

## **AUTISM AND MENTAL HEALTH**

# **THE VIEWS OF PEOPLE ON THE AUTISTIC SPECTRUM ON THEIR MENTAL HEALTH NEEDS AND MENTAL HEALTH SERVICES**

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## **WHAT IS ARGH (AUTISM RIGHTS GROUP HIGHLAND)?**

ARGH is run by and for autistic adults in Highland; we joined together to form a group with the aim of improving the lives of autistic people. The founders of ARGH were inspired to start a group to fill a gap: groups existed locally for people with mental health issues and people with a learning disability but there was nothing exclusively for autistic people. We were the first group of our kind in the UK and are still the only one in Scotland; independent from any other body we are self-governing and self-funding; a group controlled entirely by autistic people to promote the rights of autistic people.

We want to show people that autistic adults are autonomous; we want to speak for ourselves and we want to change the presumption that we need others to speak for us.

We feel that coming together as a collective makes many individual voices stronger; by working together one person's weaknesses are overcome by another's strengths, we believe that everyone has something unique to offer and something to gain by working in this way. These are principles that we want to see reflected in wider society.

Through offering training we inform service providers about what autistic people really experience, this is a way to improve services for all autistic people.

We hold meetings for members, produce a newsletter, campaign for improved services and challenge discrimination as a group and as individuals in our daily lives. "Nothing About Us Without Us" is really important to us because all too often we feel that people do things "for" and "to" us rather than allowing us to take the lead and live our lives in the way we choose.

We have a member's only online message board that links autistic people across Highland. This means that no matter where in Highland someone lives they can access a safe autistic space to talk to other autistic people. Many autistic people benefit from meeting others whether online or in real life. It can be of great support to meet others who have similar experiences or who may be more able to understand you because of the shared experience of being autistic.

## **WHAT IS HUG?**

HUG (Action for Mental Health) is a network of people who have experience of mental health problems.

At present July 2010, HUG has approximately 400 members and 14 branches across the Highlands. HUG has been in existence now for 15 years. Between them, members of HUG have experience of nearly all the mental health services in the Highlands.

HUG wants people with mental health problems to live without discrimination and to be equal partners in their communities. They should be respected for their diversity and who they are.

We should:

- Be proud of who we are.
- Be valued.
- Not be feared.
- Live lives free from harassment.
- Live the lives we choose.
- Be accepted by friends and loved ones.
- Not be ashamed of what we have experienced.

We hope to achieve this by:

- Speaking out about the services we need and the lives we want to lead.
- Challenging stigma and raising awareness and understanding of mental health issues.

## **HUG's aims are as follows:**

- To be the voice of people in Highland who have experienced mental health problems.
- To promote the interests of people in Highland who use or have used mental health services.
- To eliminate stigma and discrimination against people with mental health problems.
- To promote equality of opportunity for people with mental health problems irrespective of creed, sexuality, gender, race or disability.
- To improve understanding about the lives of people with mental health problems.
- To participate in the planning, development and management of services for users at a local, Highland and national level.
- To identify gaps in services and to campaign to have them filled.
- To find ways of improving the lives, services and treatments of people with mental health problems.
- To share information and news on mental health issues among mental health service user groups and interested parties.
- To increase knowledge about resources, treatments and rights for users.
- To promote cooperation between agencies concerned with mental health.

## **INTRODUCTION**

For some years HUG has had people on the autistic spectrum who also have mental health problems as members. Whilst HUG tries to make its meetings as accessible as possible, and some people on the autistic spectrum attend them without any difficulties, we are aware that some of our meetings are not as easy to contribute to if people are on the autistic spectrum and this might reduce the opportunities for people to raise issues specific to Autism and mental health.

We were therefore delighted when ARGH (Autism Rights Group Highland) was set up by autistic people. Exclusively for autistic people, whether they had a mental illness or not, it has a far more credible voice than could have been provided within the body of a generic group about mental illness such as HUG.

Over the years there has been contact between HUG and ARGH and, in the summer of 2010, we decided to see if we could create a joint report on the subject of Autism and mental health.

