Promoting Resilience, Independence and Self-Management in Intellectual Disability Services

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Abstract

The concept of consumer empowerment to ensure health care and treatment is appropriate to meet their needs, is widely embraced. Most progressive caring services implement processes to enable consumers and their families to participate in all aspects of care planning, delivery and evaluation.

This paper provides a framework to promote resilience and independence of people in intellectual disability service settings and describes processes providers can introduce to encourage people with intellectual disability to manage their own care and treatment. Implementing PRISM (Promoting Resilience, Independence and Self-Management) is facilitated by use of specific tools, protocols and methods to ensure people with intellectual disability are able to take change of their own care and treatment.

Keyword: Intellectual disability; Self-management; Resilience; Independence; Judgement

Abbreviations: PRISM: Promoting Resilience, Independence and Self-Management; PAC: Protocol for Appropriate Care

Introduction

People with intellectual disability and their carers have to navigate a number of challenges. These include making sense of service and care arrangements that are not specifically developed to cater for needs of people with intellectual disability [1]. Services are often organized to meet the needs of those with a higher level of comprehension, reasoning, problem solving, planning, abstract thinking, judgement and an ability to learn from experience. An inability to manage complex service arrangement, socialize appropriately and self-manage to the extent those without intellectual disability can, makes accessing mainstream services complex and difficult for people with intellectual disability [2,3]. The issue of stigma and discrimination of people with intellectual disability within mainstream services also continues to remain a concern [4-8].

A large proportion of people with intellectual disability also have multiple co-morbidities, both physical and mental health-related [9-11]. These can further interfere with their ability to function in personal, social and occupational spheres. An important care and treatment goal must remain comprehensive assessment and appropriate interventions to meet identified needs, and to enable the individual to function to the best of their abilities, despite their disability and comorbidities.

It is true that some people with intellectual disability may not be able to take complete charge of all aspects of their functioning, however, it is important that services have systems and processes in place to promote resilience and independence and ensure people with intellectual disability are able to self-manage to whatever extent they are able to [12]. Use of specific tools and methods can ensure the goal of promoting resilience, independent and self-management is achieved and people with an intellectual disability and other co-morbidities receive consistent, comprehensive and appropriate care.

Care plan must be comprehensive and holistic

It is not uncommon that people with intellectual disability receiving care in both independent and supported care settings

have to self-manage many aspects of their life [13]. This ranges from looking after their personal care, physical and mental health illnesses, as well as social and emotional issues that are inevitable when interacting with organization and societal systems that may not have specifically considered the needs of people with intellectual disability.

The essential starting point for intellectual disability services providers has to be to promote resilience and independence of consumers and enable them to self-manage as many aspects of their life and functioning, as is possible for them to do [14].

The Intellectual Disability sector attracts some very caring, compassionate and committed professionals interested in devoting their life to support people with long standing disabilities and needs. It is important that all professionals and carer working in the Intellectual Disability Sector embrace the concepts of empowerment and promoting self-management and re-frame the care provision to include empowerment and enablement. Uncertainly can be reduced by ensuring appropriate information that is customized to the needs of people with intellectual disability and enables them to engage in decision making.

PRISM

Promoting Resilience, Independence and Self-Management (PRISM) is a framework to enable people with intellectual disability to take charge of decisions in relation to their care and treatment. This framework endeavours to achieve for consumers as much responsibility and independence in making decisions about their own care and treatment, as is possible for them to achieve [15].

In introducing PRISM to promote resilience, independence, and self-management, even though it is important to be cognisant of existing attitudes, culture, environment, practice and also systems and processes, the concept is driven from a simple starting point - `I must manage my own care.' With implementation of systems, processes and practices that are an integral part of PRISM, emphasis is on developing of a shared culture and understanding to deliver care to people with intellectual disability.

