

Residential care programmes for developing communication and life skills in adults on the autism spectrum

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Editorial

The author has over 20 years' experience at director level in the specialist care and education sector, particularly in the field of autism. She helped to set up and develop the first transitional residential service in the country for young adults with autism and complex needs. She now runs a national organisation, Living Autism, helping people with autism to find the most appropriate services for their individual needs. This paper is based on a talk Manar presented on her experiences and the case studies used are based on real-life situations from all around the UK. The names used are fictitious. This paper will be of interest and value to anyone working with children or adults as it identifies the key areas which need to be assessed and suggests the type of strategies that will help develop understanding and skills.

Introduction

In essence, the core of our approach to supporting people with autism in residential, supported living or any other setting is to find ways to help autistic individuals tap into their skills and strengths. The challenges each person experiences are identified and strategies and approaches developed to deal with these challenges so that they can reach their full potential. People on the autism spectrum are no different to anyone else in their need to learn social communication and life skills. Most of us leave home at some point and realise that living independently is very different to living in an environment where many things are done for us. Some of us learn the hard way that we should not put red socks in with white laundry, or that walking away from a pan on the hob and forgetting about it will fill the kitchen with a horrible burnt smell and will turn the pan into an unusable mess.

We also find out that social communication can be very tricky. We have to learn to manage difficult

situations with bosses, colleagues, partners and children. It is true that people on the autistic spectrum will find social communication and life skills more challenging and they might need to learn the skills in a different way to non-autistic people. However, they should be afforded the same opportunities to learn and develop in these areas.

Benefit of residential services

Residential services can help people with autism and complex needs by providing a safe environment in which to try out and develop new skills. They can provide consistency – in the use of communication approaches; consistency in structure and routines; and consistency in supporting sensory differences. Many autistic individuals need consistency across 24 hours to help reduce the anxieties brought on by the unpredictability of the world we live in. Furthermore, residential services offer several staff with whom individuals can interact which in turn reduces isolation and enhances resilience.

Communication

Communication is a vast subject. Differences in the way people on the autistic spectrum communicate vary so much from one person to the other. We have to keep this constantly in our minds. People such as Carly Fleishmann (2012) who co-wrote *Carly's Voice* and Tito Mukhopadhyay (2012) who wrote *How Can I Talk If My Lips Don't Move?* remind us that we must look beyond what is immediately apparent to us. Neither Tito nor Carly speak words. They utter sounds. They are not able to articulate spoken language. However, when taught how to use another medium – pen and paper or computer – they showed that their cognitive and language abilities are at the same level as most people of their age.

How can residential placements support communication?

Most residential placements have access to a Speech and Language Therapist (SALT). A SALT can put together a communication profile for the individual for all staff to follow which is recorded in the care plan. This provides consistency in communication. From their side, staff can make observations across 24 hours and feed these observations back to the SALT so that communication profiles can be amended and updated as progress is made. There are some questions that must always be asked.

These questions help us to remember to look beyond what we initially observe. They are as follows:

1. What is the person communicating to us?
2. How can we ensure communication becomes more productive?
3. What do 'key words and phrases' mean to the individual?
4. What do we mean by what we are saying?

Four short case examples below show the importance of understanding communication and making our own communication clear.

Case study 1

Jake is in his mid-twenties and has limited verbal communication. He uses key words and phrases. When frustrated he is known to become angry. He regularly knocks on the staff room door and says “cup of tea” repetitively. Staff make him a cup of tea. He takes it and throws it against the wall. Here staff are assuming that Jake’s key phrase “cup of tea” means that he wants a cup of tea. However, Jake has learnt that ‘cup of tea’ leads to interaction with staff. The strategy here is to find a more meaningful and productive way for Jake to let staff know when he needs to interact with them.

Case study 2

Philip is in his mid-thirties, is non-verbal and lives in his own flat. Members of staff help to provide activities for him to undertake in his own living room. He sits at his dining room table which is near the window to do the activities. After a short while Philip jumps up and starts to bang with his fists very hard on the window. Staff moved the dining room table away from the window. He still jumps up in an agitated state; however, he does not go to bang on the window. Here staff have worked out that Philip might be light-sensitive which is why he bangs the window when he is sitting near it. They believe that he jumps up in an agitated state when he is becoming fed up of the activity.

The strategy here is to sit him away from strong light sources and to move him onto another activity before he becomes fed up and agitated. A clear activity chart with ‘now and next’ would also be helpful.

Case studies 3 and 4

Adam is learning to live more independently. He has speech. He needs prompting to undertake personal hygiene and domestic task skills. His support worker says to him “Jump in the shower”. Adam replies “Why would I want to do that? I would hurt myself”.

Rob is becoming more independent. He has speech. He goes to the administration office and asks to see the manager about something. The administrator tells him, “She is tied up at the moment. She’ll be with you in a minute”. Rob then asks “Who has tied her up?” He also becomes agitated when it has taken more than one minute for the manager to appear. The message for staff in both these cases is to remember that our words can be taken literally. Do we really mean what we say?