This report is the result of that partnership. A HUG worker developed a questionnaire to send to people on the Autism spectrum and this was adapted by ARGH. This questionnaire was distributed by ARGH and also publicised and distributed by HUG.

In total 5 questionnaires were returned by ARGH members.

The HUG worker then facilitated a group discussion by ARGH members to look at the subject of Autism and mental health. 5 people participated in this discussion.

This report is a reflection of these consultations. It was written by the HUG worker and adapted and approved by the ARGH committee and accepted by the HUG Round Table.

In keeping with ARGH members' wishes it is, as far as possible, the direct voice of autistic people and is written from that perspective.

In a typical HUG report we would involve around 80-100 people. We acknowledge that the small number of people involved this time means that this report can only be regarded as a snapshot of life for autistic people (who may also have or have had mental health problems) but, nevertheless, we believe it to be a very useful insight from which important lessons can be learnt.

ARGH members are autistic people without a learning disability; this means that those autistic people with a learning disability are not represented within this report.

## **WHAT IS AUTISM?** *(Definitions and descriptions supplied by ARGH)*

For the purpose of this report the term 'Autism' is used to refer to all conditions on the autistic spectrum, including Asperger Syndrome.

Autism affects social interaction and communication; it has implications for how individuals participate in everyday life.

Autism is the result of experiencing the world differently, i.e. being either hyper or hypo-sensitive in any or all of the 5 senses, or having difficulty interpreting and integrating sensory stimuli.

This makes it difficult:

- to cope with certain sensory stimuli or to react *appropriately*
- to communicate to others how we feel and what we need
- to understand how other people experience the world
- to adjust to changes in routine or in the environment, incl. unexpected events

**Autism** is a life-long condition and affects approximately 1% of the population (Terry Brugha 2009)

### **What causes Autism?**

Research is ongoing and many believe that a single cause is unlikely. Neuro-psychology theory suggests that the cause for Autism may lie in a difference of connections within and between certain areas of the brain. There is a genetic component, which means that more than one person in a family may have an Autism Spectrum Condition (ASC).

### **How does Autism affect people?**

**People of perceived lower intellectual ability and Autism** may not be able to acquire speech, or their verbal communication may remain very basic. They may only function well in a highly structured environment with clear routines, predictable and tolerable sensory stimulation and access to communication strategies that suit them as individuals. They may always need help with personal care and general life skills.

**People of average or higher intellectual ability and Autism** usually acquire good verbal communication skills, but tend to take words and phrases literally, prefer to talk about facts rather than feelings, go on about their favourite subject, may sound 'like a book' and may struggle with conversational rules. They also tend to find it difficult to understand others and take in their point of view and their feelings.

**Many autistic people** experience pain and anxiety from sensory stimuli, which would normally be considered unnoticeable, tolerable or even enjoyable. This includes certain auditory frequencies or loud sounds in general, bright or flickering lights, particular smells and tastes, touch, temperature and movements. They might therefore avoid busy places (or become greatly distressed in them), cover their ears or turn their view inwards or resort to strategies like pacing, rocking, humming or stroking/kneading a particular texture in order to shut out the painful stimuli or in

order to integrate them better.

**Most autistic people** notice details rather than the whole picture and have difficulty sifting the important from the unimportant. This leads to a need for sameness and predictability and resistance to change. It can also lead to great expertise in certain areas or a chosen subject and the ability to stick with one activity for a long time. Single-mindedness, attention to detail and a lack of social convention have lead many autistic people in the past and present to contribute great insight and inventions in many areas of science and the arts.

## **THE IMPACT OF BEING AUTISTIC ON PEOPLE'S MENTAL HEALTH**

The experience of Autism on mental health can be described in two main ways:

We believe that a much greater proportion of people with Autism experience mental illness and mental health problems than general society. This is because we believe that Autism makes us more prone to mental illness but also because we believe the reaction of society to our experience creates the conditions that precipitate mental illness.