Preparatory phase

PRISM has been conceived using lean six sigma principles [16]. There is an explicit focus on minimizing waste and duplication of processes. Value adding activities are identified. At every step, a question is asked about value. Only value adding activities are pursued. An automated back-end evaluation process occurs concurrently by checking deviance from agreed processes to minimize any errors and omissions. There is a focus on ensuring all people with intellectual disability and their carers receive appropriate and adequate information about supports available to them. More importantly, this is done in a consistent manner so that they can take charge of their care and treatment. Unnecessary duplication in clinical care assessment and planning processes are eliminated, but essential assessment and treatment processes

are monitored to ensure these are not overlooked. During a care episode, as soon as the consumer is ready to take charge, this is formally identified and `Take Charge Sheet' activated.

The reality is that even people with normal intellectual and cognitive functions struggle because the health care system is poorly organized [17]. During the preparatory phase, attention is paid to the environmental contributors that may be interfering with the systems' ability to promote resilience, independence and self-management to the person with intellectual disability. PRISM tools and methods are then customized to ensure self-management is promoted. Inevitably some amount of system redesign is necessary to ensure PRISM processes are aligned with the vision and direction of the Intellectual Disability service provider. In implementing PRISM, the service provider also has an opportunity to review its own environment and if necessary, state, reiterate and/or align its principles of care delivery with the principles espoused by PRISM. This allows clarity of purpose and direction for the service and removes any element of discordance that may occur with introduction of a new service delivery strategy and method.

Most service providers are clear about what needs to be done, however, the principles driving care delivery are not always clear to recipients of care, and indeed to their carers. PRISM processes ensure that agreed systems and processes are communicated and applied consistently.

Key Principles for PRISM

Three key components provide scaffolding to achieve this principle.

a)   `Taking charge':

To whatever extent a person with intellectual disability is able to, they are encouraged to take charge of their care and treatment. This differs from the traditional case management in which a case manager (and therefore the service provider) takes responsibility for ensuring the recipient of care receives agreed interventions (which form their care plan) and takes responsibility of monitoring processes to ascertain whether intended outcomes are being achieved.

In PRISM, the person with an intellectual disability is resourced and empowered to take charge. They maintain a 'Take Charge Sheet' that lists all aspects of care that are expected to be completed (by the service providers and by them) and also specific time frames within which these need to be completed. The Take Charge Sheet must be written in a manner that makes sense to the person with intellectual disability. Service providers are encouraged to use pictures, audio files, and other visual cues, to ensure that the person with intellectual disability is able to comprehend the contents of this sheet. If expected events and tasks are not completed, this is discussed with the care provider at the very next occasion.

PRISM requires every handover to occur with the person with intellectual disability. The Take Charge Sheet is the frame of reference to consider progress and whether target outcomes are being achieved. The Take Charge Sheet is an important communication tool for discussion to occur about goals that need to be achieved. It is also a reminder of tasks that have to be completed and supports that the person with intellectual disability (and their carers) have access to.

b)   Error free care:

PRISM requires implementation of an agreed protocol for appropriate care (PAC) by the Intellectual Disability service provider. The protocol details exact tasks that must be undertaken within a specified period of time. These include essential tasks that must be undertaken at the initiation of the contact with the person with intellectual disability, at the point of assessment of needs (including assessment of psychosocial needs and safety needs) and investigations that must be undertaken. The PAC sheet also separates tasks by responsibility for the person with intellectual disability and each member of the multidisciplinary team involved in the provision of care to the consumer. This ensures clear allocation of task responsibility as well as elimination of duplication and re-work as all personnel involved are clear about task allocation.

If there is deviation from the PAC, this is picked up instantaneously and remedied. If deviation cannot be corrected immediately, this is flagged with the nominated person and escalated if necessary, so that system correction can be implemented. At each handover the Take Charge Sheet along with the PAC provide the basis for handover discussion.

