



Recycling the Barriers:

**What prevents the Autonomy of those with an
Intellectual Disability? From the perspective of Carers in Essex**

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Abstract

Meeting family carers who recount their experiences of being on the receiving end of health and social care provides a 'real life' context. Family carers of those with an intellectual disability were asked to join a meeting organised by Essex Carers Network. On the 15th February 2021 two meetings were held via Zoom. Following the outcomes of these meetings a questionnaire was then distributed to all members of Essex Carers Network (to include all those who were unable to attend) asking family carers to rate these outcomes by importance. A report of the findings was then sent to Essex County Council as part of working co-productively towards constructive transformation. This qualitative research sets out to understand what prevents the autonomy and inclusion of those with an Intellectual Disability from the perspective of Carers in Essex. The findings were that the apparent barriers that prevent Autonomy are in the majority the same barriers that have existed over countless decades. *“The ability to become family-centred requires a shift in the beliefs professionals have about families and the models which guide the translation of beliefs into practices that truly support and strengthen family functioning”* (Dunst, Trivette & Deal, 1994, p.225)

Introduction

During the course of an average human lifetime there have been immense lifestyle changes for people with an intellectual disability. There is a need to briefly reflect upon the past which will provide a greater appreciation of the epic transformation in the lifestyles of people

with an intellectual disability over the past seventy years. Some of the people with an intellectual disability, who lived through these changes, have enlightened society with their narratives as have their families.

In the 1940's people with an intellectual disability were predominantly placed in institutions. Life within these institutions is reflected in an anonymous quote within Mencap's "Changing attitudes" (n.d.). *"Being in the institution was bad. I got tied up and locked up. I didn't have any clothes of my own, and no privacy. We got beat up at times but that wasn't the worst. The real pain came from being a group. I was never a person. I was part of a group to eat, sleep and everything ... it was sad"* (p. 4). Mabel Cooper (recently deceased) was a renowned self-advocate and reflected on her time in an institution. *"In them days if you had learning difficulties or anything that's where they used to put you. They didn't say, 'Oh, you could go into a house and somebody would look after you.' They would just say, 'You, you've gotta go into a big hospital and that's it."* (Atkinson, Jackson & Walmsley, 1997, p. 29).

A major pioneer for 'change' was Judy Fryd (Mencap, n.d.) who wrote a letter to 'Nursery World' to seek out other parents (of people with an intellectual disability) to form a group of support. In 1946 the 'National Association of Parents of Backward Children' was formed. This group evolved into Mencap, now nationally regarded as major campaigners for people with an intellectual disability.

The Learning Disability Coalition (n.d.) attributes the work of Gunzburg, H. C. (1968) as the start of an improved lifestyle for people with an intellectual disability. Gunzburg, H. C. (1973) evidenced that there were

many people with an intellectual disability who could make the transition to living in the community if they received support.

The Education (Handicapped Children) Act 1970 came into force to make provision for children with an intellectual disability to be educated within a school environment. “*Children suffering from a disability of mind*” (sic) could no longer be judged as uneducable. This was followed by the Education Act 1981 which made available mainstream schools for children with an intellectual disability.

Ward, L. (1988) recognised that participating in the local community, building and maintaining friendships, is equally as important to the self-esteem of people with an Intellectual Disability as it is to others.

The latter part of the 20th Century heralded the implementation of the Disability Discrimination Act 1995 opening a legal gateway towards inclusion.

Within the first decade of this century “Valuing People” (DOH, 2001), the “Convention on the Rights of Persons with Disabilities” (United Nations, 2006) ratified by Great Britain in 2009, “Valuing People Now” (DOH, 2009), and the Equality Act 2010 were published, enforcing the ideology of civil rights, independence, choice and inclusion.

Murray, P. (2002) identified that leisure activities are vital in order for people to develop friendships (support structures) which are integral to one’s wellbeing. From this research it was identified that relationships

were at the “*heart of inclusion*” (p. 77) and the barrier to mainstream inclusion would continue whilst disability pertains to being ‘different’.

The Disability Discrimination Act 1995, the “Convention on the Rights of Persons with Disabilities” (United Nations, 2006) ratified by Great Britain in 2009, “Valuing People Now” (DOH, 2009), the Equality Act 2010 and The Care Act 2014 are now in place to promote equality and inclusion for people with an intellectual disability. Now these are in place it is essential to ascertain whether or not they have successfully supported people with an intellectual disability to live a socially inclusive life and have autonomy. With that purpose this paper explores family carers frustrations and their perceived barriers to achieve social inclusion and autonomy for their loved one which will additionally provide the reader with the understanding of what family carers need in order to promote autonomy and inclusion for the person with an Intellectual Disability.