We believe that we are more biologically susceptible to mental illness and that our condition makes us more prone to anxiety and depression:

*"For me it's anxiety, OCD and depression, due to hypersensitivity, perfectionism and being resistant to change."*

*"Growing up in a world that I didn't (still don't) understand was very stressful for me; I used to think there was something wrong with me, maybe I wasn't trying hard enough."*

*"In my case it makes me much more prone to anxiety and depression. It makes me much more easily affected by adverse occurrences than someone who doesn't have Autism."*

*"I don't understand other people and they don't understand me, which causes the anxiety."*

*"I still feel that I (and other autistics) stress levels are higher than non autistic people, even when I'd consider myself to not really be under stress I'm still stressed."*

However, of huge importance is the impact of people in wider society on us and, at times, our attempts to become like other people. The lack of awareness by mainstream society, their negative attitudes and the lack of adaptation to our condition causes considerable stress which inevitably can lead to mental health problems.

Being expected to fit in:

*"Society; the constant daily struggle and grind; even a simple conversation; I feel I will be misunderstood."*

*"Because we want to do things right, we are seen as different. We want to do things right but are seen as inflexible."*

*"There is a pressure to conform and belong."*

*"It is difficult to know when people are joking, when to relax the rules and when to stick to the rules. This can cause a great deal of anxiety."*

*"It can lead to me not speaking or socialising because I don't know how to act. I can become really withdrawn."*

*"I am still quite new to my diagnosis but I now realise that many of my feelings of frustration and my anxiety in situations often stem from the communication and understanding difficulties between me and the rest of the world. I know that it is sometimes very difficult for other people to understand that some things in my life have to be the way they are for me to be able cope, but it helps if they can at least try to accommodate this. Often what happens is that people are just dismissive about the condition, maybe insisting that I just need to change! Thinking I am just awkward or difficult or somehow I have a choice about things that often I don't."*

*"Being very different and in a minority isn't easy. Society isn't set up for difference and it's not tolerated, particularly at school/work."*

*"We place great value on routine and things remaining the same. This gives great security. If you remove this security it leads to anxiety and depression."*

*"I was told that I wasn't a team player or that I was taking over. I could never get it right. I was an expert and in charge. I thought I was being straight forward but it didn't go well so I stopped doing anything so then they said I wasn't assertive enough."*

There is a feeling among some of us that our situation is getting worse and that, far from being more accepting and accessible, society is becoming a harder place to live in:

*"Society is changing. The things we rely on for routine are changing, like the seat on the train, the noise of people. Now there is less etiquette; the rules are less clear. There used to be a standard way of dealing with people. Now we have to work out what to do and if everyone keeps on doing different things we get lost."*

Sometimes it is not just about having a condition that society is unwilling to accept; it can be about bullying and harassment:

*"Social bullying comes in; they pass comments because they know I have a diagnosis."*

*They make assumptions about you and bully you. They use it and you are not defended."*

*"My closest friends are the ones who have done the most bullying."*

*"You have to have a thick skin and keep away from everyone else."*

*"Negative reactions have led me to self-harm; it's very hard to feel hostility or the threat of hostility everywhere I go... there is a group of people who I come across a lot (even though I try not to) who have made it their business to be as awful as they can... name calling etc., sometimes it feels like they're everywhere."*

*"They treated me as if I was an alien from Mars who had two heads; barring two or three people who were polite to me, and among these able people I was largely disliked, outcast and taunted, left alone."*

*"Amongst intellectuals I feel much freer than with ordinary people in the street, who throw stones at me because I have a funny hat on."*

Some of us have only recently been diagnosed as autistic. The lack of a diagnosis has caused us difficulty and confusion, while having a diagnosis has helped us to understand our situation:

*"Since being diagnosed I find it easier now. I feel I understand myself and my condition."*

*"Knowing why it happens means that I don't go in to meltdown and gain the skills to deal with it."*

*"If you know everything about your condition it can be possible to find safe places and ways of coping and adapting."*

*"Not knowing that I was autistic meant that I didn't really know who I was. So when people said bad things about me I listened to them. This led to depression and anxiety. I thought that I was the only person who felt the way I did. I didn't realise that there were other people who viewed the world in a similar way to me."*