Since PRISM endeavours to achieve error-free care, monitoring is in real-time and check for compliance is not left for a retrospective audit. Less than one hundred percent compliance is considered unsatisfactory. With the person with intellectual disability fully aware of actions on the `Take Charge Sheet' and within `PAC', at the handover, there is an opportunity to remedy any deviations from PAC straightaway. There is no retrospective auditing as emphasis is on achieving one hundred percent compliance for tasks to be completed and immediate `exception reporting' for all matters that cannot be remedied.

c)   Efficient coordination:

Most common reasons for waste of time and effort are inefficient coordination and untidy communication. PRISM processes have been developed to ensure unnecessary transactions can be minimized. Since people with intellectual disability and service providers are working from the same song-sheet there is an opportunity to explore and eliminate any duplication in documentation of information and eliminate all non-value-adding transactions. For example, internal written referrals, staff handover sheets, message boards, admission registers, communication sheets and other register, review sheets

etc., are all banned. One person with intellectual disability has one care plan and everyone involved must work from that plan. This is the plan that they own. It identifies needs, guides achievement of specific goals and intended outcomes, irrespective of the service provider and facility at which the consumer may be receiving care and treatment.

PRISM in residential care settings

In a residential care setting, rolling out PRISM involves a number of structured steps.

Preparatory phase:

The admission process is managed in a structured manner. In addition to completing comprehensive needs assessment, including assessment of health and psychosocial needs, and identifying what investigations or assessments are needed, the person with intellectual disability is prepared well to manage their comorbidities and stay in the residential care accommodation. This requires educating the person with intellectual disability about the concept of promoting resilience, independence and self-management using the PRISM Pack.

The PRISM Pack is not only an orientation and information pack available on the resident's bed side for ready reference, but also an educational tool. The PRISM Pack makes explicit the residential care provider's commitment to enable the person to self-manage. It also has information about resources available to the person with intellectual disability and clearly describes processes that are in place to promote self-management.

Some residents may not be in a state of mind that allows them to fully understand the contents of the PRISM Pack. This requires care staff to work with the person with intellectual disability using the PRISM pack to continuously educate and orientate the consumer.

The very fact that the person with intellectual disability and their carers use the PRISM framework as a common frame of reference ensures that as the person progresses towards wellness, independence and to discharge from the residential care facility to independent living, they are progressively equipped with necessary information and skills to manage their symptoms. The PRISM pack conveys a simple message – "Take Note, Take Charge, Take Home"

• **Take Note:** To ensure the consumers and carers have access to relevant information about the service, service providers and supports available and information is made available consistently, a Take Note information pack is available to the person with intellectual disability and their careers. The Take Note pack has information developed in such a way that allows a discussion amongst all involved to enable the person with intellectual disability and carers to `take note' of the care provider's orientation to promote, resilience, independence and self-management, and about supports available for them.

- **Take Charge:** A Take Charge sheet is a template that contains a clear and explicit statement inviting the person with intellectual disability to take charge of their own recovery. The Take Charge sheet facilitates care processes to empower the person with intellectual disability to take charge of their disability, illness, care and treatment. At every stage of care, including at handovers, a Take Charge Sheet is used as an instrument to have a conversation with the person with intellectual disability (and their careers, as appropriate) about how they can take charge of their care, treatment and recovery.

- **Take Home:** At every transition point, especially at the end of each contact with the service (whether it is an episode of residential care or a care appointment in the community), a Take Home sheet ensures that the person with intellectual disability (and their careers, as appropriate) are absolutely clear about their care plan. Unless it is inappropriate, the Take Home sheet includes plan of care and details of care and treatment that the person with intellectual disability can take home.

PRISM in the Community

Most people with intellectual disability receive treatment in the community, with appropriate supports, they are able to manage most of their affairs, either by themselves or with the assistance of others. The essence of recovery-orientated care is to ensure that the person with intellectual disability is able to achieve the highest level of functioning including management of their day-to-day functioning and is able to make independent decisions. From achieving self-care to making independent decisions about what is in their own best interest, the focus of caring services must always be to support the person with intellectual disability to take charge of their life to whatever extent possible.