Aim

- ❖ This research is to collate the lived experiences of family carers of people with an intellectual disability with regards to achieving autonomy and consequential social inclusion for their loved one.

Objectives

- ❖ To identify where, in the opinion of family carers, practices need to be developed.
- ❖ To inform Essex County Council policy makers.

Rationale

- ❖ The author's motivation for this research originally stems from her personal experience as a family carer and observations as one of the management team for Essex Carers Network, having been a member since it's conception.
- ❖ A step towards recognising the consistent barriers preventing the autonomy of those with an Intellectual Disability and co-productively develop best practice and consequential supportive policies within Local Authorities.

Research Questions

- ❖ What are family carers perceived barriers to autonomy for those with an Intellectual Disability?
- ❖ Are these barriers consistent with previous consultations with family carers?
- ❖ What needs to be provided by Local Authorities in order to support family carers with supporting the person with an Intellectual Disability to achieve a fulfilling life?
- ❖ What potentially could be the challenges Local Authorities face when trying to develop best practice and consequential policies?

What are the Barriers Perceived by Family Carers and are they Consistent?

Within Essex there have been two Consultations with family carers of those with an Intellectual Disability:

- The system is not working with us: Learning from Family Carers in Essex 2014. Facilitated by Essex Carers Network and Essex Mencap working co-productively with Essex County Council
- Zoom consultations with members of Essex Carers Network followed up with a questionnaire distributed to all members, highlighting the points raised, to include those family carers who were unable to attend the zoom meetings. Zoom meetings were held in February 2021 and results from the questionnaire gathered in April 2021. These meetings were facilitated by Essex Carers Network working co-productively with Essex County Council.

Both these reports have been laid out in differing formats and therefore makes it difficult to do a direct comparison. Consequently, the writer will pull out family carers perceived barriers that have concurred in both of these documents.

<p style="text-align: center;">The system is not working with us 2014</p>	<p style="text-align: center;">Zoom consultations/ Questionnaire 2021</p>
<p>Pro-active support to plan for the future and to make alternative arrangements for loved ones. Support to plan gradual re-housing, while it can be carefully managed.</p>	<p>Feeling confident about the future for your family member (85%) Accommodation – what are the possible options available (56%) Planning for the future (60%)</p>
<p>Involve the whole family in planning.</p>	<p>Being seen as part of the solution not part of the problem, that my</p>

<p style="text-align: center;">The system is not working with us 2014</p>	<p style="text-align: center;">Zoom consultations/ Questionnaire 2021</p>
	<p>views as family carer matters to social care and health (68%)</p> <p>Person centred planning – how families can lead the way (40%)</p>
<p>Assemble critical information: Around which people will need to make arrangements and decisions</p>	<p>Decision making – court appointed deputyship and lasting power of attorney (44%)</p> <p>Decision making – mental capacity act and best interest decisions how families are involved (48%)</p>
<p>People feel they struggle to access information about entitlements, services and support that exist for them and their families.</p>	<p>Different kinds of support available (68%)</p> <p>Having access to good information (59%)</p> <p>Independent support and advice to explore opportunities and services (57%)</p>
<p>The role of social workers: People would like to have a dedicated social worker. When social</p>	<p>To have consistency a named social worker (65%)</p>

<p style="text-align: center;">The system is not working with us 2014</p>	<p style="text-align: center;">Zoom consultations/ Questionnaire 2021</p>
<p>workers develop a relationship with the family, it can make a profound difference. People want someone that “knows my family and how to interact positively and someone who is there for us”</p> <p>Inconsistency in relationships of professionals working with people with learning disabilities: Someone new coming to the house prompts anxiety, and this happens all the time.</p>	<p>We don’t want to keep telling our story (50%)</p> <p>Having a check in call between reviews (33%)</p> <p>Good lines of transparent communication with social care and health (68%)</p>
<p>Transitions: There is a lot of dissatisfaction around transition between child and adult services.</p>	<p>Preparing for moving to adulthood (40%)</p>
<p>Personal Budgets: These work brilliantly for some families but others are scared to contemplate them.</p>	<p>Ways to manage direct payments (16%)</p> <p>Role of an independent broker – manage budget and look for opportunities and solutions (24%)</p>