*"I was unaware of what my condition was...they would reject me and scoff and say no he is not like you. No school teachers, guidance teachers or anyone knew about it, so I was alone and my mental health was poor. In fact my parents tried to bring me up normal which I was not and this about fractured my mind. If nowadays it was identified earlier and treated using the autistic paradigm then autistic spectrum people could be better in their mental health."*

## **FRIENDSHIPS**

We have needs for friendships and relationships just as other people do, but these don't always work out well and can negatively affect our mental health. We often feel uncomfortable in conventional society and are more at ease in groups that we feel understand us or we can fit in with more easily:

*"I have terrible problems in this area. I used to believe it would be great if I had a wife. Then I got married and my condition gave issues in the relationship which then failed. My experience has not been positive. It is difficult to understand if emotionally it would be the right thing to have a partner."*

*"A little bit wants a relationship but the emotional cost is far too great... you just need a few safe people. I don't want a relationship anymore I think people think I should have more relationships and friends."*

*"My mum used to pay me to socialise with school acquaintances because she wanted me to socialise. I wanted to read. There is a mismatch between what people think you ought to have. There is a pressure from friends, parents, teachers for you to have friends when you may not want them. They think you are wrong for not wanting this."*

*"It helps a lot if people can just accept, even if they don't understand and are willing to talk and negotiate around problems that arise. I find it helpful at places like church if key members have an idea of likely problem areas so when I get stuck, particularly in social situations someone can sort out things."*

*"(I would like) regular contact with others on the spectrum."*

*"Friendship is important too, on our terms though; sometimes people think they know best without even asking us. They may try to make us join in or be overfriendly when we need space. If we are genuinely listened to it makes all the difference."*

*"I find it much easier among people from New Craigs, we feel much more comfortable, we understand where we come from and find ways of coping that the rest of society doesn't accept."*

*"I find people with a mental illness are too chaotic; I find it easier amongst people with learning disabilities or people who are gay or have communication difficulties."*

*"I find it easier mixing with people from other cultures. It is easier with them because they don't notice when we are getting it wrong; they are more relaxed about it."*

*"In Uni we were there to study. The interaction was easier, it was all topic based and an interaction on mutual interests rather than social formalities."*

## **WHAT ARE THE EMOTIONAL NEEDS OF PEOPLE ON THE AUTISTIC SPECTRUM?**

Some of us don't feel that emotional needs are as important as other people see them. We have a need for a good environment but we can sometimes get by without paying a lot of attention to emotion.

However some of our needs are to feel:

- Secure, safe and understood.
- Fulfilled and have a sense of achievement.
- Have relationships and social contact with other people on the autistic spectrum.
- To be valued, have our strengths acknowledged.
- To have somewhere we feel at ease and protected in.
- To feel that we are not broken or wrong or bad.
- To feel valued in society and at work and school.
- To have stability, control and order in our lives.
- To have peace and calm.
- To be accepted for who we are with an understanding that Autism is a way of being not a lifestyle choice.

Some of us feel we have much the same emotional needs as anyone else and equally, as we are all individuals, our emotional needs will vary from person to person, just as they do in the rest of society.

## **WHAT HELPS IMPROVE THE MENTAL HEALTH OF AUTISTIC PEOPLE?**

We have a variety of needs that can make a great deal of difference to our mental health and wellbeing:

- We need opportunities to work and to study.
- We need safe places.
- We need places where we can go to and be quiet in. Places that we can retreat to when the pressure of being in a public space is too much to deal with. Places where we can recharge before we overload, both at home and when out and about.
- We need environments where we don't have to 'read' other people all the time.
- We need places where we can mix together in a social setting, a 'drop in' for people on the autistic spectrum might be good.
- An advice and support service, where we can get help with problems we don't have the ability to deal with on our own. A service that deals with everything from getting a new carpet to dealing with our neighbours. To having help in getting, for instance, a plumber in to the house, when we can neither make the phone call to get their help or deal with them being in the house if we are alone.
- We can have great difficulty in speaking out and, if we don't have family or friends, dealing with things like insurance tax returns or benefits can feel

impossible.