Some people with intellectual disability need considerable support and supervision, without which they are unable to maintain their optimal health and well-being. For this group, considerations are not dissimilar to those people with other disorders of brain and cognitive functioning who are not able to make independent decisions e.g., people with dementia, brain injury, etc. Caring services must allow them to become as independent as possible.

For the majority of people with intellectual disability who are able live independent in the community, intrusive home visits, insistence that they stay in contact by attending appointments, by telephone, etc., are in fact discouraged (unless the person with intellectual disability feels the need to have this support and intervention). Follow up appointments with carers and other support professionals, including acceptance of home visits must be an active decision-making process, not a passive acceptance of an offer made by the service provider.

The question that needs to be asked for this majority who are receiving treatment in the community is whether case management is necessary? Implementation of PRISM suggests that rather than case management, we must promote resilience, independence and self-management, to allow the person with intellectual disability to be truly independent. For people who can live independently, they should be able to `access' care, rather than service providers `providing' care. Care access considerations for them should not be any different to those who have other chronic health conditions.

PRISM principles encourage all people with intellectual disability to self-manage as many aspects of their care as possible. The system orientation is to allow the consumer to take responsibility for self-managing aspects of care that they are able to. The PRISM pack is used to convey a simple message of "Take Note, Take Charge, Take Home". The person with intellectual disability consumers and their careers is equipped with necessary information about supports available in the community (Take Note) to ensure they have access to appropriate resources in the community and encouraged to take charge of accomplishing tasks to enable them to manage their illness (Take Charge). For example, from the very beginning of their treatment, consumers are encouraged to take charge of the social aspect of their care and treatment. This includes facilitating them to manage communication with significant others. They are encouraged to keep in touch with care professionals supporting them to make an appointment for follow up. At their appointment with their care professional, they are encouraged to arrange for their review to occur with the team supporting them.

With improvement in their symptoms, they are encouraged to take charge of recommended monitoring and evaluation processes that their carer may have recommended; keep track of the fact whether investigations and assessments are being progressed in a timely manner; and even take charge of maintaining a record of some observations e.g., body weight, etc.

All consumers are encouraged to formulate care plans in their own words so that it makes sense to them and they feel able to use for future reference (Take Home).

Conclusion

To do things differently, there is always a need to be certain that the new way of thinking and doing things is likely to deliver significant gains. The logical first step in this process is a willingness to interrogate the concept and trial various elements of the concept. The promise of effective care proposed efficiency gains and improvement in the environment must be tested to ensure that the theory can be translated into practice.

Adoption of PRISM process challenges care providers to question contradictions that are sometime inherent in how care and treatment is delivered to people with intellectual disability. Even though the Intellectual Disability sector is geared to encourage empowerment and wishes to facilitate self-management, at times necessary systems and processes do not enable this to occur. PRISM allows the consumer to be empowered

with the necessary tools and methods to self-manage and take charge of their own recovery.

To implement PRISM, it is important and necessary to customize the PRISM pack to meet local needs. Existing policies and procedures and documentation requirements require refreshment to ensure PRISM principles and practices are adhered to. The PRISM pack is built around the simple message of `Take Note, Take Charge, Take Home' with the intention of gathering necessary resources to empower the person with intellectual disability, and their careers.

The PRISM pack allows necessary customization to make it suitable and relevant for the local environment while preserving the essentials. For example, `Take Note' resources must always include an information guide that contains information about supports that are potentially available to people with intellectual disability and carers, and how to access these supports. `Take Charge' sheet can be an eight to ten-point check list of essential tasks that consumers must take charge of, that are critical for their ongoing treatment, recovery and rehabilitation. 'Take Home' sheet can be a template for a care and relapse prevention plan prepared and owned by the person with intellectual disability that then becomes the point of reference for everyone involved in supporting the person with intellectual disability.

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