 2007)
  - Grey area, Ireland, 2014?
  - – Need for social skills programmes
  - – Sex education programmes
  - – Parent/family involvement in training programmes

- The ongoing care
  - Care-giving implications: understanding of older cohort of parents
  - Increased supports/facilitation of adult care
  - Research on care-giving needs of parents
  - Improved respite and support services
  - Careful planning to find right balance for parents
  - Bi-directional relationships – professional help/family members?

- Bridging the gap within the autistic spectrum
  - Provision of appropriate services to take account of all functioning areas of autism spectrum
  - No ‘one size fits all’ policy
  - Differing needs within lower and higher functioning people with autism / differing needs for parents/parents of children with higher functioning autism = group largely being ignored.
  - Improved respite facilities/shared care system for severe/mod functioning persons
  - Clear need for development and service provision for persons with higher functioning autism (home supports, halfway house, holidays, group outings)
  - Community based

- Planning for seamless transitions
  - Systematic planning for resources/support interventions/ facilitation of fluid transition period from child to adult services
  - Improved understandings by service providers and health professionals re specific issues and stresses faced by parents of adolescent and adult children with autism = better services and improved parental and family well-being

- Using emotional focused coping as strategy
  - Traditionally portrayed as being more negative in literature e.g. passive appraisals/avoidance/passivity as strategies
  - Q - Conflict with professionals who adopt strengths based approach to support individuals with disability – believe parental perceptions unrealistic?
  - Increased use of emotional focused coping – parents attempt to find meaning within the ‘linked lives’ of they and their child as carer and dependant (e.g. Easing their child)
  - Further understandings of increased emotion focused coping in older parents
  - More supportive service design for parents of adolescent/adult children with ASD’s
  - Family resiliency theory – bridge theory with practice
    - Emphasises positive attributes such as family bonding
    - Conceptualises demands, resources and issues involved in family life
    - Holistic perspective