- Early help to deal with small problems can make a huge difference and sometimes it is as simple as getting help with going to the shop when we don't feel we can manage it.
- Sometimes what seem like small things are major things for us. A promise to return a phone call can cause a huge panic if that promise is not kept.
- For people in banks, shops, the welfare system, the health service etc to have an appropriate environment and trained staff to help us and deal with our requests.
- Opportunities to socialise.
- For people to be understanding and accepting of our traits and needs and strengths.
- We often need continuity at work and in the wider community.

*"To understand ourselves (so access to diagnosis/assessment is very important) but to have help to understand people who don't think like us: non autistic people. People are a mystery to me, they are illogical and weird, and I'd like to understand what they are about."*

*I'd also like more opportunities for hobbies etc; I find it very hard to start anything new/go to new places, I wish there was a solution to that. I have no friends and I'd like one or two. I don't just want any friends though; I want people I actually have something in common with, people that I'd enjoy being with. I don't want some sort of buddy/mentoring artificial thing."*

## **OUR EXPERIENCE OF MENTAL HEALTH SERVICES**

We find that mental health services are often unaware of our needs and sometimes aim for outcomes that contradict our condition or wishes. In the past the experience of Autism was seen as something that needed cured rather than a disability and way of being that should be respected.

Sometimes we find that because we have a diagnosis of Autism our mental health is disregarded and we are excluded from services. However, when we are treated by people who understand and respect our condition, we can be happy with the help we get.

We can get frustrated that services that deal with Autism itself are provided by mental health or learning disability services when Autism is neither a learning disability nor a mental illness.

## **WHEN AUTISM IS SEEN AS A MENTAL ILLNESS**

Sometimes people mistake being different from the norm as being a sign of mental illness that needs intervention but sometimes we are very happy with how we are and resent the intervention of services to deal with something which we are content with:

*"I preferred to do experiments with nature when I was younger; I kept dunking my glove in the water. They called a psychiatrist. Why do you need a psychiatrist for being different?"*

## **WHEN SERVICES DO NOT UNDERSTAND AUTISM**

Sometimes mental health services do not understand our experiences and as a result, when they try to help us, they try to make us into 'normal' people which can cause more damage than being left alone:

*"Mental illness services helped but there is a limit, hampered by lack of understanding. I feel they only have a general level of training. There is a need for specialist training for people dealing with people with Autism and mental illness."*

*"Staff don't believe the symptoms or understand them."*

*"If the occupational therapist had understood that the lifestyle I want is not the one that she had in mind for me then it would have been easier. They should take this approach in all their work."*

We feel that many of our ways of dealing with other people and emotions are different to mainstream society and therefore some therapies are innately unhelpful:

*"Just before the diagnosis I was sent to Dialectical Behaviour Therapy and despite trying to tell them, most of it made no sense to me. It was just impossible to do. No one would listen. Even now if I call NHS 24 for help I get "have you used your DBT skills?" even though a lot of it is based around emotions and understanding, describing and analysing them; if only I could!"*

*"There is not enough understanding of Autism and asperger syndrome in particular, hence a lot of misunderstanding, misconceptions and mistakes happen during treatment."*

*"Unhelpful treatments like cognitive behavioural therapy and anything that does not take in to account the way the autistic mind works."*

*"They don't listen; they treat us as if we're broken non-autistic. Our baseline isn't as they expect, so they treat us wrongly: trying to cure us of things that aren't wrong. They make poor judgements, they don't listen or discuss things; I'm afraid to talk to them because they always get it wrong and once they have an idea they will never accept that they are wrong."*

*"I was told by the psychiatric nurse, that she didn't know anything and hadn't met anyone on the autistic spectrum before but it was OK because she'd looked it up on the internet the night before; that's no good."*

*"Mental illness services have a vision of the ideal person they want you to be that they want to twist you into even though you have no desire to be this."*