Routines and flexibility for independence

Structure and routines are essential for autistic people whose executive functioning can be impaired. This means they can experience difficulties remembering sequences of events, planning ahead or even having the motivation to tackle tasks that are of no interest to them personally. In residential facilities, staff can follow the care plan and ensure continuity of routines that will help progress independence. However, it is important for staff to remember that the autistic person needs to have prompts to help them work through their tasks whether that is to follow a list of words, a list of symbols or a board with objects of reference. These 'lists' might need to be very detailed (eg a list of which clothes to put on in what order). It might be time-consuming for staff to create these 'lists'; however, they can be invaluable to individuals being supported. Staff can alter one thing at a time to introduce flexibility so that the individual is not overwhelmed by too much change in one go. In residential settings, structure and routines can be used to promote personal care, food preparation, domestic skills and to access the wider community, to name but a few areas of personal development. When supporting people to access the wider community, it is important to think about ways in which to help individuals protect themselves so that they are not taken advantage of because of their vulnerability. There have been some cases where young adults have wanted to make friends and thought the best way to do that was to give out their phone number and address to everyone they met.

Below are some questions staff should ask on a regular basis:

1. What is an essential skill and what is a socially led skill and how do we prioritise the ones we need to concentrate on when supporting individuals with autism?
2. How many transitions between one place and another or one activity to another can the individual tolerate if transitioning causes them anxiety?
3. In what form do we present the routines or the plan for the day?
4. Are we presenting activities with a clear beginning, middle and end in order to reduce anxiety?
5. Do we plan calming activities into the day?

The next three case examples illustrate how staff addressed issues arising in relation to flexibility of thought and actions.

Case study 5

Clariss lives in a cottage on her own, supported by staff round the clock. She gets easily overloaded and will push staff out when she has had too much. Staff say she is very rigid with her routines. Routines are written in Clariss' care plan. Clariss has no visual plan to follow. Staff only prompt verbally. The strategy here is to create a visual plan which Clariss can follow herself. This could increase her independence and reduce the verbal prompting where staff might be overloading her.

With visual lists staff might be able to introduce flexibility slowly into her planned day.

Case study 6

Sam is learning to make his own breakfast. Every day he opens a jar of jam and eats the whole jar before he will move onto anything else. Staff know that eating this amount of jam is not healthy for Sam. However, he is very large and very strong and staff are wary of challenging him. The strategy used was for staff to give Sam a small jar of jam. He accepted this without any problems. Staff found that Sam always wanted to get to the end of the pot of jam and was not concerned about the amount of jam he ate. The strategy here was for staff to give Sam a clear beginning and end to every task.

Case study 7

Maggie is 10 years old. She loves to flick lights on and off. She does this so often that it is very irritating for her family and she has also broken several light switches. Maggie's parents realised that this lightflicking is a calming activity for her. So they devised a box with a light bulb and a light switch so that she could flick the light on and off to keep her calm. They introduced light-flicking time into her day so that she could always look forward to that activity which helped to keep her calm. The strategy in residential facilities is for staff to find the activity that the individual most enjoys and to ensure that this activity is planned for regularly in the day's plan.

Sensory issues in residential settings

Adults with autism like Temple Grandin, Donna Williams and Ros Blackburn tell us that sensory differences can be very debilitating and Bogdashina (2003) argues that these issues can create more difficulties for a person than other aspects of their autism. The brain can either filter too little sensory information or too much, creating hypersensitivity or hyposensitivity. In the case of hypersensitivity, the brain is overloaded with sensory information (eg lights too bright, sounds too loud, textures too uncomfortable). In the case of hyposensitivity, the brain does not absorb enough sensory information and so it can be difficult for the individual to tell how hot the water is, or to feel a sensation on the skin or to taste food, for example. Some individuals experience both hypersensitivity and hyposensitivity and some experience synaesthesia where the senses are mixed up and they might, for instance, feel specific sensations or see specific colours when they hear certain words. In residential settings, staff may have access to an Occupational Therapist who can draw up a sensory profile for the individual. Regular, thorough observations from staff across 24 hours can also inform the individual's sensory profile. Furthermore, residential facilities can have quiet rooms, sensory rooms and sensory gardens to either reduce sensory input or to increase it.

Some questions to ask in relation to sensory differences would be:

1. Do we overload the individual by talking too much and using unnecessary words?
2. Is the individual displaying sensory overload behaviours (eg hands over ears, fingers in front of eyes, avoiding eye contact, stimming)?
3. Is the individual displaying sensory hyposensitivity (eg pinching themselves, kicking themselves, using overly hot showers)?
4. Where can the individual retreat from overload?
5. Are calming activities included in their programme?

The following three case examples illustrate some of the sensory issues and ways to address these.

Concluding comments

Every residential facility will be different and each will cater for differing individual needs. There are general principles, however, that can help all residential services to support autistic people to overcome or manage their difficulties. These include:

- consistency across all staff in communicating with each individual and, in addition, thorough recording and reading of the care plans
- an understanding of and implementation of the individual's way of communicating
- provision of lists of activities and routines in a form that can be understood and followed by the individual (eg picture boards, now and next books)
- activities that have a clear beginning, middle and end
- opportunities for individuals to get away from sensory stimuli
- opportunities for individuals to increase sensory stimuli.

With the above in mind, the priority must be to help each individual overcome or manage their difficulties to enable them to access and widen their experiences and opportunities and to promote their strengths and skills.

References

Bogdashina, O (2003) Sensory perceptual issues in autism and Asperger syndrome: different sensory experiences different perceptual worlds London: Jessica Kingsley Publishers.

Fleischmann, A and Fleischmann, C (2012) Carly's voice: breaking through autism New York: Simon and Schuster.

Mukhopadhyay, TvR (2011) How can I talk if my lips don't move? Delaware: Arkade Publishing.

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