

# An Exploration of the Views of Adults with Asperger Syndrome/ High Functioning Autism in Relation to Independent Living.

Jill Coogan BSW(Hons)



# INDEPENDENT LIVING ?

- ◉ Pay your bills and manage a household?
- ◉ Live on your own ?
- ◉ Travel to work and social occasions independently?
- ◉ Earn a wage?
- ◉ Support yourself financially?
- ◉ Dependent on risk assessment?
- ◉ Based on ability?
- ◉ Based on choice?

# INDEPENDENT LIVING ?

*“requires the recognition of an individual’s civil and human rights, the empowerment of disabled people to exercise choice and control over their own lives as well as their engagement in the decision making process”*

( Quin & Redmond, 2003:68).

# INDEPENDENT LIVING RESEARCH?

Renty & Roeyers (2006):

In a study of 58 participants:

10.3% independently

8.8% with a partner

55.2% with parents

25.9% in supported/residential accommodation.

# AMBIGUITY?



# FOCUS GROUP DEMOGRAPHIC

Number	Age	Gender	Status	Occupation	Living Status
1	27	Female	Single	Work experience	With mother
2	27	Female	Single	Trainee chef	On her own
3	23	Female	Single	Full-time student	With parents
4	27	Male	Single	Full-time student	Student house share
5	23	Male	Single	Full-time student	With parents
6	27	Male	Single	Unemployed /work experience	Flat share/ parents at weekend

# PERSONAL GOALS ?


- Client/Service users perspective
- Equality in terms of gender
- No reference to diagnosis.
  
- Recommendations to be practicable and not require policy and legislative changes.
- Findings could be used by the CAA to inform future service provision.
  
- Findings will assist parents.

# FOCUS GROUP QUESTIONS?

- How do the participants define independent living?
- Do they consider themselves to be living independently?
- What do they perceive as the greatest barrier to independent living ?
- If it were possible would they choose to live on their own?



## FINDINGS ?



*“Not everything that steps out of line  
and thus ‘abnormal’ must necessarily  
be inferior”*

(Hans Asperger, 1938).

*“Depression is a common trait in people with AS.  
How could they not be depressed when the world  
doesn’t understand them, doesn’t connect  
emotionally to them and doesn’t understand the  
things which drive them”*

(Bollard, 2007).

# THEME 1: DEFINITION OF INDEPENDENT LIVING

*“Being able to do things around the house even if you don't live on your own”.*

*“Being able to manage things on your own if the need arises, you may not be away from your own home but if you are able to do things around the place yourself without needing too much assistance”*

## THEME 2: BARRIERS TO INDEPENDENT LIVING

*“I haven't had a job in three years and its really annoying. I love living at home but I want to get out 'cause I have lived there all my life”.*

*“finances.....that just comes first before everything”.*

*“I have seen the good, the bad and the really ugly of what it's like living with people. People can be really nasty. I was in one house and one girl was like so nasty....she was bullying me into moving out”.*

## THEME 3: IMPACT OF AS CHARACTERISTICS ON INDEPENDENT LIVING

*“people would say you need to do it now and I'm like come on I said that I will do it in my own time, I do do those things you just haven't noticed them yourself”*

*“my mother tells me you have to make lists. I say to her you have your way of doing things and I have mine. I have my own way of doing things”.*



*“I think that it is difficult for some people with Aspergers to make and maintain friendships”*

*“unfortunately for me , I try to get along, make friends for as long as I can but lately the people I know have moved on and it's been a case of it's kind of hard to stay in touch with them”*

*“You have to psych yourself up every day..... I know I have to deal with people but I don't want to but I have to”*

*“sometimes I'm good at timekeeping but sometimes I feel like I might get so many appointments that I can forget the times and dates of stuff and then it seems to build up and I get so stressed out”.*



*“Who I was, is who I am. For who I am will always be within.*

*Passion, determination and resilience, the many trials of life weaken me.*

*My lack of understanding customs and rules, these are my faults.*

*External misunderstandings give me strength, I fall from grace in who I am*

*Never will I lay down for long. Binding me will only make me struggle harder*

*Who am I ?, I am me “. (Getty, N., 2014).*

Maslow(1943).....Dignity of Risk.

*“without the possibility of failure, the disabled person is said to lack true independence and the mark of one’s humanity is the right to choose between good and evil” (Dejong, 1979).*

*“respecting each individual’s autonomy and self-determination to make choices for himself or herself, even if healthcare professionals believe their choices endanger the person’s health or longevity” (Disability Practice Institute, 2014).*

Seligman (1975):

Introduced the concept of '*learned helplessness*'.

He argued that the more a person is protected and sheltered under the guise of not being able to take care of themselves, the more dependent they become.



# BABY BIRD THEORY !!



*“my mother tells me you have to make lists. I say to her you have your way of doing things and I have mine. I have my own way of doing things”.*

*“we fight over the stacking of the dishwasher”.*

*“I can keep my side of the flat reasonably tidy, not by other people's standards but it's under control.*

*“being able to do your own laundry, cook your own food, keep yourself organised without somebody standing over your shoulder to see how you've done this and that”.*

*“biggest stressor?, my mother !”*

*“I'm not going to burn the place down but she will still stand behind me and supervise”.*

# RESOLUTION ?

## Professionals:

- ◉ Understand the parent's perspective.
- ◉ Acknowledge their fears.
- ◉ Have your research done.
- ◉ Communicate with parents.

## Parents:

- ◉ It is ok to be afraid.
- ◉ Trust the professionals.
- ◉ Step back and fight the urge to control and supervise.

I am indebted to you for your honesty, humour, time and support. During the focus group you supported each other and despite the lack of theory of mind which is generally associated with AS, you offered unsolicited advice and words of encouragement to each other. When we discussed the issue of bullying and vulnerability, I was very angry to think that as a society we are constantly developing new ways of enforcing the belief that some people are '*less than*'. When I listened to the recordings afterwards, I realised the participants would have discussed this topic further but I changed the subject. Clearly some truths are just too real to listen to. However the participants' hopes for the future inspired me, all they want is to work, travel, be happy and be loved: just like the rest of us.