*"If you have a problem and need help, the mental health system responds badly: you have to have a support group, friends, a hobby, talking treatments, socialising, when this is the last thing you need."*

*"I got packed off to the DBT; it was all about emotions. They said think back to before, but I was always like this! They said I wasn't co operating so I had to make things up to please them."*

*"They started trying to cure the bits of my character; why are you trying to change that? That is who I am!"*

*"I am constantly told that my sensitivity to noise is unnecessary; it is just dismissed."*

*"So what if I have to line things up and have things in a line in the cupboard! Mental health services see it as a problem but I am happy with it."*

*"I had to go to a day centre and it was complete hell..."*

When we are waiting to see a psychiatrist our anxiety about the appointment and the waiting area can be unhelpful:

*"Psychiatry appointments feel like I am going in to my final exams; it just gets worse and worse."*

Sometimes it seems that if we have a new diagnosis of Autism then the previous problems are seen as 'just' Autism not mental illness. There does not seem to be an acknowledgement that we can have mental health problems as well as Autism:

*"Now they have almost washed their hands of me. They now ignore my mental illness now that they have changed the label. I get no help now. They haven't acknowledged that the problems are still the same but now I get no help. I can understand it but it doesn't help."*

*"We don't seem to be able to get in to mental illness services – they ignore you, discharge you, move you on to another department. They don't seem to seek out specialists or refer on."*

Some of us have a belief that people with Autism respond to medication in different ways and that this needs more study and acknowledgement:

*"We don't always react as expected to drugs; we metabolise them differently but few doctors know or respect this; they say we're wrong or telling lies if we don't react to drugs as they'd expect."*

*"Being given drugs when I didn't really know why, telling the doctor they didn't work and not being believed. Some drugs make me sleep all day but they say they should keep me up and thought I was telling lies."*

*"We need understanding first before they give out drugs."*

*"They give me antidepressants"[which are unhelpful]*

Sometimes we don't know what our diagnosis is or resent the diagnosis we are given and the consequences of the diagnosis:

*"I don't actually know everything I've been diagnosed with [except Autism and OCD] over the years things have been mentioned but not referred to again."*

*"Being told I was socially phobic which I don't believe..."*

Sometimes we do not find it easy to be treated in the company of some other people with a mental illness who are not autistic as their lifestyle can be sometimes be hard to cope with.

## **GOOD PRACTICE**

Despite many of us being disappointed at the help we get from mental health services, we have also experienced good practice. This usually occurs when people acknowledge our own personal perspectives and needs:

*"My psychiatrist is good. If he is going to be late, he knows I will panic and sends someone out to let me know."*

*"I was at A & E the other day. The nurse was brilliant. Once they knew I was autistic they took me to a quiet place."*

*"My psychiatrist is very good at some things, such as realising that running late or changing appointment times causes me much anxiety."*

*"My psychiatrist's office is a real mess and he has apologised for this, just the fact that he accepts small things which may seem stupid to others are a real problem to me helps. I still hate being in his office but do cope better because of the understanding."*

*"My psychiatrist acknowledges when things don't go right and by acknowledging it as a problem, he doesn't solve it but he makes it less; appreciating and respecting that; it means something to me."*

Many of the good practice examples that we would appreciate, such as knowing that appointments will occur on time and that we can avoid noise, confusion and bustle with our helpers would be of direct benefit to those of us on the autistic spectrum but we believe, are simple standards of conduct that would improve the life of any person in contact with mental health services. We feel that when people look at the whole person and accept difference then good practice will usually result from this.

## **PSYCHIATRIC HOSPITAL AND AUTISM**

We have mixed feelings about psychiatric hospitals. For some of us, they represent a place where we feel safe and secure and for others, the stay is nothing to remark about. However a few of us feel distinctly uncomfortable in them. We find the lights bright and harsh, the noise far too difficult to put up with and the rules and regulations confusing or hard to understand.

*"At times when I have been an in-patient I have never wanted to leave."*

*"It can be problematic when routines change, it's often noisy, lighting is a problem for me and so is the food and eating arrangements."*

Sometimes the lack of understanding of Autism can be off putting to us.

