Shuffling the Deckchairs: Multi-agency Working and the Continuing Lack of Identification of People with Vision Impairments

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Many orientation and mobility (O&M) professionals working to meet the needs of children and adults with vision impairment may do so as a part of multi-agency rehabilitation teams. However, from a study of current literature in the fields of vision impairment, multiple-disability and intellectual disability, it is apparent that multi-agency participation does not invariably identify with accuracy, all those requiring a service. This article discusses how those professionals working in multi-agency frameworks support those in need when their service delivery agenda is based merely on a subset of the total population that should have their needs addressed.

Much has recently been spoken and written about multi-agency working and what multiple agency participation means for those services supporting family members with vision impairments. Current professional literature has a considerable amount of research that examines the benefits of multi-agency working. For example, Sloper (2004) indicates that families, who have been assigned key workers to act as the main coordinators of services they receive, have reported an improved quality of life. Sloper further claims that as a direct result of case-coordination families appear to receive better and quicker access to services, and consequently have better relationships with service providers than those who not been case-managed. Roaf (2002) has suggested ways that multi-agency approaches have provided a shift from simple problem-solving towards a holistic approach to collaboration in service provision. Atkinson and her fellow workers (2002) have identified several positive outcomes for services that have adopted a multi-agency approach in service delivery. These outcomes include (a) access to services not previously available to children and families, (b) improved educational attainment and (c) a reduced need for more specialist services. It seems clear that adopting a multi-agency approach to service provision can lead to a win-win situation in which there are improved outcomes for children and families with vision impairment, as well as in the provision of significant benefits for the staff and services that are part of a multi-agency framework.

The comprehensive rehabilitation team is an obvious example of multi-agency working. It is a team on which there may be rehabilitation teachers, coupled with rehabilitation counsellors, working beside and with
orientation and mobility (O&M) instructors, with input from low vision specialists. Occupational therapists may also provide support by training or retraining individuals with motor difficulties. There will be, at some level, participation from medical and allied medical staff and it would not be uncommon for the team to receive some support from a psychologist as well. If the client was located within an educational setting, this team would more than likely also receive input from a variety of educationalists as well as from other staff. Consequently, many O&M instructors see themselves as part of an elaborate and sophisticated multi-agency team with the goal of meeting the needs of individuals within a wide ranging client group.

However, I have started to become concerned about the current use of ‘multi-agency working’ as a descriptive term. The term seems to me to be rapidly becoming one of the many ‘buzz words’ that people use, (as another example, ‘the paper-less office’) a term that everyone uses these days, with all concerned declaring that they are part of a multi-agency team. Yet when we dig more deeply we discover that they are in fact still working in isolation, shuffling the deck chairs (so to speak), and generally surrounded by a paper volcano of printed material.

Lloyd, Stead, and Kendrick (2001) describe multi-agency working practices as providing ‘a terminology quagmire’. For example, I am relatively sure that you, the reader, during your career, must have been involved in some inter-agency, joint working, multi-professional, cross sector collaborative team or other. There are a great many terms widely used to describe the multi-agency concept, each representing a slightly different working practice. Just by turning up at work the opportunity of being part of an inter-agency team appears these days to be fairly high.

But, and here is the crux of this article, if the benefits of multi-agency working are there for all to see, and as a result there are now more rehabilitation teams than ever before, teams specifically for adults with vision loss and teams specifically for children with vision loss all working within multi-agency frameworks, why is it still the case in so many instances that far too many adults and children who have additional and multiple disabilities over and above their vision impairment have sight problems that are still unrecognised and who remain consequently untended. I will further illuminate this point by highlighting some articles in the vision impairment and intellectual disability arena that have recently identified people with low vision and blindness who were previously unknown to these multi-agency based rehabilitation teams and thus prior to identification were not receiving, for example, any support such as daily living skills and independent skills appropriate to the needs generated by their vision impairment.

**Vision impairment, multiple disability and intellectual disability**

Looking back at the last decade, a reasonably typical example illustrating people with an undetected and unknown vision impairment is Broek, Janssen, Ramshorst, and Deen (2006) research indicating that 92% ($N=76$) and not 30% as previously thought, of people with severe and profound multiple disabilities in a Dutch care organisation were shown to have a significant vision impairment. Broek et al., reported that the severity of the vision impairment in their participants was closely related to severity of intellectual
disability. Concomitantly, Splunder, Stilma, Bernsen, Arentz, and Evenhuis, (2003) studied 900 adults with intellectual disability and confirmed Evenhuis’s (2001) study of 672 adults with intellectual disability, finding that prevalence and severity of vision impairment are especially high with adults who have severe and profound intellectual disability. Splunder’s study also indicated that ‘non-refractive vision impairment is congenital or acquired at an early age,’ (Splunder et al., 2003, p.128), thus demonstrating that this specific group could have been identified earlier, and strategic and targeted rehabilitation services then implemented. Again this type of lack of identification and the subsequent non involvement by any rehabilitation team is reported by Koutantos (2000) who confirmed his hypothesis that there were many more children with vision impairments in Crete, a small country population than were previously known.

What is common to these studies is that they had identified people with previously unknown uncorrectable vision loss who were being supported by a variety of agencies but none of these people with significant vision loss were getting support to address their vision impairment needs, including meeting their necessary and sufficient rehabilitation requirements.

The literature appears to confirm Aitken’s (1997) contention that although the traditional triage-like “let’s deal with the most serious impairment first” approach to serving children with multiple disabilities is gradually changing due to developments in legislative frameworks, and is being replaced by multi-agency working, there are still many professional boundaries that emphasise the primary disability of the individual, to the neglect of addressing the other needs that person may have. Interestingly enough, Aitken (1997) and Millar and Aitken (1996) further suggest that the term ‘multi disabled and visually impaired’ (MDVI) may create an artificial categorisation by referencing vision in the title. Other issues, for example, augmentative and alternative communication needs that could support rehabilitation may not be attended to, whether the service professional is part of a multi-agency team or not.

Although Aitken (1997), and Millar and Aitken’s (1996) views appear to be at the opposing side of my stance, both sides agree that current practices that are part of multi-agency partnerships do not fully identify the number of people requiring the services of specialist professionals including those from specialist rehabilitation teams.

Ravenscroft, Blaikie, Macewen, O’Hare, Creswell, and Dutton (2008) ask these important questions; Why is it that we still do not know how many people we should be serving? Why is it that we increasingly, it seems, do not know where all the individuals with disabilities in the population we are to serve are located? And why is it when we look into the near future, the answers to these very basic questions do not seem to be forthcoming?

Policy makers and planners of integrated service provision models, including those on rehabilitation teams aiming to meet the needs of people with vision impairment face the difficult task of delivering services based on information that may not describe the full scale or spectrum of people they should be serving. Perhaps a simple analogy would help to express my concerns. Not having accurate details about the numbers (and potential numbers) of service-users out there is surely like an architect planning a large public building, but not knowing how
many people will go into it, or consequently what the internal and external requirements should be.

Without doubt, people with vision impairments require an integrated multi-agency tailored service provision of which rehabilitation teams are part, but in order to plan and develop such services, surely we, as supposedly well-trained and competent professional service providers, first need accurate demographic client profiles?

References


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