

# Service user involvement in the development of services for autistic adults without a learning disability: Barriers & Enablers

Ohigana Otache Social Work Consultant Manchester City Council

Twitter:  
@ohiganaotache

## Background

A 2017 study by the National Disability Authority (NDA) identified several gaps in the availability of, and access to services for adults with autism without a learning disability. A lot of research papers around service user engagement in research and education but very little around service development

## Methodology

Engaged autism leads and service users in three local authorities  
Engaged Service Users, Providers, Voluntary sector and Professionals (social work practice & commissioning)  
Literature review of 34 papers including grey literature and policy documents in the UK, Europe and USA

## Co- Design Process

### Meaningful Inclusion

Service User participation was less consultative and more collaborative with more service user control  
Participants defined the scope and set rules for the co design process  
Agreed the principles which should underpin and inform any service for autistic people

### Ownership

A shared ownership of documenting output. Notes from the meeting were shared via email and participants encouraged to make amendment or include additional information  
Joint decision making  
A survey sent out more widely to other autistic adults and their carers on the information gathered

### Shared Focus

Participants were asked to define:  
What the service should look like,  
Who should deliver it and  
How the service should be delivered.

### Outcome

Participants were asked what outcomes the service needs to consider when designing the service for autistic adults  
Participants agreed how outcomes should be measured  
Participants agreed tools including feedback mechanisms should be used to capture these

## Implication for Practice

Adult Social Care develop agency guidance through a service wide policy and protocol for service user involvement. The policy should include plans to enhance service user understanding and knowledge for effective service user engagement  
Develop a skilled workforce that responds positively to the presenting needs of autistic adults who do not have a learning disability  
Adult Social Care should include an autism checklist within the referral/assessment process to prompt front door staff, assessors, and social workers to consider a presentation of autism when responding to a referral.