## **COMMUNITY MENTAL HEALTH SERVICES**

We had little to say about this except that it seemed to be unusual for autistic people to get help from community mental health services. And that many of the professionals had a limited understanding of Autism:

*"They also try to cure us: that's impossible."*

*"If we're being seen for something co-existing they [often] know nothing about Autism. If they know nothing about Autism then they can't do their job: they don't know who we are."*

## **SHOULD THERE BE SPECIALIST AUTISM SERVICES OR SHOULD MAINSTREAM SERVICES BE MORE ACCESSIBLE?**

We have mixed views about this. Some of us feel strongly that Autism specific services would be ideal and feel very offended that a condition that isn't a learning disability or mental illness should come under the umbrella of those services. Some of us feel we should have a mixture. We should have some specialists who just deal with Autism but we should encourage all mental health (and other) services to become more accessible to people with Autism. This would involve training more staff

in Autism and having some specialists that we could be referred to if necessary.

Some of us think that as there are experiences that are specific to Autism then we sometimes need access to specialists:

*"For example counselling is very different for autistic people. It comes back to them being able to understand we are not broken we're different. They have to learn to listen and to take what we say as true for us. We get judged wrongly because we're not how they think we should be."*

## **WHAT SPECIFIC SERVICES ARE NEEDED?**

We need help in a number of areas, some of which have been previously mentioned. But important areas include:

- More work to raise Autism awareness.
- More help with life changes and transitions.
- Treatment that is based on accepting that autistic people have different thinking patterns and that these should be accepted.
- Access to a text and email service at New Craigs, that can be used without having to go through an office or people in person.
- More research into 'neurodiversity'.
- Access to psychology (as long as they understand Autism).
- Help with the anxiety and depression that arises from Autism.
- Clear up why children are diagnosed by psychologists and adults by psychiatrists.
- Peer support.
- To have help with sensory needs.
- To have clear and accessible and constant services.
- A drop in centre to meet other people with Autism.
- Counselling by specialists in Autism.
- Assessment of environments so that they cause low sensory arousal.

Some of us feel that we would do better supporting each other and not relying on services.

Some of us think that the hospital environment that used to exist at Craig Dunain with its routine could be good for some people, if adapted and modernised. A safe ordered community or village may be ideal for some of us who do not appreciate mainstream society.

## **PRIORITIES FOR CHANGE**

The main priority for change is that we need people to be aware of and accepting of

autistic people. In order for this to happen we need people to understand our wishes:

*"We do not want to be normalised."*

*"We are not here to be fixed and changed; just helped. People need to know that we are different and won't change."*

*"I've never met a normal person but we are conditioned to appear 'normal.' I remember going to my first nursery. Because I didn't play with other children they took my toys away to make me socialise."*

The diagnosis of adults with Autism is still relatively recent and this can mean that many of us didn't know we were autistic until recently. The new diagnosis can take some time for us and our community to adjust to.

Whilst we need improved understanding by everyone, we also need much better understanding and skills from the professionals who ultimately try to help us. Much of this awareness raising should be carried out by autistic people.

## **LAST WORDS**

*"Having people actually listen to us; not people who speak for us. Charities/groups that are for parents or composed of non-autistic people don't really know what it's like and that should be accepted. Parents know what it is like to be parents and professionals know what it is like to be professionals: that's what they should speak about, not tell us how we feel/should feel."*

*"I can now understand where so many of my difficulties arose from the past at school, university, work, marriage; of where things went wrong or could have been handled better by me and those around me....now I think the biggest help for my mental health is for me and those around me to accept that ASC exists, it's real for me (however it seems to those on the outside) that I can't change who I am and (as far as I am aware there is no cure) so we need to mutually accommodate each other as best we can."*

*"Everything is a three way process, I need to work at being able to work, rest and play with the rest of the world, they need to do their best to accept and accommodate me as I am and we all need to work at understanding and helping each other."*

## **ACKNOWLEDGEMENTS**

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