<p style="text-align: center;">The system is not working with us 2014</p>	<p style="text-align: center;">Zoom consultations/ Questionnaire 2021</p>
<p>Skills and employment: Carers would like to see a stronger offer for skills development and employment.</p>	<p>Support for my family member to live their best life and achieve their potential (86%)</p> <p>Feeling like your loved one is valued and supported rather than seen for the things that challenge them (62%)</p>

This paper concerns family carers perceived barriers preventing the autonomy and social inclusion of people with an Intellectual Disability. The writer wishes to touch on the thoughts of people with an Intellectual Disability in order to present a holistic approach. Essex County Council commissioned an enquiry to explore the life ambitions of young people with a disability in Essex. Great Expectations was published in 2016. Within the document the aspirations of young people with an Intellectual Disability were recognised as being no different to most young people within society. These young people with an intellectual disability want:

- Family, friends and relationships
- Fun
- Jobs and careers
- To live as independently as possible
- To be part of a supportive community, and
- To influence and play a part in the world around them

Interestingly the thoughts of family carers reflecting on their experiences of their sons' and daughters' transition echo the barriers perceived in the above table.

“We don't get told what's available as a child gets older”

“We're finding it difficult to find out where we stand financially and legally. There is a lack of information ... who do I go to first? Where's the key point of access? You need serendipity”

“Getting the right social worker, right help, right attitude, right questions. Without this, you won't get things”

“Social workers are the gate-keepers. You have to keep badgering them: 'What's going on?’”

Potential Challenges Local Authorities May Be Faced With

It has to be acknowledged that the writer does not work within the Local Authority, and only those within would be able to fully identify the challenges faced within Social Care with regards to budgets, internal politics, internal policies and the disabling or enabling attitudes within their organisation.

“Social work has increasingly moved away from its commitments to direct work with individuals, families and communities and from a preventive role. For that reason, social workers, especially in local authority social work departments, may be put in a position of

‘professional bad faith’. That is, they may be required to fulfil a role that conflicts with professional values and principles and indeed with those reasons which provided them with the motivation to enter social work in the first place. Direct work and preventive work have been less a feature of social work in recent years and there may be a need to revisit first principles in relation to preventive work.” ... “The inability to operate according to such core principles may also in part account for the fact that many social workers leave the profession”. (Asquith, Clark, & Waterhouse, n.d., p.4 & p.16).

It also has to be understood that people with an Intellectual Disability and their families start from a disadvantaged position entering a terrain under the control of the Local Authority. In order for families and the person with an Intellectual Disability to be empowered is in the control of their Local Authority. *“To empower – to ‘give or delegate power to, to authorise’ (Collins’ English Dictionary) – is an action taken by those who hold the power. The recipients of the power (the object of the verb) are passive. The very grammar of the word indicates that the powerful will exercise their power even in the very act of empowerment.”* (Dowson, 1997, p.105).

Conclusion

Despite Essex County Council’s response to ‘The System Is Not Working With Us’ in 2016 (produced 2 years after the consultation in 2014). The barriers that prevent people with an intellectual disability having autonomy and living an inclusive life still exist. It is the writer’s consideration that if Essex County Council truly want to work co-productively with Essex Carers Network members, then there should be

further focus on these explicit concurring perceived barriers in order to find solutions that work for both parties and break down these barriers in order for those with an Intellectual Disability to be able to live an autonomous inclusive life as is their Human Right.

The writer also believes that there should be further research with regards to people with an Intellectual Disability having a consistent social worker. The writer believes that a consistent social worker will resolve many of the perceived barriers. Perhaps Essex County Council could be transparent and share their reasoning for not providing this?

Dunst, C.J., Trivette, C. M. and Deal A. G. (1994, p. 198) cited Vosler-Hunter (Vosler-Hunter, 1988, pp. 2-3, emphasis added) *“If, as parents and professionals, we strive for open and honest communication, mutual respect for our skills and knowledge, and shared planning and decision making, (any) conflicts will not necessarily go away, but a working relationship will be established that can only serve to improve services for our children”*

***“Clarify the goals towards which the person aspires.
Identify the barriers which may prevent the realisation of these goals.***

Work toward removing the barriers.”

(Beresford, 2004, p.256)

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